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Gynecologic Oncologist Views Influencing Referral to Outpatient Specialty Palliative Care

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Abstract

Objective—Early specialty palliative care is underutilized for patients with advanced gynecologic malignancies. We sought to understand how gynecologic oncologists' views influence outpatient specialty palliative care referral to help inform strategies for improvement.

Methods/materials—We conducted a qualitative interview study at six National Cancer Institute-designated cancer centers with well-established outpatient palliative care services. Between September 2015 and March 2016, 34 gynecologic oncologists participated in semi-structured telephone interviews focused on attitudes, experiences, and preferences related to outpatient specialty palliative care. A multidisciplinary team analyzed transcripts using constant

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comparative methods to inductively develop a coding framework. Through an iterative, analytic process codes were classified, grouped, and refined into themes.

Results—Mean participant age was 47 (SD 10) years. Mean interview length was 25 (SD 7) minutes. Three main themes emerged regarding how gynecologic oncologists view outpatient specialty palliative care: (1) long-term relationships with patients is a unique and defining aspect of gynecologic oncology that influences referral, (2) gynecologic oncologists value palliative care clinicians' communication skills and third-party perspective to increase prognostic awareness and help negotiate differences between patient preferences and physician recommendation, and (3) gynecologic oncologists prefer specialty palliative care services embedded within gynecologic oncology clinics.

Conclusions—Gynecologic oncologists value longitudinal relationships with patients and utilize specialty palliative care to negotiate conflict surrounding prognostic awareness or the treatment plan. Embedding specialty palliative care within gynecologic oncology clinics may promote communication between clinicians and facilitate gynecologic oncologist involvement throughout the illness course.

Keywords

palliative care; qualitative research; early integration

Introduction

Specialty palliative care improves quality of life and may increase survival among patients with advanced cancer.¹⁻⁶ Both the American Society of Clinical Oncology (ASCO) and the Society of Gynecologic Oncology (SGO) recommend early integration of palliative care into standard oncology care.^{7,8} Despite these recommendations, available data suggest that specialty palliative care use for patients with advanced gynecologic cancers remains low.^{2,9} While several studies have identified barriers to integration of palliative care within medical oncology,¹⁰⁻¹² factors influencing use of specialty palliative care in gynecologic oncology have not been explored.

Gynecologic oncologists are unique in providing medical *and* surgical treatments. Their involvement with patients begins at diagnosis and may continue into surveillance or end-of-life care. In the United States, advanced palliative care is often delivered by specialized clinicians. Palliative care clinicians may be inpatient or outpatient and are distinct from primary care providers. Understanding how gynecologic oncologists view outpatient specialty palliative care services may help to improve the provision of palliative care to patients with gynecologic cancers.

We sought to understand gynecologic oncologist views that influence the utilization of outpatient specialty palliative care. We used a qualitative approach, which is uniquely suited to investigating questions of “why” or “how” when there is little preexisting information, and to understanding behaviors and systems.^{13,14} We chose to examine the use of outpatient palliative care because outpatient referrals occur earlier in the illness than inpatient consultations,¹⁵ which may facilitate more comprehensive palliative care provision and

adherence to ASCO and SGO recommendations. Our goal is to provide the groundwork to inform development of future strategies for improving provision of palliative care in gynecologic oncology.

Materials and Methods

Study Design

We conducted a qualitative, in-depth interview study to understand gynecologic oncologists' views on outpatient specialty palliative care.

Sample and Recruitment

Participants included 34 gynecologic oncologists at six National Cancer Institute-designated cancer centers with well-established outpatient palliative care clinics. We selected cancer centers with a diversity of geographic location, gynecologic oncology program size, and palliative care clinic structure (Table 1). Eligible participants were attending-level gynecologic oncologists with an outpatient practice of at least one half-day per week. Study authors were excluded from participation. Potential participants were initially contacted by email. Follow-up to schedule interviews was conducted via a combination of email and direct contact by local colleagues.

Data Collection

Interviews were conducted via telephone between September 2015 and March 2016 by an investigator trained in semi-structured interviewing techniques (C.M.H).

Standard in-depth interviewing techniques focused on oncologist experiences and practices surrounding referral to outpatient specialty palliative care. Participants were asked open-ended questions, with follow-up probes to elicit rich description of individual experiences. Questions were designed to be non-leading and the interviewer was trained to pose questions in a neutral and non-directive manner. Participants were asked to reflect on personal patients and discuss hypothetical patients presented in brief vignettes. The full interview guide is available in Supplemental Data Content 1. This study was approved by the University of Pittsburgh Institutional Review Board (PRO15070206).

Data Analysis

Audio-recorded interviews were transcribed verbatim. A coding framework was developed using qualitative description, a technique to describe events or phenomena and the meanings participants attribute to them.¹³ Initial codes were developed inductively through line by line coding of a subset of transcripts. Concepts and codes were discussed, compared, and refined by a multidisciplinary team with expertise in palliative care, gynecologic oncology, qualitative research methodology, advanced practice nursing, anthropology, and public health, using constant comparative methodology.¹⁴ An investigator trained in qualitative analysis (C.M.H) applied the final coding framework to all transcripts and a second investigator (S.C.) coded 50% of interviews, with comparison undertaken to ensure inter-coder agreement. All disagreements were discussed and resolved by consensus. Through an

iterative, analytic process codes were classified, grouped, and refined into themes.¹³ ATLAS.ti Software (V 5.5.9 Berlin, Germany) facilitated data analysis.

Results

We contacted all eligible gynecologic oncologists (35 in total) at six different institutions. Thirty-four participated for a response rate of 97%. All participants were board certified or eligible in gynecologic oncology. Clinician characteristics are listed in Table 2. Average interview length was 25 (SD 7, range 14–45) minutes. The views expressed when discussing hypothetical vignettes were similar in content to those expressed when reflecting on personal patient experiences.

In analysis of participant interviews, three themes emerged related to how gynecologic oncologists' views influence use of outpatient specialty palliative care:

(1) Long-term relationships with patients is a unique and defining aspect of gynecologic oncology that influences utilization of outpatient specialty palliative care

A majority of participants (27/34) discussed long-term relationships with patients as influencing use of outpatient specialty palliative care services (Table 3). Gynecologic oncologists were evenly split between reporting that these relationships increased versus decreased palliative care referrals.

Participants noted that patients were more likely to accept referral from a physician with whom they had a longitudinal relationship due to better physician ability to address negative connotations of palliative care and increased patient trust in physician recommendations. As one participant explained:

I think you develop a trust with the patient and it's just another thing that you're recommending to them, and it's not seen as out of the blue, it's just part of the care. [...] I think if you're comfortable and they trust you, they're going to kind of accept and trust what you're recommending.

Many participants noted that their relationships with patients obligated them to obtain the best possible care for the patients, thus increasing palliative care referrals. As one participant explained:

Compared to medical oncology and surgical oncology I think we have a unique bond with our patients because we go through much more of their treatment with them, versus the surgical and medical oncology where they only see fragments of the patient, so I think we have a unique relationship with the patients where they really bond with us and that gives us the opportunity to really make sure that all of their needs are being met and to really make sure that they get in to see the supportive care team.

Another added:

I think we do see them over a long time, their entire treatment course versus parts of their treatment. So I think that gives us a little bit more credibility with the patients. I think it could be done either way but, I think that's something unique to

the field and we should take advantage of that, make sure the patients get the best care that they can.

Other participants felt long-term relationships with patients decreased use of outpatient specialty palliative care; they attributed this to their desire to maintain a longitudinal relationship and continue to personally provide a broad spectrum of care:

We're the only specialty that actually does chemo, and does surgery, and does end of life stuff, not everybody does everything, but that's kind of why I went into it, is so that I could follow my patients from diagnosis to death or cure depending on the situation, but to me that's a really integral part of my practice, is helping people with end of life issues, so I don't really like to give that up.

For many participants longitudinal relationships were a reason for choosing gynecologic oncology, and providing palliative care was a valued part of their job. One participant discussed concern for losing that valued relationship when referring to palliative care: "Well I think just that we take care of the patient from diagnosis until death, that part of that taking care of them at the end, I feel like is part of my job, that's why I chose this field, and I don't want to give my patient away completely."

(2) Gynecologic oncologists value palliative care clinicians' communication skills and third-party perspective as a means to increase prognostic awareness and help negotiate differences between patient preferences and physician recommendations

All participants discussed the well-known value of palliative care clinicians in complex symptom management. The majority of participants (29/34) also identified palliative care clinicians' ability to communicate and provide emotional support to patients and families as a major reason for referral (Table 4). For example, one participant described the value of palliative care clinicians in family meetings:

I mean number one, they are better communicators than most surgeons [...] and then we also, besides having a rushed schedule, don't possess the communication skills, or at least I don't think we do, to facilitate those conversations as eloquently as the palliative care folks do.

Palliative care clinicians were described as "absolutely key in helping the patient to navigate an extremely difficult and very intensely sad situation" and an important part of helping families communicate.

Many participants described using outpatient specialty palliative care to help increase patients' prognostic awareness – i.e. their understanding of their prognosis and illness trajectory. One participant said they would refer when a patient was struggling with "realizing they had recurrent cancer and perhaps not fully understanding their state of disease"; another for "more realization of their state of disease and what the expectations are for outcome". Participants also frequently referred to palliative care when a patient's poor prognostic awareness was perceived to influence her treatment preferences. One participant described referring because "the patient was having and continued to have for a long time, sort of the denial of you know, that we are out of active treatment options". Another spoke of

referring “the person that you need the most help with because you’re not getting through to them and you think that well maybe somebody else can get through to them”.

Participants felt palliative care clinicians were “very good at addressing goals of therapy and trying to align patient expectations with the reality of what is going on” and that additional clinician input facilitated acceptance of prognosis. One participant explained, “You have a patient who sort of is kind of not listening, not hearing or not processing that, I just feel like they need to hear that from maybe a different perspective, or a different voice.” Another considered, “It may be more about talking and being able to hear information from a source other than their primary physician that I think they all know but they don’t want to acknowledge.”

Many participants felt that the ability of palliative care clinicians to provide third-party input was key to influencing and guiding patients. As one participant explained, “sometimes having a surveyor who’s not perceived as the architect can be very helpful.” For this reason, participants frequently referred to palliative care to help negotiate conflict when patient or family treatment preferences differed from their recommendations:

Bringing in an objective care provider when someone is at a point where we may feel that it’s clear what they need and they may be in conflict with that. I think that can be beneficial, sort of helps us and supports us in moving that patient toward a transition in their care that we want to see happen.

One participant described referring to palliative care when patients or families resist a recommendation to transition away from active treatment:

We need to make that transition and they’re very resistant, so that will be someone who maybe them, or more often than not the family member’s not ready to embrace hospice but they still have significant needs that have to be met, so we’ll often get the palliative care team involved because they’re very good at objectively providing another layer of information for the family that helps them along in that decision making.

Participants also discussed referral when patients would not accept recommended treatments that were more aggressive. One participant referred to palliative care due to “patient refusal to let me take care of her in the most appropriate way.” Another referred when a patient declined recommended treatment:

This particular patient [...] had surgery for advanced disease and who I recommended adjuvant treatment for. She declined adjuvant treatment and opted for cancer surveillance, but I offered to refer her to palliative care so that they could discuss with her her disease. I felt that it would likely recur.

(3) Gynecologic oncologists prefer specialty palliative care embedded within gynecologic oncology clinics

A majority of participants (22/34) preferred embedding palliative care services directly into oncology clinics, primarily to facilitate optimal communication and continued involvement of the gynecologic oncologist throughout the disease course. Embedded services were also

felt to optimize efficient delivery of services and decrease logistical barriers encountered by patients (Table 5). These views were expressed similarly by participants practicing at institutions with and without embedded palliative care services.

Half of participants discussed the importance of communication between gynecologic oncologists and palliative care clinicians, with many voicing concern about referral leading to loss of control and awareness of patient care. As one participant explained:

My only concern with referring any patient out would be potentially loss of total control of what was going on, inability to know what other people are doing for her. I mean we have electronic medical records but they're not going to call and tell you everything they decided to do on every patient.

Another discussed concern about losing awareness of patient care:

Ideal would be [...] conversations about issues that may not be able to be discussed via the EMR, so that if something comes up that one of the physicians doesn't know about go ahead and discuss that face to face, phone conversations. Major changes don't need to happen and be put in the chart and the other person not know about it.

Embedded palliative care services were felt to provide the close proximity and direct contact identified by participants as important to facilitating quality communication:

The more that you embed, they come to see you and they see the nutritionist and they see the palliative care person [...] and if [the palliative care clinician] saw the patient in your consult room, you would take five minutes to talk face to face probably, before or after, whereas even if it's just the floor below, they go down there, unless it's like a big problem you don't pick up the phone and talk to them, you read their note, they read your note. I just think when more than one service is taking care of a patient, the more that there's face-to-face communication the better for the patient.

Half of the participants who advocated for embedded palliative care services specifically expressed interest in utilizing non-physician clinicians. Participants made analogies to successful nurse-led systems in chemotherapy support, discussed cost-effectiveness, and referenced successful non-physician-based palliative care structures.

Having the advanced practice provider and the nurse available, making them part of the work flow within the office visit, as just another, you see the chemotherapy nurse, you see the palliative care nurse or advanced practice provider [...] just like practice nurses for chemotherapy patients or radiation nursing for patients undergoing radiation treatment.

Discussion

Through in-depth interviews, gynecologic oncologists described their use of outpatient specialty palliative care as strongly influenced by long-term physician-patient relationships, as helping to increase patient prognostic awareness and navigate patient-physician conflict, and as ideally embedded within the gynecologic oncology clinic. While some gynecologic

oncologists felt long-term relationships with patients increased use of outpatient specialty palliative care services, others felt that these relationships decreased use, illustrating a variability and complexity to referral decisions. Participants at each institution expressed each viewpoint, suggesting that variation occurs at an individual rather than an institutional level. Participants frequently discussed longitudinal relationships with patients as a unique component of their professional identity that distinguished them from other oncologists, suggesting that gynecologic oncologists may require a unique approach to the integration of specialty palliative care that preserves and respects these primary physician-patient relationships.

Participants universally used outpatient specialty palliative care for assistance with complex symptom management, consistent with well-recognized indications for referral.¹⁶ Additionally, participants highly valued specialty palliative care for a specialized communication skill-set and for their role as independent from the primary treatment team. This suggests that while both patients¹⁷⁻¹⁹ and physicians²⁰⁻²² value long-term relationships, sometimes these relationships benefit from involvement of a third-party to help identify conflict etiology and develop a mutually acceptable treatment plan. This finding underscores the importance of close and direct cooperation between palliative care clinicians and oncologists, and supports the need for integration of specialty palliative care into standard oncology care.

The majority of participants preferred palliative care services embedded within oncology clinics, consistent with gynecologic oncologist commitment to longitudinal relationships and desire for oversight and active involvement across a broad spectrum of care. Importance of communication between clinicians was frequently discussed, with many participants expressing concern that referral would decrease their awareness and involvement in patient care. Systems that promote close communication and collaboration between palliative care clinicians and oncologists, for example, by embedding palliative care within gynecologic oncology clinics, may increase likelihood of referral. Additionally, use of non-physician palliative care clinicians may help address concerns about cost effectiveness and capacity to manage the large volume of referrals that could occur if current recommendations for early palliative care for patients with metastatic cancer were implemented^{7,8}.

Study strengths include a diverse, multi-institutional sample and high response rate. Institutions were academic with established outpatient palliative care clinics, thus results may not generalize to community practices or settings where palliative care is less available or provided via different delivery models. All institutions were in the United States and thus results may not be generalizable to countries with varying healthcare system structures. In particular, gynecologic oncologist views on integration and desirable approaches may differ in systems with universal health insurance or in which primary care providers play a larger role in continuity of care and end-of-life.

In summary, we found that gynecologic oncologists highly value their longitudinal relationships with patients, and seek to involve palliative care clinicians for symptom management as well as for help in navigating these long-term relationships when differences arise between patient preferences and physician recommendations. Our study illustrates that

new approaches to palliative care provision and integration are most likely to be adopted by gynecologic oncologists when the oncologist-patient relationship is supported and maintained. Embedding palliative care clinicians within gynecologic oncology clinics and utilization of non-physician palliative care clinicians are two promising approaches to integrating palliative care services that facilitate continued and active gynecologic oncologist involvement in patient care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Institution Characteristics

Palliative Care Clinic Characteristics						
Institution	Gynecologic Oncologists (#)	Name	Location	Proximity to Gyn Onc Clinic	Date Established	Staffing (physicians, APPs)
University of Pittsburgh Medical Center Pittsburgh, PA	9	Supportive and Palliative Care Clinic Supportive and Palliative Care Clinic	Women's Cancer Center at Magee-Womens Hospital Gynecologic Oncology Clinic at Magee-Womens Hospital	Same building, different floor Embedded in Gyn Onc Clinic	2008 2014	0.15 FTE MD 1.0 FTE CRNP 0.10 FTE MD
University of North Carolina Chapel Hill, NC	8	UNC Palliative Care Clinic UNC Palliative Care Clinic	UNC Lineberger Comprehensive Cancer Center Off site	5 minute walk indoors 5 minute drive	2008 2008	0.8 FTE MD 1.8 FTE NP
University of Alabama Birmingham, AL	6	Supportive Care and Survivorship Clinic	Kirklin Clinic	8 minute walk indoors	2002	0.4 FTE MD 0.8 FTE APN
University of Washington Seattle, WA	8	Palliative Care Clinic	Seattle Cancer Care Alliance	Same building, different floor	2001	2.6 FTE NP
University of Virginia Charlottesville, VA	4	Palliative Care Clinic	Emily Couric Clinical Cancer Center	Same building, different floor	2001	3.0 FTE MD 1.0 FTE NP
University of California San Francisco San Francisco, CA	3	Symptoms Management Service Symptoms Management Service	Mission Bay Campus Mount Zion Campus	Same building, same floor Same building, same floor	2015 2006	0.5 FTE NP 0.7 FTE MD

APP: Advanced practice provider

FTE: Full time equivalent

Table 2

Participant demographics

<i>Characteristic</i>	<i>n (%)</i>
Age (years)	
35	3 (9)
36–45	14 (41)
46–55	11 (32)
56–65	4 (12)
>65	2 (6)
Sex	
Female	19 (56)
Male	15 (44)
Race	
White	23 (67)
African American	3 (9)
Asian	7 (21)
Hispanic	1 (3)
Time in practice, since residency (years)	
<5	4 (12)
5–10	8 (24)
11–15	7 (20)
16–20	5 (15)
>20	10 (29)

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Table 3

Long-term relationships with patients is a unique and defining aspect of gynecologic oncology that influences utilization of outpatient specialty palliative care

View	Representative Quotes
<i>Increases</i> utilization of palliative care	I think our patients may be more willing to see the supportive care team, especially if we're recommending that they go, because I think that they have much more, I wouldn't say better relationship but I think we have a longer relationship with them than say a medical or surgical oncologist who only sees them for kind of periods of time. Whereas in GYN oncology I really feel like we are those people, again, from time of diagnosis to end of life. And you know, these are often women who we have a long standing relationship with, with both the patient and their families, and I think that, I would imagine that sometimes makes kind of the introduction of palliative care, or the concept of palliative care, or hospice care, or addressing goals of care, actually a little bit easier for us, than for some other cancer care providers, because we have such long relationships with these people Because we do surgery and because we do chemo and because we do the long term follow up for our patients and we know them so well, I think it in many ways it just makes it easier to have very frank conversations with patients about things like involvement of palliative care
<i>Decreases</i> utilization of palliative care	I think we bond with our patients much more and there's more of a relationship than there might be with surgical oncology or medical oncology because they transition patients back and forth, we tend to keep patients throughout their course [...] I think the way, maybe medical oncology less, surgical oncology more, but the way the specialty sees themselves in other fields, they're all too happy to disposition the patient to another provider, hoping that the patient will stick with that provider, but we in GYN oncology, and that's one of the things I liked about the field, like to retain that patient through the whole breadth of their experience I actually like managing a lot of the symptom stuff, because if I'm managing that I can number one know when my treatments are working, I know when to back off, I know when to stop. If someone else is managing all that then I'm not really managing her recurrence. It's sort of a philosophical thing that I sort of picked up in training, that it's actually part of my job.

Table 4

Gynecologic oncologists value specialty palliative care clinicians' communication skills and third-party perspective as a means to increase prognostic awareness and help negotiate differences between patient preferences and physician recommendations.

View	Representative Quotes
Communication skills and emotional support	<p>One of the best things I think they do is communication. Really the time that they spend communicating with the families to kind of bring everybody on the same page is something that is a skill set that most GYN oncologists don't have and also don't have time to do.</p> <p>You know patients that are having a lot of stress too, maybe don't have good social support, that they can kind of help them work through how to talk with their family and all that kind of stuff, I feel like that's more part of their training than mine.</p> <p>And then patients who are having a lot of difficulty with dealing with the sort of the logistics around how they're going to talk to their family members, oftentimes, especially at the point at which it's clear that their diagnosis, they no longer have a curable disease, so family issues, emotional distress, issues with helping them address death and dying both with themselves and a lot of times with their families.</p>
Third-party clinician used to increase prognostic awareness	<p>If you have a patient who is really struggling, to hear it from a different person's perspective I think can be good.</p> <p>And then by engaging the palliative care folks, like I said before, you have multiple people talking about the same issues, so it tends to reinforce in the patient that it is important for them to understand where their disease is and that they may want to start thinking about end of life issues.</p> <p>If they seem like they really need additional people to talk more, or they seem maybe not as understanding of their prognosis sometimes if they would listen to a second provider coming from a different angle I think it's helpful to get them that information</p>
Helps negotiate patient-physician differences	<p>Patients who are referred to palliative care, and I can think of several examples of this, are usually patients who, either by myself or my nurse practitioner, were breached about hospice or were having pain control issues with their existing support system and we were trying to change their pattern of care from being admitted for pain control and/or realizing they had recurrent cancer and perhaps not fully understanding their state of disease, need additional counseling, from someone other than my nurse practitioner or I, as their primary caregivers, might have trouble conveying the seriousness of where they were [...] At that time we tried to breach hospice, she was not accepting. So, as per my previous comments we sent her for palliative care support.</p> <p>Really clarifying what chemotherapy can and can't do, that's a discussion I would have with her too, but sometimes when that's kind of had by multiple different people I think then it's a little bit easier for someone to shift and say this is no longer achieving what we want to accomplish and it can be a little bit of an easier of a transition, or sometimes patients feel a little bit more at peace with that decision. You know it's always a better thing when it's kind of the decision to stop chemo is initiated both by the provider and the patient rather than just the provider saying I'm sorry you can't have any more chemo, no one wants choices taken away from them.</p>

Table 5

Gynecologic oncologists prefer palliative care services embedded within their own clinics.

View	Representative Quotes
Prefer embedded palliative care services	<p>I think the model of having palliative care available in the clinic where patients are being treated, being seen for their clinical services and being treated, is probably the best model for outpatient.</p> <p>I think in a perfect world we'd have a representative or two of their service in our clinic setting. I think that would be the ideal scenario, where we could identify patients during the clinic that were flagged as being at a point in their treatment where they may be benefitted by palliative care services as an outpatient and have them available to those patients during their clinic visit, I think that would be the ideal scenario. So that they're not going somewhere else. And that they were actually integrated into our clinic setting, that would be ideal.</p> <p>My ideal scenario, that the services are basically incorporated in the same facility and that there's good communication. I feel like they're more accessible because we're generally around the same area, so you can have more of an open discussion with the other team members. So I think that dialogue amongst the providers is more available.</p> <p>And we work as a team, they'll come out as soon as they're done talking to my patient they'll tell me what they think, I'll tell them what I think and then we'll sort of you know, come up with what we think is the best plan.</p> <p>Having a provider who really works specifically with our group, with GYN oncology patients, who is physically based in our office, five days a week, I really do feel like that is ideal for our patients.</p>
Interest in non-physician embedded palliative care clinicians	<p>Ideally they would be in my clinic just like I have my nurse practitioners and nurse clinicians and we have our own chemotherapy center for just GYN oncology</p> <p>I'd rather have a nurse practitioner that was interested in palliative care be part of our clinic, I mean we have such a high volume of patients I don't know why they have to be seen somewhere else, that's the part that confuses me, and I don't think it has to be a physician at all</p> <p>I think when we started we didn't have [nurse practitioner] down in the clinic and I definitely think that it was definitely harder to refer, because then they had to go, they had to make an appointment to go see somebody, and for some of these patients it's hard for them you know, going and then come back to the hospital.</p> <p>In the best of both worlds it should be a dual visit instead of separate visits in series, it should be together, but certainly part of the same office visit [...] and I think it's far more economical to have non-physician based teams that are palliative care based that are taking care of patients as outpatients</p>

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