CANCERcare®

Cancer Caregivers and Treatment Decision Making

A Qualitative Research Assessment

2020

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About Cancer*Care*

Founded in 1944, Cancer*Care* 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 case management, counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All Cancer*Care* services are provided by master's-prepared oncology social workers and world-leading cancer experts.

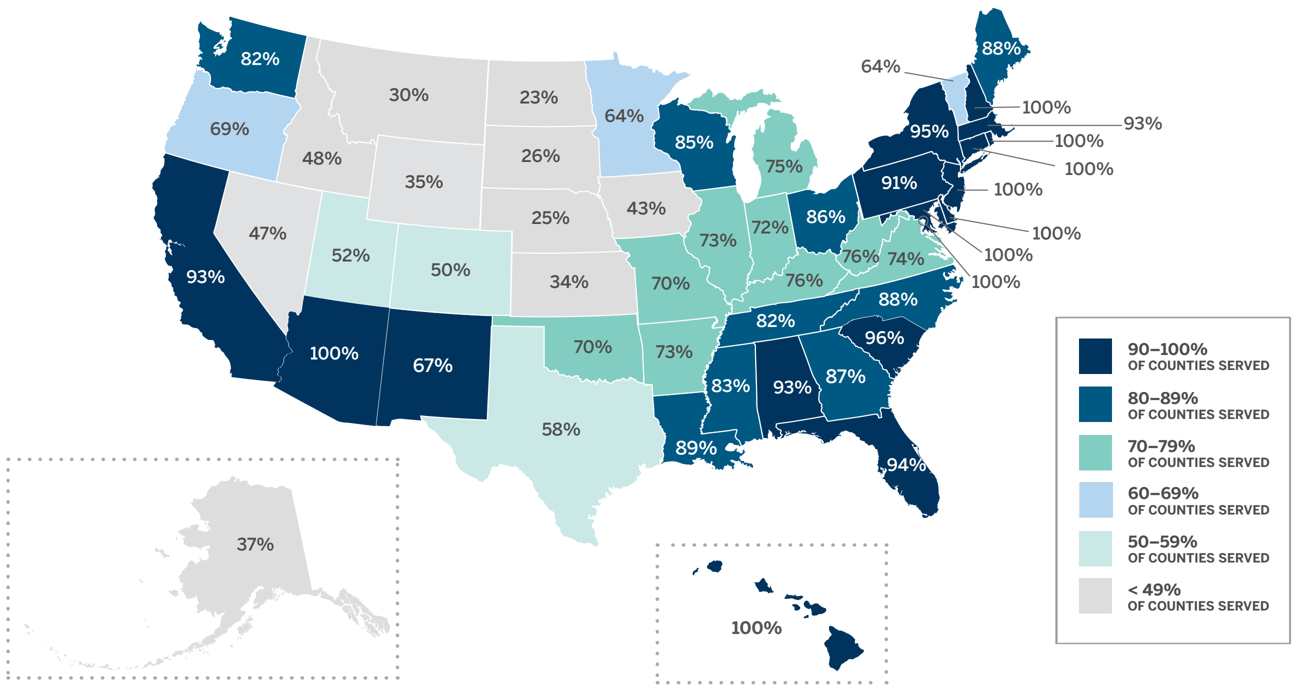
In 2019, Cancer*Care* programs and services helped 174,600 people. We distributed over 1.2 million publications and welcomed 2.4 million website visits. In the past year, Cancer*Care* provided $39.7 million in financial assistance. The size and scope of Cancer*Care* has grown tremendously since 1944, 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

Cancer*Care* is the leading national organization dedicated to providing free, professional support services including case management, counseling, support groups, educational workshops, publications and financial assistance to anyone affected by cancer.

Percentage of Counties Served by Cancer*Care*



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Executive Summary

For patients, their family and friends, a cancer diagnosis introduces numerous challenges and uncertainty that can be overwhelming and emotionally turbulent. Adding to the stress, decisions about treatments and other aspects of daily life must be made. The pressure to make high stakes treatment decisions can challenge patients' and caregivers' ability to process complex disease and treatment information and appreciate the implications of the diagnosis.

While the logistical, physical and psychosocial burdens caregivers experience are well documented in the literature, studies are just emerging regarding the ways they participate in cancer treatment decision making and the specific challenges they encounter in the process. Cancer*Care* seeks to better understand the issues and concerns caregivers face as they share in treatment decision making with patients throughout the course of care.

Through focus groups and online discussion boards, Cancer*Care* heard directly from social workers and caregivers about how they approach and support patients in making decisions. These findings will guide the development of a large national quantitative survey of cancer caregivers to help elucidate cancer caregiver experiences in the realm of treatment decision making; how they interact with other care team members, including family members and clinicians; how they define their roles and engage in shared decision making; what their needs are in helping to choose treatment and other care options; and how this population might be sub divided by similarities, to allow targeted support strategies.

Key themes from this qualitative research include:

1. Caregivers have their own decision-making experiences distinct from the patient, and those situations can vary significantly from person to person and situationally;
2. Though some aspects of decision making are as unique and personal as the individuals themselves, there are also commonalities among experiences;
3. Caregivers frequently seek information to help with decision making and to augment information received from health care clinicians;
4. Levels of engagement in decision making can vary greatly among caregivers as they balance the needs, prognosis and capacity of their loved one and other family members;
5. Making decisions for a loved one is often difficult and complicated; caregivers suggested a variety of resources to help them feel more competent and confident in the role.

Introduction

Innovation, standardization and personalization are among the key dynamics that characterize the evolution of cancer care. Tremendous advances in treating cancer through personalized medicine and novel therapies have been accompanied by the escalating costs of every aspect of health care. To meet the goals of improved patient outcomes and affordability, health care systems and payers pursue standardization and streamlining, in which humans are replaced with technology and there is an increased focus on cost cutting. Simultaneously, clinicians and health care organizations strive to deliver patient-centered care that meets the needs of individual patients with cancer and their families, which the National Academy of Medicine has declared to be a pillar of high-quality cancer treatment delivery. These opposing pressures, combined with the challenges of health literacy and disparities, have made it exceedingly challenging and complex to provide patient-centric care. Delivering and accessing cancer care in this environment requires clinicians and patients to find meaningful and effective ways to engage with each other, while at the same time, navigating unfamiliar and dynamic processes, regulations, and payment models.

In 2017, Cancer*Care* established the Patient Values Initiative (PVI) with the overall goal of enhancing treatment planning so that patients' preferences and priorities become key considerations in the decision making process. Importantly, cancer is a disease that affects whole families and those closest to the patient. Family members play an essential role in providing care for cancer patients and often are present when decisions about cancer care are being made. Evidence suggests that family involvement in decision making is associated with higher patient satisfaction and treatment adherence in general medical care.

However, the burden of caregiving can also negatively impact the quality of care provided and patient outcomes.[5,6] For example, studies have shown an association between caregiver depression and high levels of patient anxiety, with distress and increased use of aggressive and unnecessary treatments toward the end of life.[7,8]

Recognizing the significant emotional toll that caregiving exacts, many psychosocial support programs and materials have been developed to support them. Notably, however, caregivers also need resources that enable them to participate appropriately in shared decision making since they are often essential team members, intimately engaged in all aspects of care delivery, and, like patients, frequently left with the long-term consequences of those decisions.

Current Landscape

The number of individuals currently providing care for patients with cancer is startling: recent U.S. national estimates of cancer caregivers range from 2.8 million to 6.1 million adult individuals.[9, 10]

Cancer caregivers spend an average of 32.9 hours a week caring for their loved one, with 32% providing 41 or more hours of care weekly, the equivalent of a full-time job.[11] Since supporting a person with cancer can be particularly demanding, they devote nearly 50% more hours per week to providing care than those caring for people with non-cancer diagnoses.[12, 13]

Adding complexity is that cancer care decision making can shift the dynamic between patient and caregiver. While shared decision making can be straightforward when the caregiver and their loved one have a mutual understanding of priorities and preferences, the extent to which a patient diagnosed with cancer wants to, or is able to, make independent treatment choices or involve a caregiver may vary significantly. This can result in shifting roles for caregivers.[14]

The challenges that cancer caregivers face are often exacerbated by a lack of information and knowledge sufficient to make sound medical and treatment decisions. In fact, a recent study indicated that only 35% reported having the information they needed when they were first involved as a caregiver and 79% said they were frequently searching for more information.[15] Between 73% and 88% said care decisions put a great deal of stress on them.

Since cancer has become a chronic disease for many, these challenges can last for years, evolving and shifting, causing significant hardship that affects finances, housing, careers, family dynamics and much more.

Cancer has a profound effect on families. For clinicians to provide patient-centric care, the needs of caregivers must be addressed. They need guidance and resources to effectively and confidently engage in informed treatment decision making that is not only in the patient's best interest, but that also reflects the patient's values and priorities.

Research Methods

This qualitative research study was designed to explore caregivers' participation in decision making in order to inform later phases of the caregiver research program. The first part of this initiative consisted of in-person focus groups with oncology social workers, to provide a wide spectrum of concerns and experiences cancer caregivers have when engaging in shared decision making. On December 3, 2019, eight social workers from Cancer*Care* shared their learning from counseling caregivers, which highlighted the following issues:

- The transition to becoming a caregiver is full of emotionally disconcerting dynamics;
- Caregiver rationale for ignoring/exploring opportunities for assistance varies significantly; and
- Reaching out for help is driven by the need for financial and emotional support.

In the second segment of the qualitative study, Cancer*Care* connected directly with caregivers in four additional focus groups. On February 12, 2020, two telephone focus groups were held: one with caregivers of people diagnosed with Stage I or II cancers (5 respondents); and the other with caregivers of people diagnosed with Stage III or IV (2 participants). In the third segment, during the week of February 17, 2020, two online discussion boards were fielded. These included 12 caregivers of people diagnosed with Stage I or II cancers, and 9 caregivers for people with stage III or IV diagnoses. They were recruited from Cancer*Care's* client database and agreed to participate in these private, online discussions. The interviewer, who is an experienced focus group moderator as well as a cancer caregiver and cancer survivor, collaborated with Cancer*Care* staff to develop the questionnaire. Participants logged in on Monday, Wednesday and Friday and answered questions regarding their experiences in treatment decision making, and also had the opportunity to respond to the input of others.

This white paper includes caregiver verbatims to provide a 'real feel' for the learning. The quotes also illustrate the language caregivers used when discussing their roles and experiences. This information provides important insights into relevant caregiver terminology to help guide development of the forthcoming quantitative study.

Findings

Caregivers are people with many roles, and being a caregiver is not one for which they are adequately prepared.

Caregivers are typically close family members who recognized that caregiving became an imperative—something "they knew they had to do," when faced with a cancer diagnosis. However, they have important roles outside of caring for a patient. They are also parents, spouses, business owners, employees, students, children, etc. When becoming a caregiver, everyday life pressures do not go away, but may diminish in importance as taking care of their loved one becomes the highest priority.

> **"I went into automatic robot mode and did whatever had to be done those first few months. I didn't have a choice."** - Stage I & II

Caregivers have their own decision-making experiences alongside the patient, and those experiences can vary greatly from person to person and situationally.

The starting point in decision making usually stems from a conversation with a physician upon diagnosis. While many caregivers found doctors offered valuable treatment and care advice, not everyone had complete confidence in the recommended next steps. At times, the focus on the disease rather than the patient felt too impersonal and mechanical. As caregivers sought out additional information, they were faced with a steep learning curve as well as a range of choices for consideration at various points along the continuum of care from diagnosis through treatment and beyond.

There were concerns raised that clinicians recommended "standard of care" treatment without giving thought to the individual patient's circumstances. This felt very impersonal to them.

Some caregivers expressed frustration when learning there were limited recommendations and resources to help them, noting that physicians typically suggested options offered only at their medical facility, rarely volunteering that there were other institutions offering more treatment options.

As caregivers sought out additional information, they were faced with a steep learning curve as well as a range of choices for consideration at various points along the continuum of care from diagnosis through treatment and beyond. One respondent noted, however, that she was not really capable of making decisions at first because she was grappling with the diagnosis itself.

Others pointed to the differences in how they make decisions when faced with an early-stage diagnosis requiring immediate treatment, compared to decisions that may be associated with a terminal or advanced diagnosis. Balancing short vs. long term concerns regarding childcare, work, quality of life, etc. was particularly vexing and challenging. In both cases, they knew their involvement in treatment decision making could have a serious and significant impact on their loved one, family members and themselves.

Though some aspects of decision making are as unique and personal as the individuals themselves, there were also common reactions to some experiences.

When clinicians on the care team disagreed regarding treatment recommendations, it made decision making more difficult for caregivers as they needed to seek additional advice and information.

Receiving limited information on side effects also made it more difficult for caregivers to evaluate treatment options.

The severity and/or complexity of the diagnosis complicated treatment conversations with clinicians when caregivers, concerned about the sensitivity of certain issues, felt they could not be honest and open in the presence of the patient. Caregivers also mentioned that when the effects of cancer itself made it difficult for their care recipient to participate fully in decision making, they were conflicted regarding how much weight should be accorded their own opinions.

When clinicians used medical jargon, caregivers, feeling stressed and emotional, struggled with decision making and wanted simplified language they could easily understand.

> **"I'd like more time to talk to my husband's cancer team without him in the room, to talk about cold hard facts and possible outcomes."** - Stage I & II

Caregivers frequently seek information on their own, to help with decision making and augment information received from the clinical team.

Caregivers looked for medical facts on the internet, also known as "Doctor Google," using independent research to gain a basic grasp of the diagnosis and potential treatment options or clinical trials. They also connected with their own personal health care contacts to seek guidance from those they considered to be "valuable resources."

Some caregivers mentioned that joining social media support groups or discussion boards offered guidance from others with firsthand experience. Even if they did not actively participate in the conversations, just reading through posts published by their peers was helpful.

> **"So much of the terminology used is confusing, or well over my head, and I have to do so much more researching to figure out what it is or means."** - Stage I & II

Levels of engagement in decision making can vary greatly among caregivers as they balance the needs, prognosis and capacity of their loved one and other family members.

Cheerleader: For patients who wanted to make decisions independently, the caregiver frequently assumed a cheerleader role (paraphrased), providing encouragement.

Team effort: Some caregivers experienced decision making as a team effort, with a balance between the patient independently making decisions and the caregiver trying to find information on, and sometimes influencing the discussion regarding, the "right" decision.

Sounding board: Some caregivers listened to their loved one talk about issues and were asked for or provided minimal input.

Unilateral engagement: While shared decision making is essential to patient-centric care, sometimes the caregiver was excluded from the process while the patient considered their own diagnosis and prognosis. Conversely, if a patient was unable to actively participate in decision making, the caregiver assumed the primary decision-making role.

Making decisions for a loved one is often difficult and complicated; these caregivers suggested a variety of resources to help them feel more competent and confident in the role.

Caregivers desired an "objective" health care professional who had expertise in the specific type of cancer their loved one has/had. None of the caregivers included in this research were able to find this ideal resource.

Caregivers also noted the need for help with relevant financial and insurance information. Getting assistance with everyday chores and managing the logistics of patients' appointments could relieve some pressure on caregivers, freeing them up to be more effectively and appropriately engaged in treatment decision making.

> **"I always felt good about my role in this process because I tried to be very cognizant about not imposing my will or pushing what I thought was best. Right now, David is the driver of this cancer bus and where this journey is taking all of us."**
> - Stage I & II

Discussion

Caregivers are unique individuals distinct from the patients for whom they are caring. Before the cancer diagnosis, they had busy lives, responsibilities, goals and dreams. When a loved one is diagnosed, they suddenly have a new full-time job layered on their existing roles and responsibilities.

While a patient has their own way of dealing and coping with their cancer diagnosis, the caregiver must also process the situation. There is a broad range of engagments based on the emotions that caregivers may experience as they move from the shock of diagnosis through active treatment and beyond.[16] For some, the day-to-day burden can be so overwhelming that they cannot manage the added stress of shared decision making. Yet, they are aware that treatment decisions have grave consequences and recognize that it is critically important to get it right. How to consider second opinions, clinical trials, treatment options, financial implications and life itself are immensely challenging and can seem insurmountable. The caregivers interviewed through this research shared these experiences and the intense distress it caused in their lives.

For them, the role of caregiver has been full of uncertainty. Even among those with previous experience caring for a loved one with cancer, who had some inkling of what to expect, the roles and expectations shifted depending on their relationship with the patient, family members and the health care team, as well as the trajectory of the illness.

Caregivers frequently search for information about their loved one's diagnosis and potential treatment options to augment their understanding of the disease, therapeutic options and the resources presented by the health care team. This independent activity can help the caregiver cope with the diagnosis and become more capable of making difficult decisions. It can also be a source of misinformation that adds to confusion.[17] Social media engagement may provide much-needed emotional support[18] as well as identify treatment options and resources that others find helpful. This kind of anecdotal information can also be Misinterpreted, however, or applied in ways that are inappropriate.

Caregivers experience a great deal of uncertainty regarding how to make the "right" treatment choice or a "good" decision. Having clear and open lines of communication with the health care team can help to provide clarity concerning the prognosis and treatment path.[19] Families want to hear from the physician through proactive, plain language communication and guidance, especially when their loved one is unable to participate in decision making. This eases caregivers' uncertainty related to treatment decision making[17] and is especially needed as options become more complex due to new treatment advances. Caregivers find it difficult to appreciate the long-term effects of a therapy and determine how to balance quality of life with prolonging life,[20] not to mention how to view and integrate the patient's own preferences when it comes to quality of life and outcomes. They expressed the need for an impartial, dedicated health care professional to be an objective, expert sounding board.

> **"I never had a social media account until the cancer diagnosis, but the forums have been so helpful."**
> - Stage I & II

While caregivers support patients, they need support too. These caregivers agreed that support from family and friends could help alleviate the stress of having too much to do. Help managing insurance issues, applying for patient assistance programs, rearranging work obligations, finding childcare, etc., are just a few of the time consuming and mundane chores that caregivers face.[2] Easing their burdens and day-to-day anxieties can free them up to focus on and feel confident being an informed decision maker. For some, the consequences of failing to engage can lead to treatment plans that do not reflect the priorities and values considered most important to patients and their families. This can leave a lasting imprint.

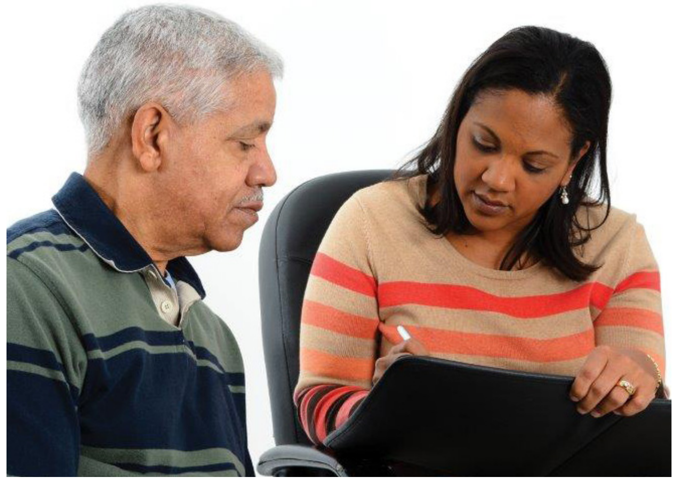
> **"I immediately called my uncle who is a retired surgeon for guidance. We asked multiple doctors and did as much research as we could via the internet. I felt I needed to collect as much data as I could to ask the right questions and make a good decision."** - Stage I & II

> **"You need someone to give you a break, just to keep your sanity."**
> - Stage I & II

Next Steps

The findings within this report have created a foundation for the quantitative phase of this research project, which will be an online survey of 2,500-3,000 cancer caregivers. This large sample size will allow the identification of meaningful subgroups of caregivers (age, gender, race, relationship to patient, etc.). It will also allow exploration of treatment decision making at various stages along the patient care continuum, from diagnosis to maintenance therapy to end of life. Segmentation will help illuminate how key variables interact in the real world, revealing a more in-depth understanding of caregiver decision making dynamics.

Survey participants will be recruited from My Cancer Circle, an online community of cancer caregivers with an estimated 1,700 recent members, Cancer*Care*'s e-mail database of caregiver clients (1,000+), as well as collaborating organizations, such as the Caregiver Action Network and the National Alliance for Caregiving. Market research panels will be used to supplement, if necessary, to achieve a nationally representative sample.



A Note on the Covid-19 Pandemic

This qualitative research was fielded shortly before the outbreak of COVID-19 in the United States. For many, the pandemic further complicated cancer caregiving and decision making. Following the outbreak, Cancer*Care*'s Hopeline monthly call volume increased by 20% to 45% year-over-year. Some caregivers related their distress about not being able to accompany loved ones to treatment or visit them in the hospital. Leaving them to suffer side effects or die alone caused overwhelming fear and anxiety.

Cancer*Care* social workers also heard that the shift towards telehealth appointments created an added layer of complexity and confusion for some. As physicians moved patient care to virtual settings, some patients and their caregivers faced new hurdles. For example, one caregiver noted, "I take off work to get mom to her treatment, but I can't be there when she has a telehealth appointment with her doctor and she sometimes forgets. It is hard to get additional time with the doctor for my questions so I feel lost sometimes as to how she is doing and what I should be doing to help."

In many ways, technology can benefit patients. It has allowed for appointments and communications with care teams to continue during this unprecedented health crisis, and in general, it can increase patient-clinician connectivity more broadly. However, as these tools become more integrated into care delivery post-pandemic, how to support patients and their caregivers in using them will require particular attention. We need to ensure that technology does not unwittingly alienate cancer patients and caregivers from their clinical care team and add even more barriers to effective shared decision making.

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