

Deconstructing the Meaning of Multidisciplinary Cancer Care

A mixed-method study of patients and providers

ollaborative multidisciplinary cancer care involves multiple specialists who discuss and guide treatment plans together, and this approach is now standard of care for patients with cancer. Whereas initial studies questioned the increased expenses and organizational complexity involved with delivering multidisciplinary cancer care,¹ more recent studies show that effective collaboration of oncology providers impacts treatment recommendations and improves survival for a variety of cancer types.²⁻⁷ Today, cancer programs widely employ the multidisciplinary cancer care process, speaking to the overall positive perception providers have about this model of care.

Though the adoption of multidisciplinary cancer care delivery is high, little is known about which specific structural features most effectively enhance cancer care. Further, the logistics and structure of multidisciplinary cancer care delivery vary significantly by institution and team.⁸⁻¹⁰ This variability includes differences in communication models, frequency of interaction, and the nature of decision-making processes, among others.¹¹

Although multidisciplinary cancer care is aimed at improving care for patients and families, little is currently known about how this type of care delivery impacts the patient experience. Despite increased focus in recent years on patient satisfaction in healthcare, there remains a significant gap in our understanding of how the multidisciplinary cancer care process impacts patients and families. Few studies have examined patient preferences regarding their initial experiences with multidisciplinary care (i.e., the short time period after receiving a cancer diagnosis).

The Experience at University of Wisconsin Hospitals and Clinics

Over the past few years, the University of Wisconsin Hospitals and Clinics in Madison, Wisc., has been redesigning its clinic structure, including the oncology clinics where multidisciplinary cancer care is provided. As is typical in other institutions, the structure of multidisciplinary teams, the decision-making process employed, and the communication models and processes used vary significantly by cancer type. As part of the conversation regarding the optimal restructuring of these multidisciplinary cancer care clinics, we developed a quality improvement (QI) project focused on understanding how patients view multidisciplinary cancer care. The purpose of our study was to obtain the perspectives-and preferences-of patients and providers on the important structural aspects of multidisciplinary cancer care during the initial phase of care to inform this restructuring. We also looked to uncover any barriers preventing alignment of multidisciplinary cancer care processes with patient preferences. As part of a QI study, an institutional self-certification form was completed, and a formal internal review board analysis was not required. Below we highlight key components of our QI study.

Method: Online Survey

To gain a broad understanding of patients' preferences regarding outpatient cancer care from a national perspective, we surveyed the membership of six virtual national cancer support groups. Survey questions were developed based on the phases of care, including initial diagnosis, first appointment, and follow-up. These questions were formulated from the multidisciplinary discussions that occurred as part of our clinic structure and redesign process and were exploratory in nature. The survey was anonymous, and we solicited voluntary responses. Support group members were asked to specify whether they were a patient with cancer, a survivor, and/or a caregiver, as well as their cancer type. Participants then answered 11 questions regarding their initial cancer diagnosis experience, including the timing of their initial visit(s) with oncology providers, their experience with multidisciplinary teams and nurse navigators, and their preferences. Responses were tabulated and percentages were calculated.

Method: Provider Interviews

To obtain the provider perspective, from June through August 2017, we conducted semi-structured interviews from June through August 2017 with multidisciplinary cancer care providers who had significant experience coordinating the initial care of new patients with cancer at the University of Wisconsin Carbone Cancer Center. We employed the basic principles of qualitative interviewing.¹² Specifically, given that "cancer providers" represent a cultural world within the medical community, we used the lens of ethnographic interviewing for this step. The interview guide was formulated using the question types outlined by Spradley (i.e., descriptive, structural, and contrast questions).¹³ We included grand- and mini-tour questions, as well as example and experience questions.¹³ The interview topic guide focused on determining provider perceptions of patients' experiences and preferences for multidisciplinary cancer care delivery, as well as understanding

providers' experiences with initial multidisciplinary cancer care delivery for new oncology patients.

Method: Patient Focus Group

Our team partnered with a local cancer support organization to obtain the perspectives and experiences of patients with cancer care in our community. After obtaining input from the program director of the cancer support group, we decided that a focus group setting would best allow patients, survivors, and caregivers to discuss their various experiences with the structural aspects of multidisciplinary cancer care. The organization promoted the focus group to its members by posting flyers at their site asking for input to help improve the care of patients with cancer at our institution. The topic guide was designed based on a review of the literature and data previously gathered through the online survey and provider interviews. Our research team reviewed and revised the drafts of the interview guide until a consensus was reached. The focus group topic guide centered on patients' experiences with cancer care, starting at initial diagnosis to after their first multidisciplinary provider visit. A flexible, open-ended, and dually moderated focus group was conducted on-site at the cancer support facility,14 and no identifying information was collected from participants.

Method: Qualitative Analysis

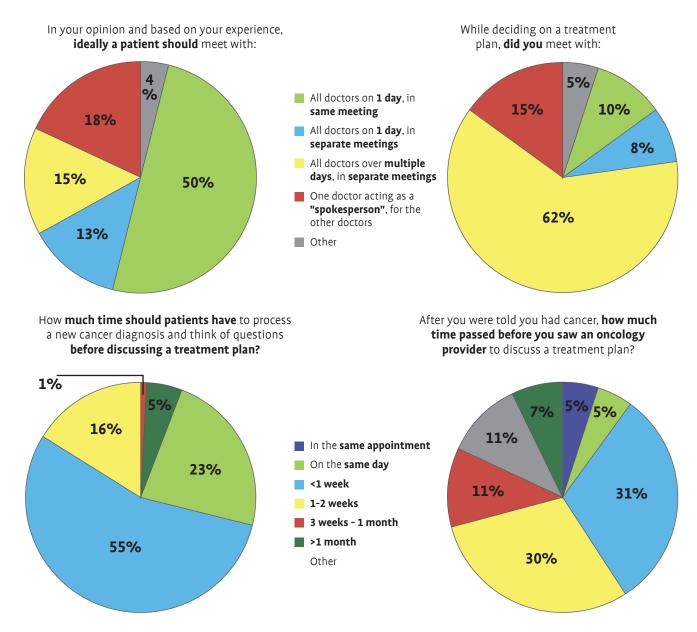
All interviews and the focus group were audio recorded and transcribed verbatim. Conventional content analysis was used to analyze interview transcripts,¹⁵ and constant comparison analysis was used to analyze the focus group transcript.¹⁶ Two authors (VRR, MMR) coded each transcript independently using lineby-line coding, and an iterative process was used to refine codes. Final agreement was reached by discussion. All study authors sorted and grouped the codes to independently identify central themes and subthemes from the interviews and focus group. Study authors then determined common themes that emerged between both the provider interviews and focus group.

Results: Patient Survey

There were 156 respondents to the online survey. Most respondents reported having colorectal cancer (65 percent), with the remainder having lung cancer (7 percent), pancreatic cancer (6 percent), or other cancer (11 percent) or identifying as a caregiver (11 percent). About 40 percent of respondents received their cancer diagnosis from a doctor or surgeon while they were admitted to a hospital. Fifty-one respondents (33 percent) reported that they were seen by a "multidisciplinary team," but of those who said they were not, 36 (55 percent) reported meeting with multiple specialists (e.g., medical oncologist, radiation oncologist, and/or surgeon) to determine a treatment plan.

After receiving their initial diagnosis, respondents indicated confusion about the next steps—39 percent reported that the next steps were not clear, and 35 percent said they did not know whom to contact with questions. Respondents also reported differences between their preferred structural aspects of initial visits after a cancer diagnosis and what they personally experienced (Continued on page 56)





*Online support group participants' preferences differ from their own experiences with the structural aspects of cancer care delivery. All support group members (156 people) were asked for their opinions on the ideal timing and contextualization of multidisciplinary cancer care appointments with providers for a patient who had just received a cancer diagnosis. They were also asked to provide information on their own experiences.

(Continued from page 54)

(Figure 1, page 55). For example, although 78 respondents (50 percent) thought a new patient with cancer should ideally meet with all of their treatment physicians in one collective meeting, only 15 (10 percent) had that experience. Of the patients surveyed, 62 percent met with cancer care providers over multiple days in separate meetings. Most patients preferred to meet with a cancer provider within a week of receiving a cancer diagnosis, yet the majority of patients (59 percent) experienced a longer wait time.

Results: Provider Interviews

In total, 10 major themes were identified from the provider interviews (Table 1, right). Comments fell into categories according to the new patient with cancer evaluation timeline that centered on the following time periods:

- Before first appointment
- During first appointment
- After first appointment
- Throughout all time periods.

Before the First Appointment

Four themes were identified that centered around the time between a diagnosis and the first multidisciplinary cancer care appointment.

- 1. *Many barriers to streamlining care*. Providers expressed a desire to streamline the multidisciplinary cancer care process to evaluate new patients, but many barriers often arise, like patients having different preferences, complexities of different cancers and disease staging, desire to be prepared for the first appointment (e.g., obtaining additional diagnostic studies prior to a visit), logistical considerations (e.g., provider availability, facility needs, staffing, etc.), need for experienced triaging, and needed access points that are available to patients.
- 2. Need to get patients "in [and] over the wall." Considering the patient experience, providers emphasized the need to connect with patients early. One provider described this as, "You just need to get them in [and] over the wall." Patients perceive that building a connection with the multidisciplinary cancer care team and identifying a contact person early is a substantial challenge for them. One nurse navigator mentioned that connections to a specific and reliable member of the multidisciplinary team within the health system can help overcome this barrier and connect patients quicker. Providers emphasized the importance of nurse navigators in the communication and facilitation of care for patients who are accessing the system.
- **3.** *Need for early contact.* Providers noted the benefits of providing information early (as soon as possible after diagnosis) to patients through prior contact rather than waiting until the first appointment. As they discussed early contact with patients, a subtheme emerged: the desire to avoid overwhelming patients while providing this initial information.
- 4. *Patient reassurance is important.* Finally, providers emphasized the importance of reassuring patients during this period of early contact.

During the First Appointment

Three themes focused on the first multidisciplinary cancer care visit.

- 1. Make the most of the patient visit. At the time of the first appointment, most providers wanted to "make the most" of a patient's visit by making it a meaningful (i.e., easy, convenient, productive, and informative) experience. Providers expressed the desire to not waste patients' time. This included ensuring all records have been obtained and reviewed prior to the visit. There was general consensus on having all appointments with various providers on the same day and dedicating time for explaining the available supportive care services that can be helpful for patients.
- 2. *Provider flexibility is helpful.* Providers felt that first visits were better when providers were flexible in regard to scheduling last-minute visits or opening time on a non-clinic day. This flexibility was viewed positively by the nurse navigators and cancer center access nurses.
- 3. Desire not to overwhelm patients. Providers also acknowledged that the first visit can be overwhelming, and they desired to minimize overwhelming information. However, multiple providers expressed that the overload of information was unavoidable.

After the First Appointment

One theme was consistently identified by all providers regarding the time after the first appointment: *a need for follow-up contact*. Providers expressed a goal of not letting new barriers form that prevent patient contact. Nurse navigators, in particular, saw their role as helping explain what was discussed in the first appointment and answer questions. This contact was described as multi-modal and includes the health record messaging system for patients, as well as the 24-hour triage line. Providers also mentioned planning future patient phone calls to continue discussions after the first appointment.

Throughout Treatment

Two identified themes were broadly applicable throughout the multidisciplinary care timeline.

- 1. Considering the multidisciplinary process as a whole, providers thought *direct provider-to-provider communication was critical*. Nurse navigators appreciated the ability to talk with other nurse navigators about a patient's plan. The medical oncology fellows described helpful communication via the chart and phone calls with other providers as well.
- 2. With many participants included in the multidisciplinary process, providers considered it helpful to have *one designated provider primarily responsible for each patient*. This would include any primary communication with patients and coordination with other specialists. The medical oncology fellows thought that there was a good system in place to designate a primary "owner" of a patient case, though others thought this was not always true.

Table 1. Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Timing: Before First Appointment

Provider Interviews

Theme 1: There are many barriers to streamlining care.

Subtheme(s): 1) Patients have different preferences, 2) complexity of different cancers and disease staging, 3) desire to be prepared for the first appointment, 4) logistical considerations, 5) need for experienced triaging, and 6) many access points to care.

Representative quote(s): "I've heard two different perspectives. Some patients want to be seen right away after their diagnosis; they want all their options, and they want to decide before they leave clinic that day what their treatment plan is. And I've had other patients who get their diagnosis, and they want to wait a couple weeks to let it sink in." (Nurse Navigator)

"I think that who they meet first depends on what type of cancer they have and the order that their treatment standard of care needs to be delivered." (Medical Oncology Fellow)

"Record collecting for patients that are not in our system is another big issue. Making sure we have all the records and reviewing the records to see what they have and what they still need—that needs to happen before they [the patient] can be seen, too. If a patient shows up and they haven't even gotten all their records, then what's the point of them making the trip all the way here?" (Nurse Navigator)

"If we have any questions at all about the urgency, we ask the provider because access is a big problem right now. Most of our providers are booking out at a minimum of two weeks." (Cancer Access Center Nurse)

"I do a tremendous amount of coordinated care so once someone gets into this system, I can call a patient and get a lot of valuable information in order to streamline their care and triage things over the phone, [like] ordering staging workups, tests and labs. I think I know the diseases and the surgeons well enough to reduce travel burden and reduce redundancy in ordering." (Nurse Navigator)

"I think the biggest issue is definitely there are too many access points coming into the same thing." (Nurse Navigator)

Theme 2: A need to get patients "in [and] over the wall."

Subtheme(s): 1) Initiate contact, 2) personal connections are helpful, and 3) nurse navigators are important.

Representative quote(s): "I give them my direct number just in case they have any type of questions...I'm always available for them to ask." (Nurse Navigator)

"[Other providers] know that they can call me to get someone into the system." (Nurse Navigator)

"I always like to tell people, 'If you have a pancreatic head mass that's resectable, then you're going to land on an OR [operating] table whether I'm in the picture or not. I can make that journey much more pleasant." (Nurse Navigator)

Theme 3: A need for early contact.

Subtheme(s): 1) Provide information early and 2) give that information but don't overwhelm.

Representative quote(s): "When someone gets diagnosed on the inpatient [side, and you go] in to just tell the patient, 'Hey, we're the oncology team. I'm aware of your case. We need x, y, and z done and then we'll talk more in detail.' And that seems to be a good kind of in-between discussion. ... Meanwhile, we'll get you into the clinic and get any additional testing we need to give you a better answer to your questions." (Medical Oncology Fellow)

"I honestly think that before that first appointment, if you give them [patients] too much information...it will just completely confuse them. And then the questions they come in to ask will not necessarily have the focus that they might otherwise have had." (Cancer Access Center Nurse)

Patient Focus Group

Theme 1: Difficulty processing after a diagnosis ("the blur").

Subtheme(s): N/A

Representative quote(s): "I do agree that getting hit with the word cancer—you go into shock. You're not really listening to what the doctor is telling you right then. My husband was called in with me, and he wasn't listening any more than I was. We were both in shock. And you just leave the doctor's office, and you get in your car and you drive home. You're just gone." (Focus Group Participant)

Table 1 (continued). Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Theme 2: "Somebody there to catch you."

Subtheme(s): Desire for support.

Representative quote(s): "I like this gentleman's idea where you get the news [a cancer diagnosis] in whatever format you get it. And there is somebody there to catch you when you get that news and...say, 'I would really like to call you or have you come in...and make another plan so that we can kind of get beyond the scope that I have cancer and now we need to talk about what we're going to do about this.'" (Focus Group Participant)

Theme 3: A need for early contact.

Subtheme(s): 1) Set expectations and give practical information about first appointment, 2) contact needed before appointment, and 3) desire for streamlined communication.

Representative quote(s): "So maybe, even on the appointment you make—the appointment to speak with the doctor or the surgeon or whoever is going to be the one to tell you that you have this [cancer]—that they would tell you in advance that this appointment is going to take longer. Allow yourself extra time." (Focus Group Participant)

"Call and say, 'I understand you have a diagnosis of cancer,'—maybe it's been identified, maybe it hasn't—'Would you like to set up an appointment? Would you like to talk for a little bit? Do you have some questions?' I mean even...if you're not ready to talk, just say, 'I'm not ready to talk.' And, 'Fine. When would you like me to follow up?'" (Focus Group Participant)

"So we came here, and we had a tour of this place. And then somebody called me and then they were trying to schedule appointments. There was a bunch of calling back and forth, and I turned into a terrible person and hollered, 'This is about my life! Telephone tag is not fun!'" (Focus Group Participant)

Timing: At First Appointment

Provider Interviews

Theme 1: Make the most of a patient's visit.

Subtheme(s): 1) Desire to make first appointment meaningful, 2) all provider visits in one day, and 3) dedicated time for support services.

Representative quote(s): "Getting those pieces and interpreting the information so that they're [patients are] seeing the right disciplines while they're here and making the most of their visit...I think is really important, and I don't know that that's always happening." (Nurse Navigator)

"The ideal thing is to have an answer right away....So usually, if they need different pieces of answers, then definitely the patient would prefer to have it on the same day or at the same time—ideally in one visit." (Medical Oncology Fellow)

"It just pains me when I've had discussions with our patients to only find out after they've completed treatment that they didn't know that there was social work here. They didn't realize they could get a nutritionist consult free of charge." (Cancer Center Access Nurse)

Theme 2: Provider flexibility is helpful.

Subtheme(s): N/A

Representative quote(s): "I think the majority, if not all the providers, are very good at being flexible and helping the patient while they're there [at the cancer center] instead of having them come back." (Nurse Navigator)

Theme 3: A desire not to overwhelm patients.

Subtheme(s): N/A

Representative quote(s): "It really depends on how informed the patient wants to be. There's a surprising number that say, 'Just tell me where to be and when to show up.' Or, you know, 'We'll talk about it.' And it is a lot of information. It's information overload, and that's the fine balance with everything." (Medical Oncology Fellow)

Table 1 (continued). Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Timing: At First Appointment

Patient Focus Group

Theme 1: Providers are "in their own bubbles."

Subtheme(s): 1) No perception of a team, 2) nurses help bridge the gap, and 3) reassurance by protocols.

Representative quote(s): "I never got the idea [that] there was any team approach. I never had that. I never felt that my oncologist talked to my surgeon. I had the operation, I had the mastectomy, and that's over. Then they'd hand me over to the next person. I never felt...any real communication between the doctors that were supposed to be helping me with the problem. There must've been, but I don't know." (Focus Group Participant)

"I found that the nurses, they communicate with each other and other members of the team well. They know each other, and they really helped to collaborate between them [the care team] to schedule a meeting and make sure that everything lined up." (Focus Group Participant)

"Despite having several groups, I think there was a standard protocol so that even when they [patients] were passed—start with radiation, followed by surgery, followed by chemo—the protocol is there so they [patients] pretty much know what the protocol is. In that sense, they [patients] could loosely string it [their treatment plan?] together—that's...okay." (Focus Group Participant)

Theme 2: Personalization is preferred.

Subtheme(s): 1) Having a choice and 2) personalized information.

Representative quote(s): "I've always met doctors in linear succession. It [a multidisciplinary approach] was never offered." (Focus Group Participant)

"I did end up with three books of information. I think that the navigator did want to sit down and say this is your book, and I'll help you." (First Focus Group Participant)

"It's customized for your condition." (Second Focus Group Participant)

"I think so. That was pretty good." (First Focus Group Participant)

Theme 3: Information issues.

Subtheme(s): 1) Too much information, 2) not enough information, and 3) information offered at the wrong time.

Representative quote(s): "Did they hand you a big book?" (Third Focus Group Participant)

"Yeah. If we wanted to talk about the big book, I'd have plenty to say about that..." (Second Focus Group Participant)

"Somebody plopped this big, three-ring binder into your hands, and no one sits down, I didn't think, and really explains the panoply of services that are available." (First Focus Group Participant)

"She [the provider] seemed like she really wanted to let me sit there and settle in and go over the book with me, but my husband kept saying, "We've got to get out of here.' And that's the kind of guy he is. You go in, you do your thing, you get out, and you're done. And that's hard when one person wants to spend time and the other one doesn't, and you didn't make [prior] arrangements." (Focus Group Participant)

Timing: After First Appointment

Provider Interviews

Theme 1: A need for follow-up contact.

Subtheme(s): No "new" wall.

Representative quote(s): "[After the first visit I contact the patient], reiterating what happened during the clinic visit because they're overwhelmed and can't understand anything, interpreting test results, and having these lengthy conversations on the phone." (Nurse Navigator)

Table 1 (continued). Themes and Subthemes Identified from Analyses of Multidisciplinary Cancer Care Provider Interviews and Patient Focus Group

Patient Focus Group

Theme 1: A need for follow-up contact.

Subtheme(s): 1) Phone call and 2) address follow-up at the first appointment.

Representative quote(s): "Even a phone call, I think, would've been nice for checking up, even like a day or so afterward. You don't physically have to go to the doctor's office. I understood what my case was...But all those waits for the next appointment to find out what happened." (Focus Group Participant)

"Even that first day with the oncologist—just to have somebody say that there are other resources and we'll be in touch with you." (Focus Group Participant)

Timing: Throughout Treatment

Provider Interviews

Theme 1: Provider-to-provider communication with multidisciplinary teams is critical ("teams within teams").

Subtheme(s): 1) Processes for provider-provider communication, and 2) it's good to have one contact person.

Representative quote(s): "I would say that there is ongoing communication, like during the handoffs. So before...the chemo is about to end, usually the medical oncologist would be telling the surgeon, 'Hey I'm about to be done. Do you want to meet with the patient to speak about surgery?' And then the surgeon would hand off to the radiation doctor, saying, like, 'I did the surgery. He needs so many weeks of recovery and then you can do radiation.' So, I think this process is well established." (Medical Oncology Fellow)

"It's also good on the back side to have a resource person so that if they [patients] have questions or if they're overwhelmed with all that information, they can just contact that person and sort it out. That's where I feel like my role comes [in]." (Nurse Navigator)

Theme 2: Singular ownership of a patient is valued.

Subtheme(s): N/A

Representative quote(s): "Whoever is mainly managing the patient is the primary, and then we work as a team. But it is obvious that there is someone who has ownership of the patient, and somebody who is just consulting and providing assistance with this patient." (Medical Oncology Fellow)

Patient Focus Group

Theme 1: Provider recognition of personal preferences and differences are valued.

Subtheme(s): 1) Acknowledge preferences and 2) that patients are all different.

Representative quote(s): "I told my doctor, 'Just call me anytime when you get that lab result. I want to know.' And he understands that I'm the kind of person who wants all the facts. Doctors should start understanding how to facilitate and educate their patients as well." (Focus Group Participant)

"Just to say I understand you as an individual...we talked about how different people are, and someone who could understand you and link you to the system because they know the system and they can actually help you navigate it." (Focus Group Participant)

"Patients are so different. There are some patients that just go in and receive a diagnosis and don't ask a question. They do everything the doctor tells them. They don't want a second opinion. They just want to follow along and don't ask, 'Can I have a lumpectomy instead of a mastectomy?' They just go with the flow. And then there are patients, like me, who are asking questions and say, "You know, I read on the Internet..." (Focus Group Participant)

Theme 2: Singular ownership of a patient is valued.

Subtheme(s): N/A

Representative quote(s): "You feel like there's no continuum and that gives patients a sense of being isolated. That no one really cares about you as a person from day one until day whenever, when you go through the process." (Focus Group Participant)

(Continued from page 56)

Results: Patient Focus Group

Seven participants joined the focus group, all of whom had a cancer diagnosis and one individual who was also a caregiver for a family member with cancer. Nine major themes emerged from the focus group (Table 1, pages 59-62).

Before the First Appointment

Three major themes emerged for the period prior to a patient's first visit.

- "The blur." Reflecting on their experience at the time of their cancer diagnosis, several participants described a "blur" after learning they had cancer, during which they were not able to hear or comprehend much of what was being told to them.
- 2. Somebody there to catch you. One participant said that they needed "somebody to catch" them during this time. This person would provide support and ensure proper follow-up for the patient. Others agreed that early support was needed.
- **3.** *Need for early contact.* Patients agreed that early contact is helpful after receiving a cancer diagnosis, including early phone calls to help them feel connected. During this early contact, patients emphasized the need for more practical information about what to expect at the time of their visit (e.g., parking information and appointment length). They also thought it was difficult to find basic information about their cancer ahead of time. One participant expressed frustration about this early contact, which lacked streamlined phone calls and included "phone tag," leading to a negative experience.

During the First Appointment

Three themes focused on the first multidisciplinary cancer care visit.

- 1. Providers are "in their own bubbles." Significant frustration arose around participants' perceptions regarding the lack of a coordinated team approach from their providers. Several patients discussed having negative feelings because they thought their various providers were not speaking among one another. The participants said that this lack of communication improved with use of nurses who helped bridge communication gaps and reassure patients that protocols are being followed.
- 2. Information issues: enough information, but not too much information, and information at the right time. When discussing the setup and flow of the first visit, participants spent time addressing what the ideal amount of information would be to receive at a first visit. They expressed frustration with both not receiving enough information about the important details of their cancer treatment and available support services available and receiving an overwhelming amount of information that was too difficult to absorb. Several participants also discussed the timing of information delivery at the appointment, describing efforts to provide additional information at a time that was more optimal mentally or for practical reasons (such as not having planned for childcare after a certain time).

This study found that many patients were initially uncertain of who oversaw their care or of whom they could contact for questions. This confusion improved when patients had a single contact person, which was a main theme identified in our findings.

3. *Preferring personalization.* A solution to the issues patients described included offering patients choices about the structure of their visit and giving information customized to their particular disease processes.

After the First Appointment

One theme that emerged was the *need for follow-up contact*. Following the first visit with providers, several participants said that they either appreciated or would have a appreciated a follow-up phone call as a check-in to answer any additional questions and to offer more information about the support services that might be helpful for them. Patients also wanted this follow-up to be addressed specifically at the first visit to provide reassurance that follow-up would happen.

Throughout Treatment

When discussing the entire cancer care continuum, participants reiterated multiple times that *all patients are different*. They suggested that patients be asked when and how to be given information and how their visits should be structured. One participant specifically mentioned that patients are also different when it comes to their first-visit needs, especially considering how far some need to travel for their first appointment. In emphasizing personalization, several participants described very positive experiences where their provider knew them and tailored information delivery to their preferences.

Participants also discussed a need for *one identified provider to take responsibility of communicating with patients.* Others agreed with this idea, stating that their cancer treatment involved many steps with different providers responsible for each step.

Comparing Patient and Providers' Perspectives

Following the individual analyses of the provider interviews and focus group, we compared themes to identify overlapping areas. *Early contact prior to the initial multidisciplinary cancer care visit* and *an established follow-up plan after the first visit* were important to both patients and providers. Throughout the multidisciplinary cancer care process, patients and providers also viewed *identification of a provider with singular ownership of the patient* as important.

Discussion of Survey Findings

In this mixed methods study of provider and patient perspectives on multidisciplinary cancer care, the need for early and consistent contact between provider teams and patients was clear. Foremost, in the vulnerable and overwhelming time after receiving a cancer diagnosis, patients look for reassurance and information that multidisciplinary cancer care teams can provide prior to the first visit, and patients value continued contact and support throughout their care. Secondly, this study identified that patients have a range of preferences regarding the structural aspects of multidisciplinary cancer care, and this can present a challenge to the multidisciplinary cancer care team that is trying to streamline patients' care. However, the ability of providers to acknowledge the preferences of each patient is highly valued by patients.

The need for early and consistent communication expressed by multidisciplinary cancer care providers and patients is consistent with previously identified themes in the literature. In a large study involving interviews and focus groups with 37 patients with cancer and 40 multidisciplinary providers, Admi et al. found that there is confusion and ambiguity regarding the early roles of healthcare providers after a cancer diagnosis.¹⁷ Similar to the providers in our study who described an initial barrier to finding a contact person ("the wall") as frustrating for patients, the providers participating in this study described the need to overcome hospital-community interface barriers with communication and navigation.

Like our online national cancer support group survey, which suggested that a sizeable percentage of oncology patients did not have an identified contact person at the time of their diagnosis and comparable experiences described by our focus group participants, a qualitative study involving phone interviews of 38 patients with cancer in Canada found that good communication is a central consideration for patients early after a cancer diagnosis.¹⁸ This study found that many patients were initially uncertain of who oversaw their care or of whom they could contact for questions. This confusion improved when patients had a single contact person, which was a main theme identified in our findings. Although there are limited studies exploring patient perspectives, most show consistent themes surrounding communication barriers and single points of contact.¹⁹

Nurse navigators' roles are uniquely aligned to improve patient-provider communication and break down barriers, which was thoroughly explored in a 2018 National Academies of Sciences, Engineering, and Medicine report on the proceedings of a workshop dedicated to effective patient navigation in oncology.²⁰ In this report, the role of navigators was emphasized to help reduce communication and healthcare system barriers, as well as to provide emotional support to patients.²⁰ Patients and providers in several other qualitative studies agreed on the critical role nurse navigators play in communicating with and supporting patients.^{21,22}

Overall, studies examining patient preferences regarding the specific structure of multidisciplinary cancer care (i.e., timing of visits, participants involved, etc.) are lacking. Our findings indicate that patients vary in their preferences regarding these structural aspects, and many patient-related factors are likely to play a role. This variation in patient preference, coupled with the complexities inherent to cancer care, is at odds with providers' desire to streamline care, as multiple providers discussed in our interviews. These barriers, such as the time needed to obtain necessary diagnostic information, which limits the ability to see the patient as soon as possible, have been previously acknowledged.^{23,24} An excellent effort to incorporate patient preferences into the multidisciplinary cancer care process was conducted at Virginia Mason Medical Center in Seattle, Wash., by Hagensen et al.²⁵ The group implemented a "Know Me" form at intake to address the differences patients express regarding their interpretation and hope for their cancer prognosis.²⁵ Our findings support these types of efforts to improve providers' understanding of patients' varying preferences regarding care delivery processes.

The response inconsistencies from the cancer support group participants about what they preferred as their multidisciplinary cancer care structure and what patients actually experienced is concerning. Because standardized approaches are helpful, our findings suggest that incorporating intentional efforts to address patient preferences in a standardized way throughout the multidisciplinary cancer care process are likely to be beneficial. A process to initiate early contact once a patient has been identified as needing multidisciplinary cancer care could follow a template to ensure patients receive helpful information and, most important, have an identified point of contact for any questions (see Figure 2, right). At the first visit, a consistent effort should be made to specifically arrange post-appointment contact, such as a follow-up phone call or health records message (according to patient preferences), to improve communication and eliminate barriers. Finally, patient preferences regarding multidisciplinary cancer care should continue to be investigated to help providers align multidisciplinary care delivery with identified preferences, while considering the variability that exists in patients' preferences and needs.

Although this study contributes new data to the sparse literature in this area, there certainly are some limitations. Admittedly, our study is small in scale, based on its roots as a QI initiative at a single institution. The online survey was a small convenience sample meant to provide an exploratory overview of the perspectives of a broad patient group and therefore did not provide a definitive assessment of all patient perspectives. As such, the perspectives of all patients and providers regarding the issues affecting new patient multidisciplinary cancer care were likely not uncovered through this study. Despite this, the themes presented from our study are consistent with previous studies, and the patient and provider perspectives from our study align in key areas. Further studies with larger, nationwide, and patient and provider samples would help to establish the ideal methods of incorporating patient preferences in multidisciplinary cancer care. Secondly, the role of primary care physicians in communication and coordination processes was not specifically explored because this was beyond the scope of our QI efforts. This is an important area that some have investigated²⁶ and would be important to consider in future investigations, particularly when resources for navigators are limited.

Figure 2. Template to Standardize Early Contact Methods

Before First Appointment

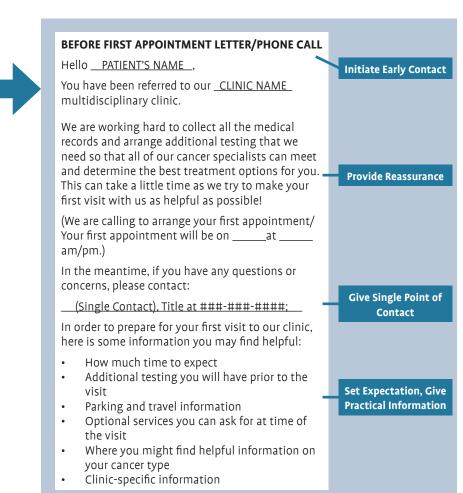
 Standardize an early contact approach via a phone call, letter, electronic message, etc.

At First Appointment

- Elicit patient's personal preferences for receiving information
- Ensure provider-provider communication prior to discussing recommendations with patient
- Identify for the patient which team will take on primary communication role and reinforce single point of contact.
- Arrange specific follow-up communication

After First Appointment

• Initiate follow-up per patient preferences (e.g., phone call, electronic message, etc.)



In conclusion, early contact by multidisciplinary cancer care providers with new oncology patients helps eliminate perceived barriers and provides reassurance during the particularly vulnerable time for patients—the time following a cancer diagnosis. Patient preferences regarding the structural processes of multidisciplinary cancer care are varied, and efforts to improve multidisciplinary cancer care processes by incorporating the patient perspective should ensure early and continued contact, as well as assessments of personal patient preferences to guide interactions and prioritization.

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