

“Along for the Ride”: A Qualitative Study Exploring Patient and Caregiver Perceptions of Decision Making in Cancer Care

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Background. Shared decision making is a cornerstone of an informed consent process for cancer treatment, yet there are often many physician and patient-related barriers to participation in the process. Decisions in cancer care are often perceived as relating to a discrete, treatment decision event, yet there is evidence that decisions are longitudinal in nature and reflect a multifactorial experience. **Objective.** To explore patient and caregiver perceptions of the choices and decision-making opportunities within cancer care. **Design.** Qualitative in-depth interviews with 37 cancer patients and 7 caregivers carried out as part of an evaluation of a cancer center’s effort to improve patient experience. **Results.** Participants described decision making related to four distinct phases in complex cancer care, with physicians leading, and often limiting, decisions related to disease assessment and treatment options and access, and patients leading decisions related to physician selection. Though physicians led many decisions, patients had a moderating influence on treatment, such that if patients did not like options presented, they would reconsider their options and sometimes switch physicians. Patients had various strategies for dealing with uncertainty when faced with decisions, such as seeking additional information to make an informed choice or making a conscious choice to defer decision making to the physician. **Limitations.** Patients were sampled from one academic cancer center that serves a predominantly Caucasian, Asian, and Hispanic/Latino population and received complex treatment. **Conclusion.** Because of the complexity of cancer treatment, many patients felt as though they were a “passenger” in decision making about care and did not lead many of the decisions, though many patients trusted their doctors to make the best decisions and were comforted by their expertise.

Keywords

decision making, oncology, qualitative methods

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Patients should be engaged in decision making about their treatment as part of an informed consent process.¹ Charles and colleagues^{2,3} foundational work characterized four elements of shared decision making in medical encounters: 1) at a minimum, the physician and patient are involved; 2) information is shared by both parties; 3) both parties work toward consensus; and 4) agreement on treatment is reached. Much research, synthesized in systematic reviews, has been carried out with both physicians and patients to understand the barriers to patient participation in decision making. For the physician,

these include time constraints, lack of applicability due to patient characteristics, and clinical situation.⁴ For patients, barriers to participating in decision making include lack of time and impersonal relationship with the physician, poor physician communication, the challenging

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physical environments in which conversations must take place, poor health literacy and concerns of adverse effects, and the imbalance of knowledge between the physician and patient.^{5,6} Research on patient decision making has largely focused on decisions regarding treatment, or relating to a particular clinical encounter.^{2,3,7,8}

The definition and assumptions underpinning patient decision making have evolved over time. More recent work on conceptualizing patient involvement in decision making has argued for a broader view to reflect that decision making is influenced by the entire clinical encounter, and even longitudinally across many encounters.^{9,10} Additionally, it is recognized that there are different levels at which patients wish to be engaged in decision making, from purely consultative to equal partnership between patients and physicians.^{8,11} Decisions as phenomena are situated at a patient level, within the context of an entire care experience and personal life, rather than simply at an encounter level.¹²

Patient decision making within oncology is particularly important to study as cancer care decisions can have life-altering physical and emotional consequences, and treatment options are continuously evolving.⁶ Within oncology, there has been much research on preferences for decision-making participation, and barriers and facilitators to participation, often with a focus on choosing specific treatment.¹³ Facilitating factors for patient engagement in cancer treatment decision making seem largely related to physician attitudes and subsequent behavior, such as consideration of patient preferences and the use of support systems or decision aids.⁶ However, less is known about how patients perceive their opportunities for participation and decision making in their cancer care more generally, which may be a step toward meaningful patient engagement throughout the course of clinical oncology care. Using a broader view of decision-making (e.g., Clayman and colleagues¹²), the aim of this study was to explore patient perceptions of the choices and decision-making opportunities during the course of cancer treatment.

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Methods

Design

Qualitative in-depth patient and caregiver interviews were carried out as part of an evaluation of a quality improvement effort of a National Cancer Institute-designated comprehensive cancer center program. The aim of the interviews was to understand the overall experience of cancer care, particularly with regard to access to care, communication, coordination, information, and involvement in decision making. We conceptualized patient decision making broadly, reflecting it in questions such as whether patients felt involved in their care, able to participate in decisions, and whether they felt like a partner in their care; this article reports the findings from the interviews related to those questions. This study received a nonresearch determination from the Stanford Institutional Review Board as an evaluation of a quality improvement initiative.

Sample

Patients were purposively selected to reflect a range of tumor groups (breast, head and neck, gastrointestinal (GI), gynecological, blood, lung) from a list of eligible patients.¹⁴ Eligible patients were new patients receiving at least two treatment modalities (surgery, chemotherapy, and/or radiation) as we were interested in decision making within the context of complex treatment. A total of 267 patients were sent a letter from the evaluation team inviting them to participate in the evaluation at least two months after their first visit with a cancer provider. The letter was followed-up by a phone call from the interviewer who extended a verbal invitation to participate. At the time of the follow-up phone call, 178 (67%) did not answer, return voicemails, or the call could not be connected; 60 (22%) agreed to participate or nominated a caregiver on their behalf to complete an interview; and 29 (11%) patients declined. Patients who were interested in the study, but did not speak English or feel well enough to participate were given the option of nominating a caregiver on their behalf. Of the 60 patients or caregivers who expressed interest in an interview, 16 (6%) declined or did not answer at the scheduled interview time.

Data Collection

For the convenience of the participants, interviews were carried out over the telephone by one of the authors (DZ). A semistructured topic guide was created and refined after the first three interviews; refinements included broadening

the language to reflect treatment “options” rather than treatment “decisions” as the first participants indicated there were no “decisions” made, but later indicated there were “options” for their care (see supplemental material for topic guide). Questions related to decision making covered the following topics: whether patients felt they were given options, who was involved in decision making, what influenced their decisions, their sources of information, whether their treatment plan reflected their preferences and values, and whether their doctor considered their quality of life in planning treatment. Interviews lasted 46 minutes on average (range 20–100 minutes) and were audio-recorded. Interviews were carried out between March and October 2018. The first (LMH) and second (DZ) authors debriefed at frequent intervals following interviews to reflect on the data collection process and initial analyses. LMH is a trained qualitative health services researcher who has conducted a range of studies within the area of serious illness. DZ has qualitative research training and training in interviewing vulnerable groups.

Analysis

Interviews were analyzed thematically using a deductive and inductive approach that involved identifying a priori codes determined by our evaluation questions and searching for emergent themes. Transcripts were imported into QSR International’s NVivo 12 Pro for analysis. At the start of analysis, five transcripts were selected and coded independently by two researchers (LMH, DZ). Transcripts were initially coded for content related to a priori categories including presence or absence of options during care, information needs, and involvement in decision making. Emergent themes that were related to those experiences, such as previous experiences with cancer and priorities, were also coded. The researchers then met to compare coding, agree definitions and interpretations of existing codes, and discuss emerging themes to integrate into the coding framework. They continued to independently analyze data for content and met regularly to revise the coding framework and ensure consistency in coding. After coding all data, we looked for patterns across codes to create clusters of higher level, thematic categories.¹⁵ This process revealed initial patterns related to the perceived presence or absence of decisions and points during the care process during which options were available or decisions were made (e.g., deciding a treatment plan or physician selection). We then used a matrix to systematically look individually at patient cases (rows) along the dimensions of decision making and presence or absence of

Table 1 Participant Characteristics ($N = 44$)

Characteristic	<i>n</i> (%)
Patient	37 (84.1)
Caregiver	7 (15.9)
Sex	
Female	28 (63.6)
Primary tumor group	
Breast	12 (27.3)
Head and neck	12 (27.3)
Gastrointestinal	7 (15.9)
Blood	4 (9.1)
Gynecological	4 (9.1)
Lung	4 (9.1)
Other	1 (2.3)
Patient age group	
≤ 39	4 (9.1)
40–49	5 (11.4)
50–59	10 (22.7)
60–69	10 (22.7)
70–79	10 (22.7)
≥ 80	5 (11.4)
Patient race/ethnicity	
White	25 (56.8)
Asian	9 (20.5)
Hispanic/Latino	5 (11.4)
Unknown/other	5 (11.4)
Patient’s preferred language	
English	42 (95.5)

options (columns), and how they related to points of care. As checks of validity, following guidance by Miles et al.,¹⁵ we examined each case for replication of emerging patterns, checking the meaning of outliers, looking for negative cases, and reshaping our thematic framework so that it was inclusive of the entire dataset. This was an iterative process of checking and rechecking the matrix, and reviewing individual transcripts to ensure patterns were replicable across the dataset.

Results

In total, 37 patients and 7 caregivers were interviewed representing 44 individual patient cases. Participant characteristics are presented in Table 1; quotes have been anonymized using codes to indicate tumor group, patient number within tumor group, and whether the participant was a patient or caregiver.

We identified decisions as opportunities or junctures in which there was a following action (or inaction) taken; for example, deciding to proceed with a treatment, or not, or changing a treatment regimen to accommodate a

change in circumstance. We found four discrete stages within cancer care in which decisions were made, one of which was physician-led (disease assessment), one patient-led (physician selection), and two of which were physician-led, but patient moderated (treatment options and receiving treatment). We also identified ways in which patients and caregivers dealt with uncertainty in decision making and where uncertainty led to conflict in care.

Physician-Led Decision: Disease Assessment

Determining disease type or stage was perceived of as the first key decision led entirely by physicians and not typically disputed by patients. This decision was firmly in the realm of the doctor who acted as gatekeeper to treatment. Patients who were told their cancers were incurable typically sought additional testing or opinions from other doctors who might decide their cancer was treatable, especially in relation to surgery. Thus, patients were reliant on physicians to make a favorable assessment and decision to treat their cancer.

We were just hearing no, like we don't do that [procedure], we won't do that here. So we spent a few months actually looking around the country, traveling around the country a little bit looking for somebody that would do it. (Blood cancer 2, patient)

Patient-Led Decisions: Physician Selection

For patients with difficult to treat cancers, as in the above quote, selecting a treating physician went hand in hand with physician decision making about their disease, especially as most patients required surgery, and thus identifying a capable surgeon was the first priority. For patients with more common or treatable cancers, the first decision following a diagnosis was where to seek treatment and from whom; this was usually limited by the patient's insurance coverage, except for those seeking a last chance treatment option. Patients typically relied on their primary provider's knowledge of specialists, recommendations from friends or family, or their own online research to find a physician. Some patients sought out a specific physician who specialized in their cancer type, while others wanted to be in a "research institution" (Thoracic cancer 4, patient). For example, one patient put a lot of effort into researching and selecting the best doctor and facility for her condition. She felt this was the key decision to make for her care, and after that, trusted the doctor as the expert to make the right treatment decisions for her:

I saw [. . .] one oncologist and two breast surgeons and there was a Dr. [A] that was at [another facility], she was amazing, she was great. [. . .] and then when I saw Dr. [B] he just kind of was like, here you go, this is your plan, what do you think? And this was like, great, when do we start? (Breast cancer 12, patient)

Indeed, most patients talked about the expertise of their doctor and their reliance on their doctor's knowledge for providing the most effective treatment for their cancer. Physician selection was also a prominently discussed decision among patients who were dissatisfied with the treatment options presented by their first doctor, and thus sought out a different doctor who could offer them treatment more aligned to their preferences. Once patients had identified their surgeon or principal oncologist, other specialties like medical oncology or radiation oncology for adjuvant therapy were arranged within the cancer center and often viewed as part of the "team."

Physician-Led, Patient-Moderated Decisions: Treatment Options and Receiving Treatment

Two aspects of decision making in cancer care were clearly led by physicians, but ultimately the patient moderated those decisions by expressing preferences: determining appropriate treatment options and how treatment should be received. From the patient and caregiver point of view, there were generally few if any options and subsequently few decisions to be made in regard to treatment which was limited by physicians. Some patients perceived that their diagnosis or medical condition determined what treatment was available, and thus perceived there was only one option for treatment:

The original treatment plan was decided by [the doctors], 'this is what we do for triple negative breast cancer in your situation and when we see this', and blah, blah, blah. (Breast cancer 5, patient)

As one patient acknowledged, there may have been options for her care, but the way it was presented by physicians did not make it seem like there were options:

They did not necessarily offer [treatment options]. Or, if they did offer, they did not bang you over the head with it, so maybe you forgot (Gynecological cancer 3, patient)

Some patients acknowledged an inherent imbalance in knowledge which meant that deciding between different

treatment options, if there were any, was ultimately determined by the physician:

In the end, everything will be done like they want it, you know? Because they have to have more knowledge. (GI cancer 2, patient)

Indeed, many patients felt that their doctor was the expert and that important decisions, such as treatment selection, were best suited for the doctor to make. Patients who were given options were sometimes strongly encouraged toward a treatment presented as most efficacious by the doctor. Going with the doctor's recommendation was perceived as an active decision to trust the doctor, but that trust was contingent on being informed and having transparency in the treatment process.

I was informed of all, Dr. [X] is very good about that. I was informed of all the options, and she strongly recommended, and backed it up with some statistics, [non-chemotherapy drug], for instance. It's the most effective. Regular infusion chemotherapy is not as effective. (Thoracic cancer 4, patient)

Patients generally wanted the best chance for cure and therefore a *best* option was interpreted as the *only* option, as refusing treatment was generally not considered a viable option:

That was the recommended treatment for it. I know that [patient] can refuse treatment at any point because it is her body, and he discussed other things, but I think it is probably, as it was explained to me, I feel like it was probably the best drug combination for her (Breast cancer 10, caregiver)

Some patients perceived that options meant they had back up treatments available (primarily in relation to chemotherapy) if the first line was unsuccessful or not well tolerated. It seemed that these patients were reflecting that rather than choosing between two equivalent treatment options, they would proceed with the best available option, but if it was not tolerable, then they could opt for a second choice which was still supported by their doctor:

[The doctor] said, "I think we ought to just do [drug]." And [drug] is immunotherapy which means you do not get the bad effects you can get with chemotherapy. That was much better, and he kind of inferred if it did not work well, I could get something else, but he would start with that, and I really was not given options for anything else (Blood cancer 04, patient)

Few patients had genuine treatment decisions to make, in the way that is generally conceived of in the literature on shared decision making, and were presented with two

equivalent options for treatment by their doctor with the decision being left to the patient as a matter of personal preference:

Well I have a choice of they go in and they cut I think 5 inches out of the colon and then they patch and go from there, and then another choice is to go with a permanent colostomy bag. (GI cancer 6, patient)

Once a treatment was selected, patients then perceived that they had or should have options for how and where that treatment took place, particularly for treatment received over a long time, such as chemotherapy or radiation. These were often important considerations for patients so that they could integrate their cancer care within their daily life.

We built like a plan that I still could work, but there was no other time for me left to do some things just for myself. And I said in the beginning once to the doctor, and he said, "Well, you have to make a decision. Your life or, you know, . . ." and I thought it was kind of harsh [. . . I felt] a little bit angry and I think he realized that. [. . .] The next time I saw him, he came up with a different plan, so I could make decisions. (GI cancer 2, patient)

Decisional Conflict and Dealing With Uncertainty

When decisions were led by the physician or patient as described in the previous sections, care progressed relatively seamlessly; patients moved from diagnosis and physician selection, to agreeing with an offered treatment, receiving treatment, and routine monitoring and/or changing therapy as needed. However, there were sometimes points in care in which patients found themselves conflicted with the decisions they had to make or when a singular option was not acceptable. First, with disease assessment, when patients believed they were not getting the tests they felt they needed to get an accurate diagnosis, this created stress and discord with their provider:

We had to force through the diagnosis. [. . .] it was kind of difficult to push through all of the tests that we needed to do, which though they didn't actually believe the diagnosis, so we had to push for a lot of testing. There was a lot of arguing, and then once she was diagnosed they found the tumor, and it was too large to be benign (Other cancer 1, caregiver)

With treatment selection, when patients were put in a position where they had two equivalent options to choose

from, this could create tension for the patient. Having options meant having to make a choice, which was uncomfortable for patients if they felt ill-equipped to assess the information presented to them and preferred to have the physician lead treatment decision making:

[The doctor] was like, “There are no long-term studies, but there is some research that was just published, but the abstract is available but it is not totally out there, but from that it says that again, on the margin it does make sense to go ahead and radiate that area, but we will leave it up to you. What would you like to do?” And I actually pushed back and was like, “I’m not the expert. You are seeing hundreds of patients like me, what do you recommend based on that? I appreciate that you are allowing me the chance to decide but . . .” (Breast cancer 3, patient)

The burden of decision making was compounded when both treatment options were viewed as unpleasant, as in a prior quote in which the patient had to choose between a colostomy bag or removing a section of the colon, neither of which would leave him with viable options for continuing work:

I honestly don’t think the surgeon [. . .] completely understands what it is that I’m going through. [. . .] It is a huge decision for me because I’m in a one-income family, so without me being able to earn, where am I going to be at? For the most part I’m ruined. (GI cancer 6, patient)

Some patients, particularly those who were running out of treatment options for prolonging life, had done their own research and had decided there were treatment options they would like to pursue. However, as treatment options was a physician-led decision, those options were perceived to be restricted by their treating doctor who was not willing or able to offer the patient what they wanted. This led patients back to a decision that they could make, which was to select a different physician, one who was willing to provide the treatment they desired.

[Doctor] said, “Yes, my hands are tied. I wanted to take you back into surgery and kind of clean up that area, and I thought you would be fine,” but he said, “Legally I cannot do it.” He said, “My hands are tied,” and I said, okay I want another opinion, I want a second opinion. (Breast cancer 4, patient)

While the above quotes demonstrate conflict arising from having to make a difficult decision about treatment (a physician-led process), there was also evidence of relief from not having to make difficult decisions:

Interviewer: How did that feel to hear, you know, that there aren’t options, there’s one way, but this is the way I feel confident about?

Caregiver: Relief, because we knew right then that he knew what he was doing. (Blood cancer 3 caregiver)

Likewise, one patient indicated a “smooth ride” in the absence of complex disease and hard decisions:

I am a passenger on this train, and I am willing to just ride as long as it is smooth and then we will, I mean, if hard decisions have to be made, I have not had to make hard decisions yet. If I had to, that would be different. (Breast cancer 8, patient)

At the time of the interview, some people were in the process of deciding and expressed uncertainty about their choices, whereas others described a prior process of deliberation that indicated that at an earlier point in their care there was uncertainty that was resolved. There were various ways in which patients dealt with an informational deficit and the subsequent uncertainty that arose. One of the strategies, as illustrated by the “passenger” metaphor in the above quote, was to accept the knowledge deficit and unpredictability of cancer, and trust in the physician’s knowledge and decision making. Patients who took this seemingly passive approach, often described an active, thoughtful approach to physician selection which involved doing research on a particular physician to therefore have confidence in all subsequent decision making, as described by the breast cancer patient who vetted a number of oncologists. Other patients talked about more active approaches to try to fill their knowledge gap, including seeking as much information from their oncologist, doing “research” online or at the library, talking to other patients and friends or family who also had experiences of cancer, and consulting with other doctors. Patients described one or more of the following values that they considered when deliberating about treatment: likelihood of cure or remission, possible side effects, long-term quality of life, and financial implications including costs of treatment and ability to continue working.

A Model of Decision Making Throughout Cancer Care

The alignment of physician-led and patient-led decisions to a simplified model of cancer care are depicted in Figure 1. Figure 1 maps decisions to key points in cancer care; this model does not explicitly cover survivorship as no patients were in that phase, though theoretically it may fit under “disease assessment.” The figure depicts

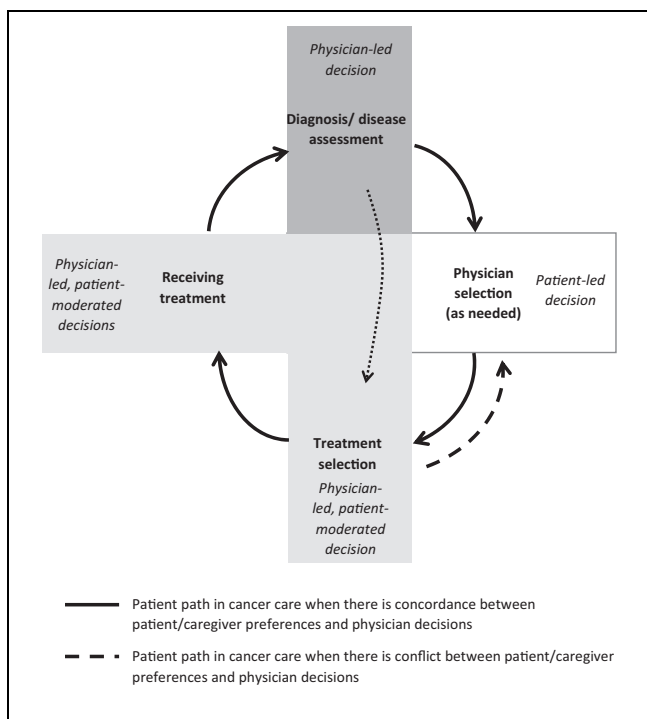


Figure 1 Patient-led and physician-led decision making throughout cancer care

care as a continuous process with opportunities for changes and decision making ongoing, especially during treatment that may be received over many months. Though decisions are described as patient-led or patient-moderated, it should be noted that their decisions represent a wider sphere of influence that patients relied on for dealing with uncertainty (e.g., family, friends, other patients or doctors, etc.) as described in the previous section. The solid arrows indicate the general progress of patients through the cancer care process when there is consensus between patients and physicians; from diagnosis, to (possibly) deciding where and from whom to receive care, to deciding treatment options, to receiving treatment, and then repeating the process if treatment was unsuccessful or there was a change in the disease. When physicians and patients led decision making as appropriate, care proceeded clockwise and with little, if any, conflict. However, where patient wishes for treatment options did not align with those offered by the doctor, conflict arose and patients looked for a different physician. For some patients, there was also conflict when receiving treatment and they were dissatisfied with their physician, though changes in physicians were only made if the treatment was unsuccessful, which was determined by additional testing and reassessment of the disease.

Discussion

The interviews with patients and caregivers identified at least four points of decision making in cancer care: understanding the disease, physician selection, treatment options, and receiving treatment. Most decisions were led by, and at times limited by, physicians. The way information was presented or communicated by oncologists led to a perception that doctors defined the range of treatment or care options, and consequently, the decisions that could be made. This, along with the unpredictability of the disease, led to some patients feeling like a “passenger” in relation to their care. This echoes the systematic review by Covvey and colleagues⁶ that indicated that physician communication could act as a barrier to shared decision making, when done poorly, or a facilitator, when done well. While there might always be options available, how they are presented will likely influence whether patients perceive that there are viable options and how much influence they can or want to have in making those decisions, with some patients preferring to defer medical decision making to the doctor.^{8,16}

We identified that patients perceived that choosing a doctor was an important first decision and not one typically reflected in patient decision-making models.^{17–19} While patients only had clear decision-making authority over physician selection, they were able to exert meaningful influence over their care by voicing wishes and preferences about their treatment. Focusing narrowly on treatment selection as the center of patient decision making ignores most of the patient interaction around receiving treatment over time as identified in our study. Our model demonstrates a longitudinal approach to decision making in cancer care. We therefore find that Clayman and colleagues’¹² decision-making model, which focuses on *clinical encounters* rather than *treatment decisions*, to be more representative of the longitudinal nature of decision making that cancer patients experience. This is reflected in the cyclical representation of care illustrated in our model. As an addition to Clayman and colleagues’ model, we would argue that each of these “encounters” are situated at each of the four time points (i.e., disease assessment, physician selection, treatment selection, receiving treatment). The longitudinal nature of treatment also means there are many encounters with the health system in which patients have preferences, such as appointment time or where to have testing done, and thus opportunities to talk about choices and options.¹⁸ This whole process view of how patients engage in cancer care and points of decision making may be a more helpful way for health systems to engage with patients.

We identified that decisions are not always a welcome opportunity for some patients who perceived that cancer care is too complex for a non-medically trained person to choose the “right” option.⁸ Making a complex treatment decision can be distressing for patients who do not have medical knowledge, feel pressured by others, or cannot foresee consequences of an irrevocable surgical decision.²⁰ Indeed, some physicians invited patients into their “deliberation” process as implied in a shared or informed approach to decision making.¹⁷ The assumption of a rational decision-making process is that sharing information helps the patient decide, but this was not the case for several patients who felt they lacked the expertise to understand and interpret that information. Exposing the physician’s deliberation process during the physician-led phase of treatment selection was uncomfortable for some patients. This is similar to previous studies which have found that physician ambivalence or equivocation about treatment can create decisional conflict for patients.¹³ A good treatment decision-making experience (i.e., no regret or conflict, with potential positive clinical outcome²¹) seemed to be the product of a physician-led encounter between the patient and doctor in which patients perceived that their treatment was the best one reflecting their goals and values.²²

Our model builds on previous shared decision-making work by indicating points in the process where physicians may be expected to lead decisions, and that decision making may come up at any point during care and should not be viewed in relation to treatment selection only. Better physician awareness of the variety of ways in which cancer patients may wish to influence their care beyond the selection of treatment are areas in which physician training could greatly improve the sense of engagement that patients experience during cancer treatment.

The sample for this study was limited to one academic cancer center that serves a predominantly Caucasian, Asian, and Hispanic/Latino population. In areas where patients have limited choice and access to cancer care, there may be differences in the perception of points of decision making that would be worth exploring. We aimed to understand decision making within the context of complex treatment; therefore, our findings may not reflect the experiences of patients with less complex conditions, those who desire less rather than more treatment or “watchful waiting” options. We opted to allow patients to nominate a caregiver to participate on their behalf as we were aware that some patients may not speak English, have had speech-altering surgery, or may have not felt well enough to participate. We wanted to be inclusive of this patient group as these caregivers

often acted as a voice for the patient during care, yet we recognize that the patient and caregiver experience of decision making may be different. We did not ask caregivers who did not attend appointments with patients to comment on their perception of decision making as we perceived them to be too far removed from the decisions made during cancer care. While conducting interviews via telephone allowed a wider geographic sample of patients and caregivers to participate at their convenience, we were not able to use any visual cues if participants did not understand a question.


Conclusions

Patients and caregivers identified a range of points of decision making in complex cancer care: from electing where to go and who to see, to the treatment options themselves, and when and where they received treatment. However, most of these decisions were physician-led, with patients only having a moderating influence and conflict arising when patients tried to lead treatment decisions. Patients and caregivers utilized a variety of strategies to deal with uncertainty when presented with having to make decisions throughout their care. Our model of decision making could be used to help better understand when certain decision-making approaches (e.g., paternalistic, shared, informed) may be most appropriate at various stages of cancer care.

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Supplemental Material

Supplementary material for this article is available on the *Medical Decision Making Policy & Practice* website at <https://journals.sagepub.com/home/mpp>.

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