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***“I pretty much followed the law, and there weren’t any decisions to make”*: A qualitative study of self-advocacy experiences of men with cancer**

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Abstract

Current conceptualizations of patient self-advocacy focus on women with cancer, leaving knowledge of male self-advocacy deficient. The purpose of this study is to describe the key components of self-advocacy among men with cancer. Adult (> 18 years old) men with a history of invasive cancer were recruited from cancer clinics and registries. Trained researchers led individual semi-structured interviews regarding participants’ challenges, how they overcame those challenges, and barriers and facilitators to their self-advocacy. All interviews were analyzed using descriptive content analysis methods and synthesized into major themes. These themes were refined after receiving feedback from key stakeholders. Participants ($N=28$) reported three major self-advocacy themes: (i) managing through information and planning; (ii) finding the best team and falling in line; and (iii) strategic social connections. These themes are richly described with representative quotations for each theme and subtheme. Based on these findings, existing models of patient self-advocacy should be adjusted to encompass how men self-advocate. Clinicians should consider how gender may impact how and why patients with cancer self-advocate so that they can best support their patients in achieving patient-centered care.

Keywords

cancer survivors; communication; men; patient advocacy; self care

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AUTHOR CONTRIBUTIONS

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher’s website.

1 | INTRODUCTION

In cancer, momentum toward greater patient-centered care and patient engagement has resulted in calls to improve patient self-advocacy. Self-advocacy is defined as the ability of an individual to get his or her needs met in the face of a challenge (Hagan et al., 2016). Self-advocacy has been widely endorsed as a necessary part of being a cancer patient by oncology patients and providers (Haylock, 2015), policy makers and advocacy organizations (National Coalition for Cancer Survivorship, 2021), and researchers (Sun et al., 2015). These groups encourage self-advocacy as a means for patients to exert control over complex treatment decisions and uncertain health outcomes, address their unmet needs, and improve their healthcare experience. Yet efforts to encourage self-advocacy may not always result in these intended outcomes.

Asking patients to advocate for their needs may place exceptionally high demands on individuals who lack communication skills, decision-making skills, and social connections. Although cancer organizations and leaders' emphasis on improving patient self-advocacy is well-intended, it risks demanding that patients behave in ways that providers do not know how to support and which may lead to adverse outcomes. It is imperative to have a conceptual framework of self-advocacy for patients with cancer so that researchers and clinicians can create evidence-based interventions to improve self-advocacy and address the needs of patients at-risk for the poor outcomes associated with low self-advocacy.

2 | BACKGROUND

Previous research has reported a conceptual framework and a valid, reliable measure (the Female Self-Advocacy in Cancer Survivorship Scale) defining self-advocacy in women with cancer (Hagan, Cohen, et al., 2018; Thomas et al., 2021). Briefly, this framework defines three major areas in which women with cancer self-advocate: (i) making informed decisions about their care; (ii) effectively communicating with their healthcare providers; and (iii) having strength through connection to others. This research demonstrates that women with cancer who are strong self-advocates have lower symptom burden and less frequent use of emergent healthcare services compared to women who lack self-advocacy skills (Hagan, Gilbertson-White, et al., 2018). While previous work purposefully focused on women because of known gender differences in communication, decision-making, and healthcare engagement (Rogers et al., 2019; Saeed et al., 2018), the exclusion of men is a weakness of the current self-advocacy scholarship.

Men with cancer need to self-advocate because of the multiple, ongoing challenges they face that prevent them from getting their needs met. Men with cancer experience significant unmet needs, including high symptom burden, informational needs, difficulty communicating with their providers, and distress (Groarke et al., 2020; Oliffe et al., 2020). Yet men generally interact with the healthcare system differently than women, attending fewer clinic appointments, talking less at appointments, and seeking out less health information than women resulting in fewer opportunities for engagement (Saab et al., 2018; Salgado et al., 2019). Traditional male gender roles emphasize control, stoicism, and strength which may impact men's self-management and help-seeking behaviors (Wenger &

Oliffe, 2014). This makes it even more important for men to self-advocate to ensure their priorities are addressed and avoid more serious problems in the future. Therefore, clarifying how and why men with cancer self-advocate can help expand the current conceptual framework and lead to more impactful clinical interventions.

This study aims to expand self-advocacy scholarship to include men by richly describing the ways in which men with cancer advocate for their needs and priorities. Our primary aim is to describe the key components of self-advocacy among men with cancer by understanding the challenges they experience and how they overcome these challenges.

3 | METHODS

3.1 | Design

This is a descriptive, qualitative design consisting of individual patient interviews. This study received human subjects approval from the University of Pittsburgh Institutional Review Board (STUDY19040262).

3.2 | Sample

We recruited men with a history of cancer from cancer clinics at the University of Pittsburgh Medical Center (UMPC) Hillman Cancer Center and the University of Pittsburgh Pitt+Me Research Registry using convenience sampling. Eligibility criteria included self-reported male gender, age ≥ 18 years, previous diagnosis of invasive cancer, and English literacy. Potential participants who indicated interest and screened as eligible were contacted by the research team to schedule interviews.

3.3 | Data collection

We used Creswell's interview techniques to perform all participant interviews (Creswell & Poth, 2017). We ensured qualitative rigor as defined by Lincoln and Guba (1985) by maintaining and documenting the credibility, transferability, dependability, and confirmability of all data through methods including investigator field notes, bracketing of biases, triangulation of data sources, and audit trails. The lead interviewer (T.H.T.) is a female nurse scientist and university faculty member trained in qualitative research and previously led similar qualitative studies. A research assistant (M.H.), trained in qualitative methods, also conducted interviews using the same interview protocol.

We developed a semi-structured interview guide (Table 1) based on a previous self-advocacy qualitative study (Hagan & Donovan, 2013). The questions were open-ended to allow participants to interpret and structure their responses according to their unique experiences. The guides' initial questions asked participants to describe challenges they experienced related to their cancer and reflect on how they addressed those challenges. The final question asked if they perceived themselves to be self-advocates.

Prior to each interview, the interviewer briefly talked with the participant to build rapport and comfort. When introducing the purpose of the study and obtaining informed consent, she emphasized the participant's expertise in their cancer experience, and that the interview was intended to be a non-judgmental account of their experiences of self-advocating. She

also stressed that the study was not intended to review the care they received and that their responses were confidential. Initially, all interviews occurred one-on-one in person at a place convenient for the participant (e.g. a quiet space in a public café). During the COVID-19 pandemic, all interviews occurred remotely over the phone. Interviews lasted on average 30–60 min, were audio-recorded, and transcribed verbatim. Participants received a \$10 Amazon gift card.

3.4 | Analysis

3.4.1 | Initial analysis—Two trained members of the research team (T.H.T. and M.H.) separately analyzed interview transcripts. We used descriptive content analysis methods, including an iterative constant comparison approach using axial coding techniques from Strauss and Corbin (1990). The investigators individually reviewed and coded several transcripts, then met to discuss and compare coding, and derived de novo codes which they iteratively refined after coding additional transcripts. Disagreements between the two investigators were resolved through discussion until consensus was met. We extracted categories of responses which we classified into overarching themes and underlying subthemes. Once data saturation of themes and subthemes was reached (e.g. no new ideas discovered), we ended recruitment. We used NVivo software Version 11 to assist with qualitative data analyses.

3.4.2 | Member-checking—To ensure the credibility of our findings, we shared our final list of themes and subthemes with all participants. We asked participants to confirm, edit, or disagree whether each theme and subtheme reflected their personal experience. Of the 25 participants who completed the survey, 19 (76.0%) indicated that the results matched their experience and 20 (80.0%) did not want to make major changes to the results. We met with participants who felt aspects of the final themes and subthemes did not match their experience and integrated their feedback into the results.

3.4.3 | Final analysis—Final themes and subthemes were reviewed by external experts in oncology to ensure the findings are concise, comprehensive, and representative of men with cancer. The COnsolidated criteria for REporting Qualitative research (COREQ; Tong et al., 2007) guided the presentation of results (see Table S1 in the Supporting Information).

4 | RESULTS

4.1 | Sample characteristics

Sociodemographic and cancer characteristics are reported in Table 2. We obtained consent from and interviewed 28 men who were an average of 64.6 years old (standard deviation [SD] = 14.6) with an average of 6.1 (SD = 7.2) years since their diagnosis. Participants were mostly well-educated, White, and non-Latino. Men reported a variety of cancer types with the most common types of cancer being prostate ($n = 10$; 35.7%), lymphoma ($n = 5$; 17.9%), and pancreatic ($n = 3$; 10.7%). Half of the participants were diagnosed at Stage I or II ($n = 14$; 50.0%).

4.2 | Descriptive thematic analysis

Table 3 provides a thorough description of each theme including corresponding subthemes and representative quotations.

4.2.1 | Theme 1: Managing through information and planning—Men identified multiple resources from which to learn about their cancer and its treatment. This included online and paper materials available through their healthcare provider, websites, public libraries, and their social networks. Men also networked with patients with similar types of cancer to help uncover what the typical path was for people with their type of cancer. By establishing what was “normal,” men adjusted their expectations for what was likely to occur throughout their cancer experience. By knowing what to expect, they learned how to handle the cancer care delivery system, including navigating multiple providers and a fragmented healthcare system.

Symptoms – including both symptoms of cancer and side effects of treatment – comprised a major area for which men looked up information. Men reported doing this for a plethora of bothersome symptoms, reflective of the variety of cancers with which they were diagnosed. While men viewed these symptoms as unpleasant reminders of their cancer that interfered with their ability to maintain their previous activities, they pragmatically approached their symptom management. For symptoms that they expected to occur, most men accepted the symptom as a temporary nuisance and sometimes would work with their healthcare providers to address these side effects. For example, many men described having fatigue but did not explicitly engage in management strategies because they knew it would likely subside once treatment ended. Some men who experienced particularly distressing symptoms (e.g. diarrhea, pain) shared their process for learning how to adjust their activities to reduce the side effects. Men generally had a very high bar for requesting symptom management strategies from their healthcare provider if they were not readily given. Only a few patients, most of whom had advanced cancer, expressed dismay over the lack of symptom management support.

Men reported experiencing emotional and existential reactions to cancer and having to actively manage these emotions by gathering information about the cancer and developing a treatment plan. They indicated that they had emotional responses to cancer – especially after diagnosis – often describing feeling shocked and overwhelmed. These feelings sometimes lingered, prompted by triggering experiences that reminded them of their cancer. A few men also noted feelings of discomfort because their cancer required them to depend on others. While the attention was sometimes helpful, it also provoked feelings of guilt and shame. Some men described lingering existential concerns about why they got cancer, worrying about the impact on their family, and their mortality.

Most men described managing these emotional and existential concerns by purposefully suppressing thoughts, adjusting their attitude, and focusing on their treatment plan. They explained how they intentionally internalized their emotions, purposefully adjusting their perspective and not allowing negative thoughts to interfere with their ability to manage the cancer. By maintaining a focus on treatment, men controlled and dismissed negative thoughts.

4.2.2 | Theme 2: Finding the best team and falling in line—When asked about how they self-advocated, men consistently described their process for finding the best healthcare provider. They referenced the immense effort they put forth to find the “top” providers, often leveraging family and friends to figure out who the most experienced, knowledgeable oncologist or surgeon was. If men were not sure that someone was an expert, they sought second opinions. If they had a provider whom they perceived as not being knowledgeable, they fired them.

Men generally looked for providers who were leaders in treating their type of cancer, thorough in their delivery of care, and able to coordinate all aspects of their care. Men consistently mentioned that having a good bedside manner was not a requirement, prioritizing knowledge and execution over friendliness or approachability. They wanted their provider to present options for how to manage their cancer along with plans of action. In presenting these plans, men reported feeling like the provider was giving them hope.

Once men had found their preferred provider, they described falling into line. Because they had done the work to find a top provider, they trusted the provider to lead the care and saw their job as following the plan presented by the provider. Since their provider was the expert, they were relieved of having to manage their care. Rather, they felt comfortable raising concerns as they arose but mostly knew the provider would initiate anything that needed to be done. For some men, relying on their provider’s expertise meant they did not recognize opportunities for participation in their care.

4.2.3 | Theme 3: Strategic social connections—While men mostly described their self-advocacy in terms of the first two themes, they also recognized the role that family, friends, and others with cancer had in their ability to overcome challenges. Men worked to manage their social relationships, being careful about who they included within their discussions of their cancer and being purposeful in receiving support from others.

Men consistently shared how challenging it was to share their cancer diagnosis with others. They typically disclosed their diagnosis to a small circle of individuals, wanting to protect others from distress and often preferring to wait until a treatment plan was established before sharing their diagnosis. They wanted to project a controlled, purposeful attitude while engaging their social networks as a way of keeping their social network strong, which in turn would keep them strong. Some men even delayed telling their partners, concerned that their partner may have a negative reaction. Some men were concerned about the professional impact of their cancer, especially if their ability to provide for their family would be impacted. After they shared their cancer diagnosis, men actively managed others’ reactions to their cancer, deliberately deciding what to share and with whom, to avoid others becoming upset or overwhelmed.

In addition to managing their social connections’ reactions to their cancer, men also described the importance of receiving support from their family and friends. Although many men indicated that they preferred to deal with issues by themselves, they did allow others to assist them in managing the obstacles they faced. This was reported mainly by men with partners. Men shared that others – primarily partners and daughters – were involved

heavily in their medical care, often prompting men to seek care initially and then helping them attend appointments, manage their medications, and other tasks. Some men indicated that they did not have others on whom to rely and were forced to manage their cancer independently. However, if friends or extended family reached out to support them, some of these men described experiencing an overwhelming sense of appreciation and connectedness that they did not have previously.

A few men described how they shared their cancer experience as a way of raising awareness. One man spoke at advocacy events to let others know it was okay to discuss their cancer story. Other men openly shared their stories with co-workers as a way of promoting cancer screening. Several men mentioned sharing their cancer experience, especially early cancer warning signs, with their children so that their children could proactively manage their health.

5 | DISCUSSION

This study adds to the self-advocacy and patient-centered care scholarship by describing how men with cancer self-advocate. Our results revealed three overarching ways in which men self-advocate, including being informed about their cancer and treatment, finding the best team to treat their cancer, and strategically managing their social support network. While they placed a high value on being knowledgeable about the expected treatments and side effects, they also put a large amount of confidence in their provider, spending significant energy to find the best provider and then entrusting the provider to manage their care.

Our findings corroborate research demonstrating that men engage in corresponding but distinct forms of self-advocacy behaviors compared to women (Kolmes & Boerstler, 2020; O'Malley et al., 2018). Appreciating these differences can assist healthcare providers in supporting patients based on the value patients place on various aspects of their care. For example, compared to men, women place a high value on communicating during clinic visits, engaging in treatment decision-making, and building therapeutic alliance with their oncologist (Geessink et al., 2018; Pozzar & Berry, 2017).

Men in this study consistently dismissed their oncologist's bedside manner. Rather, men described lengthy processes for finding the top oncologist and then following the "law" that the oncologist set for them, only interjecting if something major went wrong. This reinforces research documenting gender differences in patients' preferences for cancer care with men placing a lower value on how care is delivered and a higher value on providers' expertise (Mazzi et al., 2018; Wessels et al., 2010). At times, men's reliance on their providers' expertise seemed to cut off opportunities for self-advocacy. While confident in their providers' knowledge, they lacked awareness of when and how to engage in communication and decision-making to address their needs and priorities.

While men in this study engaged in self-advocacy related to their distressing cancer- and treatment-related symptoms, they had a very high bar for reporting these symptoms or requesting symptom management strategies. This finding is corroborated by research

demonstrating that men are less likely than women to share negative feelings and concerns with their healthcare providers (Ettridge et al., 2018; Goodwin et al., 2020). Importantly, this does not indicate that men do not have unmet symptom management needs, but that they either do not wish to report them or that they may need support self-advocating to address their symptoms.

Men purposefully engaged their social relationships to advocate for their needs and priorities, reflecting research documenting how men strategically use their social networks to manage their cancer (Wenger & Oliffe, 2014). Whereas women report self-advocating by balancing their needs with the needs of others (Hagan & Donovan, 2013), men's descriptions focus more on selectively engaging a few support persons. While men noted the benefits of having family members and friends available to support them, they also saw their role as protecting their social networks from the negative parts of cancer. This is similar to research demonstrating men's reticence about their cancer even with close family and friends (Bergner et al., 2018; Nelson et al., 2019).

Limitations to this study include a somewhat homogenous sample from Western Pennsylvania, which does not represent the experiences of all men with cancer. Future research should explore the specific self-advocacy experiences of men with specific types and stages of cancer, age groups, racial and ethnic backgrounds, socioeconomic characteristics (e.g. education and income), etc. which impact self-advocacy. Moreover, the possibility of recall bias cannot be excluded because men were asked to remember their thoughts and actions from months or years previously. Subsequent studies should explore real-time self-advocacy behaviors and needs of men with cancer to identify key points at which self-advocacy interventions could be useful.

6 | CONCLUSION

Men with cancer employ several complementary skills to self-advocate for their needs and priorities. By learning the typical experiences related to their cancer and treatment, men regulate their expectations and only self-advocate when a challenge is either unexpected or extremely burdensome. By securing a top oncology team, they entrust their care to the expert and follow their recommendations. By deciding which of their family members and friends to tell about their cancer, they manage their social relationships to get support while not encumbering others. While broadly similar to self-advocacy in women, this approach is nonetheless distinct.

7 | CLINICAL PRACTICE IMPLICATIONS

Healthcare providers should recognize the role gender plays in how and why individuals with cancer self-advocate. Understanding that men place high value on having competent providers but may avoid discussing their needs unless it is a major concern can help providers ensure the individual's priorities are clarified and his needs are met. In communicating the importance of self-advocacy to men with cancer, healthcare providers should focus on enhancing their existing self-advocacy skills and supporting their adoption of additional self-advocacy skills. Future research in patient self-advocacy should consider

the role of gender in how and why men with cancer self-advocate and tailor self-advocacy interventions to appreciate the different behaviors and values of men and women with cancer.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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DATA AVAILABILITY STATEMENT

Data is not publicly available, but the authors will make it available upon reasonable request.

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Key Points

- Men with cancer focus their self-advocacy efforts on identifying an expert healthcare provider and following their plan of care.
- Men with cancer engage in self-advocacy while receiving treatment but have a high bar for when to seek support from their healthcare providers.
- Men strategically rely on family and friends to support them through their cancer experience, preferring to convey a sense of control over their cancer which can help both them and their loved ones cope with the cancer.

TABLE 1

Interview questions and probes

1. Describe a situation that has been challenging for you to deal with during your cancer diagnosis and treatment.
 2. How did you advocate for yourself in that situation?
 - a. Was this hard to do? If so, what made it hard?
 - b. What helped you manage this situation?
 3. Do you think that you self-advocate?
 - a. Making informed decisions?
 - b. Communicating effectively with your healthcare provider?
 - c. Gaining strength through your relationships with others?
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TABLE 2

Participant characteristics ($N=28$)

	<i>N</i>	%
Age (mean, standard deviation)	64.6	14.6
Race		
White	27	96.4
Black	1	3.6
Ethnicity		
Non-Latino	27	96.4
Latino	1	3.6
Education		
High school	3	10.7
2-year college	3	10.7
4-year college	10	35.7
Graduate degree	8	28.6
Professional degree	4	14.3
Annual household income		
<40 k	6	21.4
40–80 k	7	25.0
80–150 k	5	17.9
>150 k	7	25.0
Unknown	2	7.1
Decline to answer	1	3.6
Cancer type		
Prostate	10	35.7
Lymphoma	5	17.9
Pancreatic	3	10.7
Head and neck	2	7.1
Melanoma	2	7.1
Colon	1	3.6
Esophageal	1	3.6
Leukemia	1	3.6
Lung	1	3.6
Testicular	1	3.6
Thyroid	1	3.6
Cancer stage		
Stage I	7	25.0
Stage II	7	25.0
Stage III	8	28.6
Stage IV	4	14.3
Unknown	1	3.6
Cancer treatment		

	<i>N</i>	%
Surgery	18	64.3
Chemotherapy	12	42.9
Radiation	11	39.3
Other (i.e., immunotherapy/hormonal therapy/CART-T cell therapy)	9	32.1
Time since diagnosis (years, mean, standard deviation)	6.1	7.2

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TABLE 3

Major and subthemes

Major theme

Subthemes, descriptions, and representative quotations

<p>Managing through information and planning</p>	<p>Being informed</p> <ul style="list-style-type: none"> • Researching their cancer and treatment • Networking with other patients with similar cancers <p>Establishing the “normal” path and setting expectations of what to expect</p> <ul style="list-style-type: none"> • Learning how to deal with how healthcare is provided (i.e. bureaucracy, multiple doctors) <p>“Did a lot of research of it. I’m like a junky for that sort of information, also, and so I know what I wanted to do... But mostly I just researched everything I could.” – Patient 1</p> <p>“But in that course of time, I actually read three or four books on prostate cancer.... [My care] was pretty much standard, what the book says and what my recovery was pretty much the same.” – Patient 12</p> <p>“I went right over to [the doctor], picked up my disc, delivered it to him. I say, ‘Listen, this is the tip of the iceberg. You not getting my results for 2 weeks, and I’m sitting there wondering what the [expletive] is going on.’ I just did it because I wasn’t going to go through that heavy duty [expletive]. I did not want another layer of red-tape crap.” – Patient 3</p>
<p>Managing side effects/symptoms from treatment</p>	<p>Working with healthcare team to manage side effects</p> <ul style="list-style-type: none"> • Accepting “normal” side effects • Realizing you have the control to adjust treatment to manage side effects <p>Side effects being a distressful reminder of cancer</p> <ul style="list-style-type: none"> • They were very responsive. We actually worked out a plan.... And this was all done back and forth beginning that week by phone, so it was very, very good.” – Patient 2 <p>“So I called and he said, ‘No problem, we are going to cut your drug.’ And within one or 2 days, it cleared up which gave me even more faith that should something occur, he knows how to react.... I think anyone in this situation, at the risk of being a pain in the neck to the doctor by telling them all this study, I think it’s important to let them know what’s happening.” – Patient 10</p> <p>“Yeah, I have a lot of activities I used to do I cut back on. Yeah, it’s a different way of life.... And one day, one thing will be hurting. The next day, something else will hurting. It’s always something different each day.... So you figure out a plan. Okay. Now, I’ll get up and walk around see if I can do that first. And then you just move on from there.” – Patient 11</p> <p>“Know what the normal symptoms are and understand that if you are having those symptoms, deal with it because you know it’s normal. And not only you but everyone is going through this same thing. And if you have some kind of symptom and you are not aware whether that’s normal, so ask.... I’m able to articulate more what I’m really understanding to be my symptoms. And they are able to translate that into treatment action.” – Patient 13</p> <p>“I expressed those things with the doctor – nausea and constipation, I learned how to deal with it. I ultimately found the best way to treat it myself.... I learned how to put up with the side effects.” – Patient 22</p>
<p>Managing emotional and existential responses to cancer</p>	<p>Experiencing emotional and existential reactions</p> <ul style="list-style-type: none"> • Not allowing negative emotions • Adjusting attitude and perspective <p>“I mostly just internalized things.” – Patient 1</p> <p>“So that’s how I’ve dealt with it. I prohibit negative thoughts from coming into my mind.” – Patient 3</p> <p>“I got a little angry, and I clammed up, and that lasted for about 24 h. And then somehow, I got a new attitude, and I figured there’s nothing I can do and we’ll just follow the rules, whatever they tell me.” – Patient 10</p> <p>“The first time was when I was first diagnosed, of course, and it was a shock ... And then you ask, ‘why me?’ I try to put it in perspective ... Just get it done. Do what you got to do. Attitude is the best weapon.” – Patient 11</p> <p>“It is important to maintain a positive attitude. It is a battle. And if you do not devote yourself totally to that battle, you are denying yourself maximum benefit.... That’s just my nature. But even if it’s not in one’s nature, he should work at it.” – Patient 13</p>
<p>Finding the best team and falling in line</p>	<p>Finding a good provider</p> <ul style="list-style-type: none"> • Identifying and accessing the top provider ○ Working connections and relationships to find an oncologist ○ Getting second opinions until finding good provider • Finding provider as a cornerstone of having a plan <p>“I have a friend who is actually an oncologist. And so I was consulting her. And so I do not know what I would have done without her, to tell you the truth. Because when you get all of these conflicting opinions – like I said, I’ve been through, basically, five, maybe six opinions.” – Patient 16</p>

Major theme

Subthemes, descriptions, and representative quotations

"I'm a blue-collar guy so I do not have many connections that I can pull, but since I live in this area, I lucked out in getting the best doctor and the best care." – Patient 23

"I do not particularly believe that you need to be concerned about what the treatment person might think or feel. I have read so many times in various sources that the doctors do not generally have any problems with people going for a second opinion or going somewhere else if they are not satisfied." – Patient 13

"The last cancer I had is so rare, only 200 in the whole country with it, there's not much you can talk to others about, I did not know who to go to because it's so rare... When it came time that I needed to find someone, I was the one to find them. Finding the good doctor – all doctors are relatively good, if it's not serious, I do not care about good bedside manner, as long as they are knowledgeable. I will research to find the best doctor or get a recommendation from them." – Patient 22

Identifying qualities of a good provider

- Not needing a provider with a good bedside manner
- Wanting provider to be an expert and thorough in his/her care
- Wanting provider to have options and a plan
- Wanting providers to proactively coordinate all cancer care
- "If I had two people to choose from, and one was better at the bedside manner and the other one was better at the medical side." – Patient 16
- "Even though his bedside manner wasn't the best, I do not give a damn about this stuff. I want a doctor that knows his stuff. And he knew his stuff and that's all that mattered to me." – Patient 6
- "He said he had a lot of tricks. He said, 'If one thing does not work, we'll try something else.' He said, 'What was true 5 years ago in this field is not true now.' And he said, 'We're learning new things every day.' And he said, 'We're going to get started.' Then I said, 'When?' I figured maybe a month. He said, 'Tomorrow.' So I went right in and we started up." – Patient 10
- "I do not particularly believe that you need to be concerned about what the treatment person might think or feel." – Patient 13
- "So immediately, I went to a different doctor and had my procedure done. Because from my perspective, I did not really have someone kind of saying their team approach to looking at you holistically as a patient." – Patient 15
- "I'm blessed that I have access to knowledgeable doctors, but I also go to scientific sources and journals and will ask – but at the same time I know nothing about cancer, they are the experts, and I am just doing my best to be informed." – Patient 23
- "Without a plan, I would have lost hope in an instant. I could have let the dire reports in the literature drag me into a depression, or into just giving up." – Patient 25

Following the provider's orders

- Falling in line and doing what the provider says
- Being confident to bring topics up with the provider
- "When I came here, I went to the doctor and just followed them. So I do not know that it was traumatic or anything for me. The most traumatic thing was when I found out I had cancer. Other than that, whatever they needed to do, I did... Once I accepted I had [cancer], I went along with whatever we needed to do to get it taken care of." – Patient 7
- "[Treatment] was dictated to me based on the doctor's experience. So I pretty much followed the law, and there were not any decisions to make." – Patient 9
- "I will say about [my doctor], I do not think he has much of a sense of humor. He's all business but I like him a lot... I'm not going to that facility to be entertained and to make jokes. It's pretty much as [my doctor] treats it. It's serious business and I do what I'm told. If he says, I want you to do something, I do it.... Whatever he says that's the law." – Patient 10
- "I did not have a choice, I'm just relying on their expertise." – Patient 14
- "Finding a doctor I could talk to, and who would give me answers, was my purpose in life after 2 or 3 visits to the first clinic I visited." – Patient 25
- "But it's just, having confidence. Even though you are having a discussion, you do not know what to ask. You do not know what you do not know. I'm sure he told me that I could talk, but I do not remember feeling confident enough to discuss with someone. I'm like, 'You're the doctor.'" – Patient 5

Strategic social connections

- Deciding on who and when to tell others about their cancer
- Only telling a few people or groups that you have cancer
- Protecting others from the cancer
- Managing others' reactions to the cancer
- "I figured I'd get all the facts down before I told them. This way they would not be in limbo because I was in limbo myself." – Patient 11
- "One of the issues is always how much to tell and who to tell... I did not tell my wife anything until that time came. And I think that was probably the best decision.... It's your information to share or not share because then sometimes, you feel like you have to manage how people are responding, which for managing work situations is different from managing the emotional side even your family members or close friends are going to have." – Patient 2
- "But this wasn't the kind of thing I was going to announce on Facebook and I wasn't going to tell everybody about this. And I was going to keep a very, very short list of people that were going to know anything about this. And I'm not sure why I made that decision but I did that very early. And even to this day, there's probably only a handful of key people... I'm not sure except for the fact that I felt that if I said something, it would affect the way everybody I know treats me. And I did not want that." – Patient 10
- "I told my kids since the only cause they know of is genetics, so I told them what to look for.... In the end I wanted them to know – wanted them to know and be proactive about getting care if it happens to them" – Patient 23
- Receiving support from others
- Caregiver(s) providing support to seek treatment

Major theme

Subthemes, descriptions, and representative quotations

- Caregivers being involved in medical care
 - Preferring to process things by myself
 - Not having people to provide support throughout cancer care
- “But that was a good thing. I talked to people that I really did not think were ever concerned that found out, called me. I never thought you ever cared. You find out a bunch of things that are like, ‘Woah, I did not even know these people were concerned about me.’ So it was kind of a good feeling.” – Patient 11
- “I did not want care like a caregiver, I felt better if I could do it myself. My latest [cancer] – I told people, but everyone asked what they can do for me and I would say nothing, just leave me alone.” – Patient 22
- “I think this was one of the most unexpected parts of cancer, you immediately go into survival mode. I ended up having to comfort others and coddle the people I cared about.. I could not see them break down, or else I would break down. I needed to be strong, so I could be strong.” – Patient 28

Purposefully sharing cancer experience

- Deciding if and when to talk publicly about cancer
 - Help others by sharing my story
 - Discussing cancer with a public audience
- “I told my three children, my brother, for obvious reasons because he’s 73 something like that, right, and told my two dear friends, one who is old as me, 60 something, and the other one’s going to be 50. I told them about it because I wanted them to make sure they were getting their PSA tested, right? So those are the only people I told.” – Patient 3
- “My life kind of changed when I got cancer. It was published in a local newspaper. I heard from a couple of clients saying, ‘You never told me you had cancer.’... But the reason I did not tell people is the story I heard from other people saying that you are written off. And so they wanted not to have to deal with a professional or an advisor that has that ... Talking to people obviously lessens the stress. Economically is the part that I was worried about, my own family ... I was keeping it silent, but I made it through, obviously, so that was stressful for me.” – Patient 9
- “The support and encouragement [from my congregation] has been very important to me, and so I capitalized on accepting that, not rejecting that. It’s so easy, out of self-pride or ego or whatever else to sort of push away any kind of concern or caring or action from whoever because I can take care of this myself. That’s just not realistic.” – Patient 13
- “I’ve been telling guys around the office, ‘When you get those prostate numbers, you make sure you have somebody that’ll actually check you. Do not just take their word, ‘Oh, we’ll come back in 6 months, and we’ll check it again.’” – Patient 19