

Understanding referrals to outpatient palliative care and goals of care discussions with individuals diagnosed with stage IV advanced cancer

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HCSRN – APRIL 10, 2019

Palliative care and goals of care discussions

Background

- ❖ Palliative care and hospice are associated with improved quality of life for patients and bereaved caregivers, as well as less aggressive care at the end of life
- ❖ Discussing palliative care and “goals of care” earlier in cancer care helps ensure care is patient-centered



Research Questions

- ❖ When are patients with stage IV advanced cancer referred to outpatient palliative care?
- ❖ How do health care team members feel about discussions of goals of care and palliative care referral?
- ❖ How do patients feel about these conversations (in progress)
- ❖ What related documentation can we find in the EHR (in progress)

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Methods: 1- Electronic Health Record analysis

Setting

- Large multispecialty medical group serving ~1 million patients in Northern California
- 25 medical oncology and gynecological oncology physicians
- Roll-out of outpatient palliative care program by site, 2011-2014

Inclusion criteria

- Stage IV cancer (i.e., already metastasized at diagnosis)
- Diagnosed between 01/01/2012 to 12/31/2017

Cohort construction

- Tumor registrar data used to identify Stage IV cancer cases diagnosed/treated
- Linked to electronic health record for patient and provider data
- 1,334 adult individuals identified
- 652 (49%) were deceased by end of 2017

Methods: 2- Interviews with care teams

Interviews (n=21)

- Oncology (n=13)
 - Medical Oncologists & Gynecological Oncologists (n=8)
 - Nurses, Nurse Practitioners, Social Workers (n=5)
- Palliative Care (n=8)
 - Physicians (n=4)
 - Social Worker, Nurse, Nurse Practitioner, Chaplain (n=4)

• Interview topics

- Conversations with patients with stage IV cancer
 - How and when goals of care are discussed
 - How and when referrals to palliative care happen
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- Thematic coding of interview transcripts

Deceased patients with stage IV cancer, n=652

	N	%
Cancer site		
Lung and Bronchus	234	35.9
Pancreas	88	13.5
Prostate	65	10.0
Colon and Rectum	52	8.0
Other Digestive System	44	6.8
Stomach	35	5.4
Female Genital System	27	4.1
Urinary System	25	3.8
Breast	24	3.7
Lymphoma	22	3.4
Oral Cavity and Pharynx	17	2.6
Other	19	2.9
Female	285	43.7
Primary oncologist with PC referral rate > 15%	301	49.0
	Mean	SD
Age at diagnosis	69.4	13.2

	N	%
Race/ethnicity		
Hispanic	55	8.4
White/Caucasian	378	58.0
Asian	77	11.8
Black/African American	10	1.5
Other	28	4.3
Unknown/Missing	104	16.0
Marital status		
Married/life partner/significant other	371	56.9
Divorced/widowed/separated/single	143	21.9
Unknown/Missing	138	21.2
Comorbidity: Clinical Classifications Software(CCS) score		
0	107	16.4
1-2	118	18.1
3-5	188	28.8
6-8	114	17.5
9 and above	125	19.2

Oncology and Palliative Care Utilization

- Among 652 deceased patients with stage IV cancer:

	Mean	SD	Min	Lower Quartile	Median	Upper Quartile	Max
Days from diagnosis to death	347	334.7	6	103	237	488	2103
Days from diagnosis to PC referral	194.4	270.7	-15*	15	62.5	273	1780
Days from referral to death	188.4	255.9	1	46	90.5	226	2062
Oncology visits ⁺	13.5	13.4	1	3	9	19	85
Palliative care visits ⁺	6.0	6.0	1	2	4	8	37

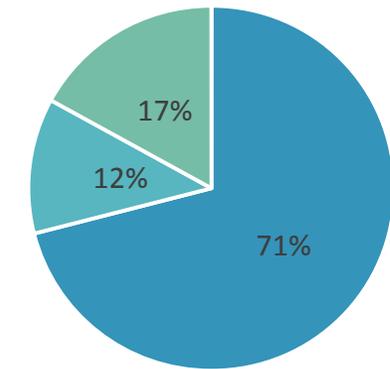
- 326 (50%) patients were referred to Palliative Care. Among them:

	N	%
Had no Palliative Care visit	73	22.4
Had only 1 Palliative Care visit	46	14.1
Had 2+ Palliative Care visits	207	63.5

Note: * negative value means referral took place before diagnosis date. + oncology and palliative care visits only calculated for patients with at least 1 visit.

“When you treat incurable disease, it’s the art of oncology.”

Referrals to Palliative Care by physician specialty, n=326



- Oncologist
- Primary Care Provider
- Other

- **Referrals by oncologists:** Among 19 oncologists with 10+ patients, referral rates ranged from 4-6% (2 physicians) to one physician who referred 72%.
- **Diagnosis to PC referral:** Median time was 62.5 days (mean 194, max 1780).
- **Diagnosis to death:** A quarter of patients died within 103 days, a quarter lived over 488 days.
 - Among the bottom quartile, 128 (83%) survived at least 30 days; among these, 45% were referred and 45% of these referrals were within 14 days of diagnosis.
 - Among patients in the top quartile for survival, 59% had a referral, but only 7% of those occurred within 14 days of diagnosis.

Logistic regression: referral to palliative care

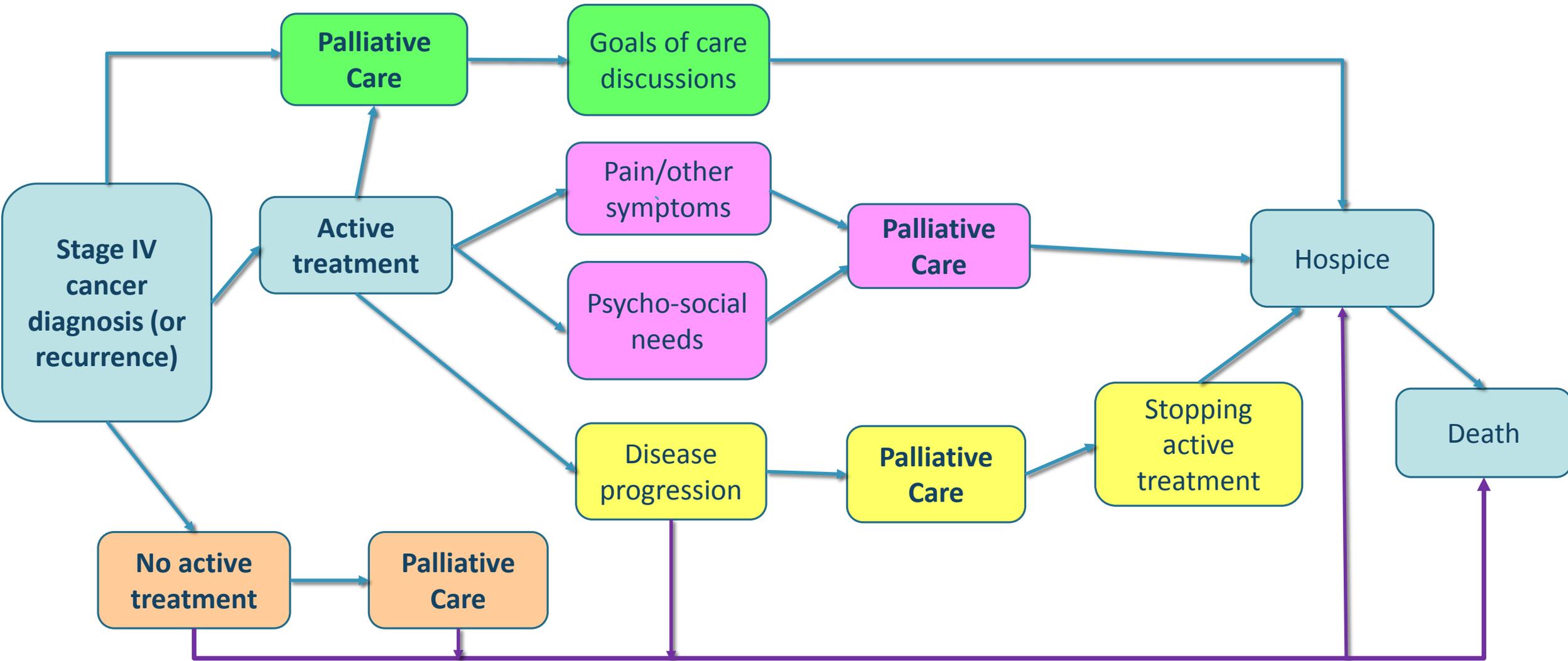
Adjusting for patient clustering within oncologists

Covariates	Odds Ratio	P-value
Age at diagnosis	0.998	0.857
Female	1.065	0.780
Race/ethnicity (ref: White/Caucasian)		
Hispanic	1.095	0.804
Asian	1.026	0.935
Black/African American	1.023	0.977
Other	0.881	0.795
Unknown/Missing	1.114	0.703
Marital status (ref: Married/life partner)		
Divorced/widowed/single/separated	0.588	0.035*
Unknown/Missing	0.480	0.006*
Primary oncologist referral rate > 15%	4.029	0.001*
Primary division of oncology visits (ref: Region D)		
Region A	1.943	0.105
Region B	0.858	0.692
Region C	2.998	0.028*
Initial diagnosis at PAMF	0.97	0.888

Covariates	Odds Ratio	P-value
Cancer site (ref: lung & bronchus)		
Pancreas	0.824	0.545
Prostate	0.858	0.693
Colon and rectum	0.744	0.436
Stomach	0.578	0.238
Other digestive system	0.743	0.453
Female genital system	1.436	0.490
Urinary System	0.404	0.091
Breast	0.952	0.925
Lymphoma	0.883	0.815
Oral Cavity and Pharynx	1.607	0.435
Other	0.646	0.456
Comorbidity: CCS score before cancer diagnosis (ref: 0)		
CCS score of 1-2	0.839	0.600
CCS score of 3-5	1.180	0.602
CCS score of 6-8	1.453	0.304
CCS score of 9 and above	2.297	0.028*

* Statistically significant at P-value < 0.05

Different paths to palliative care



Oncology referrals to Palliative Care: who, when, why

All patients on 1st, 2nd, 3rd visit

Refer everyone to expand team and enhance care: “It takes a village”

Referring early normalizes palliative care and reduces associations with hospice

For advance care planning support: “I do try to encourage everybody to seek palliative care up front in the beginning, and I kind of utilize them to do the POLST with them.”

When disease

progresses/problems surface

Advanced pain or other symptoms (can be gateway to goals of care conversations)

Psycho-social needs and family support

Skilled discussions about goals of care and dying including preferences for end-of-life care (e.g., CPR, feeding tubes, hospitalizations, hospice)

Never referred

Straight to hospice: For patients who never receive treatment, and patients ready to stop active treatment, hospice provides more services

“It’s my job”: Oncologist manages all pain, symptoms, goals conversations, and transitions patients to hospice

Patients with curable/good prognosis stage 4 disease. Patients “in denial” or who associate Palliative Care with hospice and “giving up.”



How oncologists frame referrals to Palliative Care

“This is extra help for you and me to care for you.” If they live far away, “When you’re here getting chemo, they can come by and see you when you’re here, so save you another trip.” That’s very helpful, as well.

“It’s not so much for you, but also for your family too, because **your family is going to need a lot of support with care giving.** You’re going to need help at home.” And then they realize it’s a service that gives them more help. If I frame it in that way, they don’t automatically think it’s all equated to hospice.



“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.**” ... I bring it up with the second or third visit. Not just when they turn the corner for the worst because when it goes south, you’re like, “Oh, my God. You’re condemning me to hospice, now?” So, I make it a point to bring it up earlier.

Oncologists: Benefits of Palliative Care

Pain and symptom management

“They're basically managing a lot of the side effects, so we can really focus a lot of our discussion on the cancer itself, or the chemo itself.”

“Pain management is such a big issue. I do it when I can but that's when they're on minor stuff... when they're getting Dilaudid every two, three hours and still having pain, I know better get someone to help.”

Advance Care Planning

“They talk about the power of attorney, the POLST, getting affairs ready with the family. I think they try to get that ball well aligned before things get worse and worse.”

“They have affairs set up well in advance. I think from that standpoint it reduces a lot of the chaos.”

Team care

“Another really huge benefit that I should mention is that patients get the feeling that they're taken care of by a team rather than one person. I think that really important.”

Time and flexibility

“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 15 or 20 minutes, 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're dealing with.”

Hospice transitions

“Just so much easier to talk about hospice when that time comes. They've been mentally prepared all along.”



Oncologists perspectives on “goals of care”

- What does “goals of care” mean?
 - Goals of treatment
 - Advance care planning & documentation
 - How patients’ values and preferences inform treatment
 - Stopping active treatment
- Discussion begins at 1st visit and “evolves”
- Palliative care team can support/lead discussions

“You want to be empathetic, but you want to at least be upfront and say this is a Stage 4 disease, this is advanced. I try to really stress that this is not going to be curative, whatever treatment option we talk about. **I try to use the word palliative very early and say we're just trying to control the disease. And again, we're just trying to give you relief and extend time, but we want it to be good quality time.**”

“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’re dying, no matter how much we try and have that conversation. They cannot accept the fact that they’re dying, and we ask for palliative care to step in.**”

Palliative Care goals of care discussions

- ❖ Patient understanding of illness and options for care
- ❖ Identifying patient values and goals and recommending care that aligns

“I don’t think patients really understand the difference between palliative chemotherapy and regular chemotherapy. I think those are really important distinctions because I’ve had people say, “Of course my cancer is still being treated. I’m getting palliative chemo.” And I said, “What does that mean to you?” And they said, “My cancer is going to be cured.”

“One of the things we do in palliative care is, we talk about goals of care. So, **‘I want to talk to you about how you’re feeling you’re doing overall, and give me a sense of what are your concerns, what are your fears?’** I’ll put the big, bad words out... I think it opens them up to have that conversation.”

“A lot of people don’t want to let go of their patients, too, and **they’re referring patients when it’s time to have that difficult conversation that the treatment’s not working,** or I need to tell you that you’re dying, but I can’t tell you that you’re dying, and let’s have palliative care [team] tell you that you’re dying.”

What have we learned?

Conclusions

- Referral to palliative care varies dramatically across patients and providers
- Clinic and provider level effects have a strong association with palliative care referral
- Oncologists see a benefit to themselves and patients from using palliative care to address goals of care, pain & symptoms, and psychosocial needs

Limitations

- One health system & lack data on patients who leave our system
- Lack data on hospice referrals and use, and on patient symptoms/pain/psychosocial needs
- Roll-out of palliative care by geographic area from 2012-2014

Next steps

- Analysis of patient interviews and EHR progress note data

Future research

- How are palliative care and goals of care discussed for other conditions?
- How do new cancer treatments change discussion of prognosis and goals of care?

Acknowledgements

- Pragati Kenkare, Information Management Group, Palo Alto Medical Foundation
- Mai Vu, Information Management Group, Palo Alto Medical Foundation
- Julie Roth, Director, Cancer Care Service Line, Palo Alto Medical Foundation
- Yvonne Chan, Manager, Palliative Care Department, Palo Alto Medical Foundation
- Lydia Jacobs, Tumor Registrar, Palo Alto Medical Foundation
- Oncology and Palliative Care departments at Palo Alto Medical Foundation

Funding

- Palo Alto Medical Foundation Philanthropy

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