



CANCERcare®

Patient Values Initiative: The Many Voices of Value

A CancerCare Focus Group Assessment



2017



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About CancerCare®

Founded in 1944, CancerCare® is the leading national organization providing free, professional support services and information to help people manage the emotional, practical, and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

CancerCare programs and services help 180,000 people each year. We distribute 540,000 publications and welcome 2.3 million website visits annually. In the past year, CancerCare provided nearly \$14.2 million in financial assistance. The size and scope of CancerCare has grown tremendously since 1944, but it has never wavered from its mission of providing help and hope to people affected by cancer.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

Our Mission

CancerCare is the leading national organization dedicated to providing free, professional support services including counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer. All CancerCare services are provided by oncology social workers and world-leading cancer experts.

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Executive Summary

An ever-growing dichotomy currently exists between how cancer therapy decisions are made and the established ideals of patient-centered care. Within the current oncology care landscape, cost has joined safety and efficacy as the key considerations in making evidence-based treatment decisions. Decision-support tools, including value frameworks, pathways and guidelines, have been designed and implemented to help providers deliver the appropriate treatments to patients while containing the cost of care delivery. The wide-scale implementation of electronic medical records, with encouragement from payers and healthcare delivery systems, is driving rapid and widespread usage of such tools in modern oncology care.^{1,2}

Simultaneously, the National Academy of Medicine has declared patient-centered care to be the gold standard of cancer treatment delivery.³ Yet many of the value frameworks, guidelines and pathways have not taken patients' goals and priorities into account during their development and implementation,^{4,5} nor are they a stated focus of future development. This causes inconsistency between the type of care these tools support and the goal of patient-centered care. As payers, providers and patients seek ways to identify high-value treatments, patients' preferences and priorities, including how treatment affects their quality of life in both the short and long term, have typically been left out of the decision-making process. CancerCare's unique role in helping patients navigate their cancer journey gives it a singular perspective in the recognition and response to this issue.

CancerCare strives to more fully understand the range of cancer patient experiences in the context of these pressures. Building on a foundation of pertinent research,⁶ CancerCare launched the **Patient Values Initiative**. This is a multi-pronged project intended to help integrate patients' priorities and preferences into treatment planning and decision making. As a first step, CancerCare conducted focus groups with social workers and patients to better appreciate how patients participate in treatment decision making and perceive their roles and relationships with their providers in this context.

The focus groups revealed several common themes including:

- Patients do not feel they are active participants in developing their treatment plans;
- Treatment planning discussions are often overwhelming for newly diagnosed patients;
- Few patients realize they may ask questions or know what specific questions to ask during these discussions;
- Patients want their providers to understand and appreciate the effect treatment has on their lives; and
- Patients' priorities and perceptions of their treatment change over time.

These findings, gleaned from interviews with patients and experienced CancerCare social workers, reinforce the conclusion that resources are needed to help patients articulate and providers solicit and understand patient priorities and preferences during treatment planning.

"This is my life. I need to be involved in the decisions."

— Patient with stage 1 breast cancer

In the coming months, CancerCare will field surveys among providers and patients to build upon and validate these initial findings. This research will inform the development of resources and a plan for activism. The goal is to drive real change in the care of cancer patients and families, through an agenda for action that includes a manifesto on patient-centric values and priorities and prototype tools for patients and healthcare providers, to help elucidate and incorporate patients' priorities and values into the treatment decision-making process.

"When you have cancer, you have to trust someone to help you."

— Patient with stage 4 ovarian cancer



Current Landscape

We are living in a time where tremendous advances in our understanding of cancer are leading to increased personalization or tailoring of treatments, based on each patient's individual molecular and clinical characteristics. As patients and providers assess rapidly evolving evidence and evaluate the costs and benefits of multiple, sometimes similar, treatment choices, new decision-support tools, including treatment guidelines, pathways, and value frameworks, are being developed and used in the clinical care setting. These tools have largely been shaped by payers and providers, and rarely reflect the priorities and goals of patients and their families.^{7,8,9,10,11,12,13}

There has been growing recognition that decision-support tools need to incorporate patients' preferences and values among the decision criteria if they are to be truly patient-centric.¹⁴ In the current clinical environment, patients are required to make life-defining treatment choices based on criteria they may not understand and which may not reflect what is important to them regarding their lifestyle, quality-of-life preferences, and overall well-being, both short and long term. For payers and providers, the 'right' treatment may be assessed by treatment outcomes, toxicity and cost; but for patients, the 'right' treatment takes into consideration how they live their lives, short and long term treatment effects and/or how their lives may change.^{15,16,17,18,19} CancerCare began studying how patients experience cancer and

its treatment on a quantitative basis in its 2016 Patient Access and Engagement research effort. Among the important findings is that many patients reported not having enough information when decisions were being made about their treatment plan and options; the effect treatment would have on their lives, or caregiver responsibilities; whether they would be able to work during treatment; how much treatment would cost; and other key issues.²⁰

The 2017 **Patient Values Initiative** was conceived to increase CancerCare's understanding of how patients' perceive the process of treatment planning, the role they play and the ways CancerCare may help them participate more actively. Ultimately, this effort is intended to achieve action and meaningful change by reframing the national healthcare policy dialogue to include areas of importance to patients and their families, and to incorporate patients' values and priorities into cancer care decision-making models.

As a first step in this process, CancerCare conducted focus groups with social workers and patients, seeking to gain insights into how patients see their role in making decisions about their treatment.

Research Project

Methodology

CancerCare implemented a qualitative research strategy by conducting focus groups with two populations: experienced clinical oncology social workers and cancer patients. In February 2017, three in-person, one-hour social worker focus groups were fielded, each with four to five participants. The total of 15 participants were members of CancerCare's staff of clinical oncology social workers, each of whom provides phone, face-to-face and online counseling and support to thousands of patients from across the United States, every year.

Four patient focus groups were conducted via telephone in March 2017. These discussions ran for 60 minutes and ranged from two to four participants each, totaling 12 patients across the four groups. Patients were identified through CancerCare's database of clients from across the United States; by design, none

of the patients had received CancerCare counseling services. The participants included both men and women, and represented a variety of cancer types from four different cross-sections of age and stage: early-stage, young patients (25-54 years old); early-stage, older patients (55+ years old); metastatic, young patients (25-54 years old); and metastatic, older patients (55+ years old).

The objective of the patient and social worker focus groups was to gain insight into:

- Patients' perceptions of their role in the treatment decision-making process;
- The catalyst that activated patients to proactively advocate for their own needs and priorities; and
- The vocabulary patients use when discussing their diagnosis, treatments, and clinical experiences.

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A CancerCare Focus Group Assessment

Research Project

Findings

The findings from the social worker and patient groups were similar and complementary, and are outlined below. It should be noted that while qualitative research allows groups to communicate their lived experiences and stories using their own language, caution should be used when applying the findings from this small sample size to the larger patient population. It is important to recognize, for example, that some patients are more engaged in treatment planning and shared decision making than others.

Common themes from the focus groups include:

1. Patients are rarely actively involved in the development of their initial treatment plan.

- Most of the patients included in these focus groups expressed their trust in their physician's expertise and did not want to question his/her recommendations. If they had questions at the time of treatment decision making, their questions tended to be about the specifics of the recommended plan (i.e., "Will I lose my hair?") and less likely to be about other treatment options.
- Patients generally did not realize that more than one treatment plan may have been available, or they assumed the best plan was the one their provider recommended.
- Patients' belief in their doctors recommending the best plan for them was juxtaposed with their admitting that their doctors rarely asked questions about their work and family life, responsibilities, or financial circumstances. These patients said they were reluctant to communicate their personal concerns to the healthcare team, yet at the same time, reported wanting their lives to remain as close to "normal" as possible, such as continuing to be "super mom". Some patients talked about the importance of natural medicine versus

chemotherapy while others were willing to do anything to fight their cancer. Patients rarely talked with their healthcare team about these preferences during the initial treatment planning process..

- CancerCare social workers reported talking to many patients who believed their providers did not think they were able to understand their illness or the treatment information well enough to make a decision. These patients reported feeling unprepared to undergo treatment, which exacerbated their fear and anxiety.

2. The treatment planning discussion may be an overwhelming experience for patients.

- Patients reported feeling a mix of vulnerability and fear during the initial treatment planning discussions with their provider. Many said they "could not remember most of it", and that because they were taking in so much information, they were not able to respond with questions. They all reported they wanted the best care they could get.
- Patients struggled with medical jargon, and did not fully understand words such as "remission" and "recurrence".
- Patients said that access to information would be helpful, but they wanted to control the amount of information they were given. One patient reported not asking about side effects because if there was something abnormal happening with her body, she would know and alert her care team. She expressed that if she knew of all possible side effects, then she could not face the treatment. Other patients wanted specifics and were frustrated by their providers' responses of "this affects everyone differently" or "we will know how this affects you as you go through your journey".

"It was obvious to my oncologist that I needed chemotherapy, but it wasn't obvious to me. I wished my oncologist would have started at the beginning and explained why radiation and surgery wouldn't work, and why my treatment plan was the best one... I was surprised I had to start with crummy chemo."

– Patient with stage 4 non-small cell lung cancer



3. Very few patients come to the treatment planning discussion prepared with a list of questions, about their diagnosis, prognosis or personal circumstances.

- Those patients who had questions or did research prior to the decision-making process noted that they tended to approach other parts of their life with similar attention to detail or fact-finding.
- Most patients seemed to ask similar questions, including, “What should I expect?”, “How long will the treatment last?”, or “What are the side effects?”. Questions around quality of life or ability to maintain a ‘normal’ lifestyle usually were not asked until after treatment began.
- Although patients said they felt comfortable asking questions of their team, they were concerned about wasting their providers’ time or feared being perceived as a “problem patient” who asked too many questions.
- Social workers reported hearing patients say that if the doctor likes them, then they would get better treatment.

4. Patients’ priorities and perceptions of their treatment change throughout the course of their treatment.

- Patients reported not raising questions or concerns about the side effects of their treatment until after they started experiencing them, either because they were too anxious or did not know to ask in earlier discussions. Negative experiences with previous treatment regimens seemed to influence future treatment preferences. Some patients mentioned that their willingness to undergo chemotherapy in the future decreased based on their current experiences with side effects, etc.
- The social workers noted that patients made future treatment decisions based on their own previous experiences, the experiences of other patients they knew, the success or failure of previous treatments, or the feeling that they had too many unanswered questions to be comfortable with the same treatment modalities in the future. The social workers also talked about how patients felt their healthcare teams were making decisions based on the patients’ initial set of treatment goals, not necessarily on their new (or evolving) priorities as they proceeded throughout treatment.

5. Patients want to feel as if they are being taken care of holistically, as a whole person.

- Though patients reported their primary focus was on attacking the cancer, most did not feel their doctor had a holistic view of them and their personal circumstances before determining their treatment plan. Younger patients felt their need to take care of children or work full time was not considered by their healthcare team. Generally, the patients themselves did not fully recognize these concerns or the effect treatment had on these activities until after treatment began.
- Both patients and social workers shared examples of how culture, socio-economic status, language, religious beliefs, health literacy and age affected the ways patients perceived providers, how providers interacted with their patients, and how or whether patients were able to access or understand information about their care.
- Patients of lower socio-economic status did not have easy and reliable access to computers, smart phones, or the internet, so their ability to communicate electronically with their team or leverage online tools was extremely limited. For many patients, these methods of communicating are considered a “luxury”, though patients and social workers said that many doctors have these capabilities.
- Language barriers limited the amount of critical information patients were able to relay to their healthcare team (i.e., family history of cancer, etc.), while limited access to hospitals and clinics, particularly in rural areas, affected patients’ ability to connect with their care teams.
- Even for patients who spoke the same language as their providers, disparities in health literacy compromised whether the patients fully understood the implications of what they were being asked or told.
- Demographic variations also drove differences in how patients engaged with the healthcare system. The social workers reported that some women with breast cancer do not feel comfortable discussing body image, hair loss, and intimacy concerns with male doctors. Social workers also said that younger patients experience high levels of stress associated with the unpredictability of their lives after a cancer diagnosis, and therefore often needed more psychosocial support services than older adults.

Patient Values Initiative: The Many Voices of Value

A CancerCare Focus Group Assessment

6. Figuring out how to cover the financial cost of care may be more stressful than cancer itself.

- CancerCare social workers reported speaking to many patients for whom the financial burden of a cancer diagnosis was constant. They said that many patients did not have a complete or accurate picture of how much their cancer care would cost them, and that many cancer patients experienced the acute financial effects of treatment as they struggled to manage co-payments, transportation, child care and lost employment income.
- The social workers suggested that for many of the patients they speak with, “life can supersede cancer”, and those patients who did not have their basic daily needs met were not well positioned to deal with treatment planning or the implications of their cancer diagnosis.

7. Family members and caregivers may influence how a patient makes decisions.

- Patients reported that their cancer diagnosis affects the whole family. Patients’ understanding of “what is best for my family” influenced their preferences or treatment goals. Simultaneously, social workers reported hearing from patients who felt they could not express their own individual preferences because their family, and particularly adult children, communicated their own goals for the treatment, which in some cases, were in conflict with the patients’ personal preferences.

"When I started losing my hair and asked for radiation instead, my doctor was a little upset that I changed my mind. But he looked at the statistics and came back and told me that after 10 years, chemo and radiation both showed about the same results, so he supported my decision."

– Patient with B-cell lymphoma

"Cancer interferes with your life."

– Patient with metastatic cervical cancer



Discussion

When learning of their cancer diagnoses, patients' responses are as diverse and complex as the patients themselves. Their subsequent interactions with their healthcare team and the healthcare system differ from patient-to-patient and are dynamic over time. Despite this, the fear and vulnerability they felt upon receiving the diagnosis of cancer was universal across all groups. It is during this tenuous state that they were asked to absorb new and technical information to make, or agree to, treatment decisions that would likely have a significant effect on how long they live, their quality of life, and how they and their family will fare during and post treatment.

Most focus group participants agreed that being fully informed and active in making treatment decisions simply was not possible immediately following their diagnosis. The universe of questions patients could or should ask was not clear to them until after they had agreed to and started treatment. During this interim period, they relied upon family and the expertise of their healthcare team to determine the best treatment plan.

For these patients, it was only after the initial stress of their diagnosis and beginning treatment subsided that they had a glimmer of understanding about the broader effect cancer treatment would have on their lives. As part of this realization, they voiced concerns that their doctors typically did not seek to understand how treatment was affecting their lives. They wished that their personal circumstances and preferences were

considered in treatment planning. At this point, they began to consider how their treatment aligned with their priorities and started to identify or consider changes that could be made to their treatment plan. Some began to ask about or conduct their own research into whether treatment options were available that allowed them to continue working, required less care at home, cost less out of pocket, or spared them from undesirable side effects. Some patients became more proactive and looked for a care team that was open to their questions and was willing to consider treatment regimens that reflected their evolving lifestyle preferences.

In this era of precision medicine, new discoveries translate into new treatment options. These options may mean longer life, more tolerable side effects and/or more convenient delivery modalities. However, they may cost more, pose toxicity and quality of life challenges, and/or be complex to deliver.

Resources are acutely needed now to help patients articulate their preferences and for care teams to recognize patients' priorities before cancer treatment plans are finalized and treatment begins. Pathways, guidelines and value frameworks are helpful decision-support tools for physicians. But without acknowledgement and consideration of what the individual patient values, cancer care currently takes place divorced from the true needs of patients and their families beyond the response of their cancer to therapy.

“My doctor asked me about myself, what I do, if I had kids...He got personal and had a good understanding of me. He allowed me to talk and took time to listen. He gave me his time.”

– Patient with stage 2 triple-negative breast cancer

“My kids always called me ‘Super Mom’. I was always there, always on top of things. But since my treatment started, I can’t be ‘Super Mom’ anymore. The reason I’m doing this treatment is to be here for my kids.”

– Patient with late-stage cervical cancer

Patient Values Initiative: The Many Voices of Value

A CancerCare Focus Group Assessment

Next Steps in the Patient Values Initiative

The research discussed here builds on the foundation of CancerCare's previous work to understand the full spectrum of needs a person has after a cancer diagnosis, including the practical, financial and informational concerns that are often not adequately addressed. In the coming months, CancerCare's **Patient Values Initiative** will survey providers and patients to build on and validate these initial findings. This research will then inform the development of new resources that include a manifesto on patient-centric values and priorities for use in advocacy with policymakers, and prototype materials for patients and healthcare providers to help elucidate and incorporate patients' priorities and values into treatment planning. The ultimate goal of this initiative is to help ensure that patients' initial and ongoing treatment plans reflect their personal values and priorities, while also encouraging other stakeholders to implement more patient-centric policies, tools and practices.

CancerCare strongly believes that for cancer care providers to deliver truly patient-centric care, they need to expand beyond the clinical information that is typically collected at intake. For each patient, oncology care teams may need to consider how a treatment plan can optimize a patient's quality of life, minimize the financial burden, facilitate the patient's preferred or necessary lifestyle activities, and support adherence.

Patients deserve to participate in making treatment decisions, especially considering the high physical, emotional, practical and financial stakes. However, the timing of many treatment decisions – when patients are newly diagnosed – is a barrier that often prevents them from actively participating. The oncology stakeholder community has a responsibility to help lessen the burden every patient faces after a cancer diagnosis. CancerCare is committed to giving voice to this unmet need and to providing ways to truly personalize the planning and implementation of cancer treatments.

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