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Authors

Hoskote, Mekhala
Le, Gem
Cherian, Roy
et al.

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Cancer patient perspectives on survivorship goals from the Smart Patients online community

Mekhala Hoskote¹, Gem Le¹, Roy Cherian¹, Roni Zeiger², Urmimala Sarkar¹

¹University of California, San Francisco at Zuckerberg San Francisco General Hospital, Center for Vulnerable Populations

²Smart Patients

Abstract

Background: Cancer impacts individuals' life goals. Recent cancer care guidelines recommend discussing life goals as part of patient-provider communication. The goal of this study was to understand patients' attitudes towards goal sharing with their cancer care providers.

Patients and Methods: Semi-structured questionnaires were conducted via email with cancer patients and survivors (n=39) on an online social network called Smart Patients. Participants answered open-ended questions about their life goals. They then completed a survey regarding their attitudes towards goal sharing with health care providers. The study team used an integrated inductive-deductive qualitative analysis to identify conceptual themes.

Results: Participants listed goals related to improving physical activity, control, enjoyment/leisure, and inner strength, while reducing pain, anxiety, fear of recurrence, and uncertainty. Most of these goals were life goals rather than goals specifically related to medical care. Across all goals, there was a focus on returning to normality. Our findings show that 87% of participants expect their cancer specialist to discuss their treatment preferences and goals regularly with them. However, participants were reluctant to share their goals with their providers. Respondents felt that their providers did not have an interest in their life goals or time to address them in addition to their medical treatment.

Corresponding author Urmimala Sarkar, MD, MPH, 1001 Potrero Avenue, Box 1364, Urmimala.Sarkar@uscf.edu, 415-206-4273.

Authors' contributions: US and RZ contributed to the study conception and design. Material preparation and data collection were performed by all authors. Data analysis was performed by MH and RC. The first draft of the manuscript was written by MH and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Declarations

Conflicts of interest/Competing interests: MH declares that she has no conflict of interest. GL declares that she has no conflict of interest. RC declares that he has no conflict of interest. RZ is a co-founder of Smart Patients. US declares that she has no conflict of interest.

Ethics Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the Institutional Review Board of the University of California, San Francisco (No. 18–26752).

Consent to participate: A waiver of informed consent/authorization was obtained from the Institutional Review Board of the University of California, San Francisco (No. 18–26752).

Consent for publication: Not applicable

Availability of data and material: Not applicable

Code availability: Not applicable

Conclusion: Even though cancer patient-provider communication guidelines advocate for discussions around life goals, participants in this study expressed reluctance to share life goals with providers. Further efforts to align expectations of patients and providers may facilitate adherence to cancer communication guidelines about life goals.

Implications for Cancer Survivors: Cancer survivors should be aware that discussing life goals is part of recommended communication with their cancer care teams.

Keywords

Cancer survivorship; survivorship care plans; patient education; health communication

Introduction

In 2016, 15.5 million Americans had a history of cancer [1] and, in 2018, there were an estimated 1.7 million new cases of cancer [2]. A cancer diagnosis and treatment can significantly alter a patient's lifestyle, quality of life, and subsequently their life goals [3]. Setting and pursuing life goals is crucial for patients' psychological adjustment to chronic illness [4]. Cancer treatment can be an incredibly time-intensive process, reducing a patient's ability to pursue their life goals [3].

Social, psychological, or medical goals are associated with a higher purpose of life and are an essential component of a patient's identity [5]. Life goals can be broken down into goal characteristics and goal processes. Goal characteristics comprise content, life domains, importance, difficulty, attainability, intrinsic/extrinsic factors, and time of a specific goal. Goal processes refer to the way that goals can be interacted with. For example, goal processes include pursuit, loss, disruption, or adjustment of life goals. Cancer experience and related symptoms can fundamentally alter goal characteristics and goal processes. In fact, cancer diagnosis and resulting in high levels of anxiety and depression can reduce patients' attainment and importance attributed to certain life values [6]. Goal disruption and loss are related to poorer subjective wellbeing, while goal pursuit and attainment are related to better wellbeing [7].

As described in the 2013 National Academy of Medicine, Sciences, and Engineering (NASEM) report *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, clinicians may misjudge patient preferences and priorities. Patients may also assess the benefits and risks of cancer treatment differently than a clinician would [8]. As a result, incorporating life goals as a part of patient-clinician communication could reduce misunderstandings and provide patient-centered care. The American Society of Clinical Oncology (ASCO) recently convened a multidisciplinary panel and issued consensus guidelines on patient-clinician communication in 2017. The guidelines outline that clinicians should collaboratively set agendas with their patients and provide diagnostic and prognostic information that addresses how the patient's goals of care related to their life goals, daily activities, and quality of life [9].

To explore patient attitudes towards discussing life goals with their providers, we studied cancer patients' goals and communication with their medical providers via semi-structured

questionnaires administered via email [10–13]. The goal of the study is to gauge patients' reactions to these guidelines and extrapolate the best practices for implementing these recommendations in clinical practice.

Methods

Research Setting

The study was conducted on an online social network called Smart Patients (www.smartpatients.com). Established in 2012, Smart Patients allows patients and caregivers to interact through online discussion groups, referred to as communities. There are communities for a variety of illnesses including breast, carcinoid/neuroendocrine, esophageal, kidney, lung, multiple myeloma, ovarian, pancreatic, and sarcoma cancers. Smart Patients staff monitors and moderates the online communities. A majority of active members interact with the site weekly and about 30% visit the site daily. Ninety percent of Smart Patients users are White or Caucasian and the average age is 60 years old. In October 2015, we recruited 39 cancer survivors and caregivers with varied cancer diagnoses and educational backgrounds.

Participants

A member of the Smart Patients team recruited a convenience sample of participants from the Smart Patients breast, ovarian, kidney, and lung cancer communities. Participants were eligible for the study if they (1) were 18 years old or older, (2) spoke English, (3) belonged to a Smart Patients online cancer community, and (4) had participated at least once in the community. Participants could be patients or caregivers. After screening Smart Patients users, the study team began the goal elicitation process via email. The study team explained the purpose and procedures of the study and began discussing their goals with participants via a semi-structured questionnaire. Participants were not given an incentive for completing the questionnaire. After the data was shared with the University of California, San Francisco (UCSF), the Institutional Review Board of UCSF (IRB no: 18–26752) approved this study.

Goal Elicitation

In October 2015, one investigator (RZ) emailed eligible Smart Patients users to ask about their medical and life goals. First, participants provided basic demographic information and later completed a semi-structured questionnaire (Appendix I) about their goals over email. We asked open-ended questions and had an email exchange with participants. We probed participants to elicit more details about their goals. We then showed the participants their revised responses. Once we validated the written version of their goals, we sent them a letter, outlining their goals that they discussed with the study team. Participants had the option to share the letter with their provider.

Email interview

One investigator (RZ) developed the semi-structured questionnaire with three subsections: 1) goal setting, 2) attitudes towards sharing goals with providers, and 3) the relationship between life goals and medical goals. We developed the interview guide based on a review of relevant literature[3], [5], [14], [15], and experience with the online patient community.

We asked participants for a list of their goals and whether they thought their cancer specialist could help achieve them. We also asked why participants preferred to share or not to share their goals with their providers, what would make them more comfortable discussing their goals with their providers, and whether they shared the compiled list of goals with their provider. The questionnaire asked whether participants thought having personal goals has a direct relationship with treatment decisions. Participants also answered a series of questions on their confidence, treatment plan, and relationship with their cancer specialist. Responses were given as a five-point Likert scale ranging from strongly disagree to strongly agree.

Qualitative analysis

Two of the authors (MH, RC) participated in the data analysis. The unit of analysis was each questionnaire. Transcripts were coded using an integrated inductive-deductive qualitative data analysis approach [16], known as the constant comparison method, an approach in which data are broken down, compared for similarities and differences, and grouped under similar conceptual themes [17]. Simultaneously, we also employed predetermined conceptual codes drawn from the Quality of Life Model Applied to Cancer Survivors, a conceptual model from the NASEM's report on cancer survivorship, [18] as a coding framework. After reading the email interview transcripts, the coders met to develop a coding framework that was applied to all data in the online qualitative data analysis program Dedoose (version 8.2.14). Two coders independently coded all transcripts and came to a consensus on any differences. Discussions among the study team refined the thematic categories and led to a final set of themes across all participants.

Results

Enrollment

Of the 100 individuals we invited to participate in this study, 69 initiated the goal elicitation exercise. Of these 69 participants, 39 completed an email interview about their life goals.

Description of the Sample

We enrolled 34 patients and 5 caregivers. The sample was predominantly White or Caucasian (86%), female (74%), had either Bachelor's or postgraduate degree (74%), and belonged to the kidney cancer online community (36%) (Table 1).

Perceptions of Cancer Treatment

Shown in Figure 1, over 80% of sample participants reported that their treatment plan takes into account their preferences and goals and expect their cancer specialist to discuss their treatment preferences and goals regularly with them. A majority of participants were confident that they could overcome the challenges of their treatment (82%) and did not find it difficult to follow their treatment plan (72%).

Themes

During the goal elicitation process, respondents chose to elaborate on their goals (Table 2). Both patients and caregivers expressed similar sentiments about life goals and goal sharing.

Caregivers tended to focus less on physical activity and enjoyment/leisure than patients did, and more on pain, the distress of diagnosis and treatment, and relationships.

Focus on life goals, not medical or clinical goals

Goals related to physical wellbeing: As expected, patients listed goals related to their overall physical activity, pain, sleep and rest, and strength and fatigue.

“I want to be able to play golf, visit our grandchildren, have late dinner with a nice wine, or go to an impromptu party at a moment’s notice, without being limited by the fatigue, diarrhea, or low blood counts associated with my treatment cycles.”

As this quote highlights, respondents chose to define physical wellbeing outside of specific treatment goals. Respondents considered the side effects of their treatment and contextualized how these symptoms affected their daily lives. Some patients expressed lofty physical goals such as “walk[ing] the 800 mile Baja California segment of the old California Spanish mission trail” or “going elk hunting”. While other participants mentioned day-to-day, functional activities like “driving my car, ride my horse, walk the dogs, and mow the lawn.” Across these varied physical goals, respondents wished to resume activities that would have ordinarily not been burdensome.

Goals related to psychological wellbeing: Participants expounded on the psychological effects of cancer treatment including anxiety, cognition, depression, the distress of diagnosis, control of treatment, enjoyment/leisure, and fear of recurrence. A common thread among quotes related to psychological wellbeing was a lack of control. Fear and powerlessness emotionally, mentally, financially, and physically seemed to motivate goals on managing their own and loved ones’ mental health:

“I want to remain emotionally stable (with or without medication).”

“I want to live without fear of imminent physical catastrophe.”

“I want to avoid going through chemo or other treatments again, and definitely don’t want my loved ones to have to endure it again.”

Goals related to social wellbeing: Participants expressed goals focused on affection, sexual function, enjoyment, finances, roles and relationships, and work. Cancer diagnosis and treatment reduces the time spent with family and friends. For example, one participant said, “I want to feed and love my husband, to bring joy to my children, and spend time with family and friends.” Participants frequently mentioned wanting to be present for family milestones such as “for the birth of my first grandchild”.

Participants also wanted the freedom to pursue their passions, especially for work and addressing the financial burden of cancer treatment. For instance, one participant said, “I want to quit my job and focus on being an artist with photography, videography, and my music.” Another wanted to “be able to change jobs without fear of losing insurance or paying expensive COBRA fees.” Other participants mentioned using their cancer experience “to become a patient advocate and help newly diagnosed cancer patients out.”

Goals related to spiritual wellbeing: Participants discussed spiritual wellbeing less than physical, psychological, or social wellbeing. However, participants detailed inner strength, religiosity, transcendence, and uncertainty.

“I want to have the gumption to fight for my health each day and have the grace to understand when acceptance is warranted.”

As this quote highlights, this respondent described undergoing cancer treatment as a balance between fighting and acceptance. Spirituality was a common way to cope with cancer and the associated fears that come with a cancer diagnosis. Goals focused on maintaining spirituality and strength to fight back and defeat cancer.

Goal sharing—Although a majority of participants wanted their goals to be accounted for in their treatment plans and expected to discuss their treatment goals with their providers, patients were unlikely to share their goals with their providers. A lack of interest from providers and logistical concerns emerged as the main reasons for not sharing their goals.

Reluctance to share their goals with their medical providers

Providers’ lack of interest in goals: After asking participants about their goals, we asked them how they felt about sharing their goals with their medical providers. Although some were comfortable talking to their cancer specialists about their life goals, most participants overwhelmingly exhibited negative attitudes towards goal sharing. They thought their providers’ had little interest in their goals.

“I don’t think he or she has time; I don’t think he or she is interested in discussing these issues; I don’t think he or she can help me with these issues.”

As this quote illustrates, participants felt that their goals were separate from their medical care and that providers should not address personal life goals: “These were personal lifestyle goals. My cancer team is there to help cure me. Their job is medical.” Rather family and friends should provide this support. Even if providers demonstrated a genuine interest in patients’ life goals, participants felt that providers could not help them achieve these life goals. Some participants mentioned that they have had trouble getting necessary medical attention from their providers, let alone additional counseling about their life goals. For example, one participant said, “I often cannot get him to do the things I feel I need to keep this cancer at bay. I don’t want to use up any of my ‘favors’ to ask him to fill out a survey.”

Logistical concerns related to goal sharing: Participants were also reluctant to share their goals due to logistical concerns such as time constraints and changing providers. Participants felt that discussing life goals would take time away from discussing medically relevant information. Some participants felt that they did not get enough time to discuss treatment information with their provider, thus discussing life goals out of the question.

“I’m a little reluctant about getting my oncologist involved. She’s so busy we hardly have time to discuss my tests and treatment.”

Participants also brought up the issue of changing providers. Cancer patients have a care team that is in flux. Having a conversation about life goals in light of cancer can be difficult.

Having that conversation multiple times with different providers can be emotionally difficult. Participants wanted to have that conversation with the right provider.

“The second reason is that I know at some point I will be moving on to a different doctor. While my cancer is stable and well-controlled by my targeted medicine, my current oncologist is more than adequate...I know I will be moving on to another doctor, and THAT is when these harder conversations will have to come into play.”

Additional quotes are listed in Table 3.

Discussion

Our results highlight that cancer patients have many life goals, many of which are not medically related, but rather pertain to physical, psychological, social, and spiritual wellbeing. These goals focused on strength, emotional stability, spending time with family and friends, and pursuing passions. We found that patients were reluctant to share these goals with their medical providers. Participants cited the providers' lack of interest and logistical concerns such as time constraints and changing providers as reasons not to share life-goals with cancer healthcare providers. Supporting research has found that patients also view life goals as separate and less important than treatment goals, [14] which aligned with our finding that participants considered their providers' focus to purely medical. Previous literature has found that cancer patients adjusted their life goals to changing circumstances of their illness and treatment [19].

Studies have found that cancer care providers should consider integrating life goal adjustment into rehabilitation services [20] and increasing their awareness around the meaning of life to target support interventions for patient groups [21]. In 2017, ASCO convened a multidisciplinary panel and issued consensus guidelines on patient-provider communication. The guidelines provided recommendations on how to communicate with cancer patients and survivors around goals of care, diagnosis, prognosis, treatment, and end-of-life care [9]. Recommendation 2.1 states that “clinicians should provide diagnostic and prognostic information that is tailored to the patient's needs and that provides hope and reassurance without misleading the patient.” One of the strategies for implementation directly mentioned that clinicians should assess how patients' goals of care affect their life goals. Recommendations discussed establishing goals of care for a conversation, collaboratively setting an agenda with patients based on patient and clinician concerns, reassessing patients' goals when significant changes in care arise and clarifying goals of treatment to evaluate cure versus survival versus quality of life [9]. Although not directly mentioned, life goals could be a part of addressing these recommendations.

Despite a growing body of evidence supporting the inclusion of life goals as part of cancer patient-provider communication, we found that patients were reluctant to share their life goals with their providers. Implementing these recommendations in clinical practice may prove to be difficult unless providers and health systems can address patients' concerns about addressing life goals as a part of cancer and survivorship care.

At a broader level, our results show that every cancer patient measures success differently from each other and providers. The variety and breadth of the goals shared with the study team illustrate that each patient has a different definition of success for their cancer treatment. These findings suggest that providers can reserve time to gauge the patients' comfort around discussing life goals, move conversations beyond medically related goals, and emphasize addressing life goals as a part of cancer care. As the ASCO guidelines recommend, providers should aim to match the patient's goals with their outcomes.

Our study has a few limitations. First, our relatively small sample size and demographics of our sample limit the generalizability of our findings. Nonetheless, we found common goals and attitudes towards goal sharing among our sample. Focusing on a smaller sample allows for an in-depth perspective on how patients feel about sharing their life goals with their providers. Furthermore, recruiting participants from an online social network dedicated to health issues gave us the viewpoint of patients and caregivers who are truly engaged with their health. Future qualitative studies examining life goals would benefit from a larger, more diverse sample of patients and caregivers. Second, we only conducted email questionnaires, which may be less detailed and candid than in-person interviews. However, our email interview-style gave participants time to reflect and share incredibly personal, rich aspirations with us. Our study sheds light on the discrepancy between cancer communication guidelines and patients' attitudes towards life goal sharing. Future studies with a larger sample of patients and more interviews to elicit goals and attitudes towards goal sharing would be beneficial to understand what barriers prevent these conversations and how to assess the implementation of these ASCO recommendations. Studies designing and evaluating a goal sharing intervention could provide insights on the effectiveness of the practice and how to apply ASCO recommendations in clinical settings.

Conclusions

To our knowledge, ours is the first study to uncover cancer patients' stated reluctance to share life goals with their medical providers. In this study, patients expressed that their appointments are a space to only discuss medical goals rather than life goals. This finding runs contrary to recent updates to cancer communication guidelines, which recommend that cancer providers discuss life goals with patients. Our findings imply a disconnect between recommended communication practices and the lived perceptions and experiences of a selected sample of cancer survivors. Further work is needed to determine the extent of this gap in communication expectations and develop strategies to enhance guideline-concordant cancer communication.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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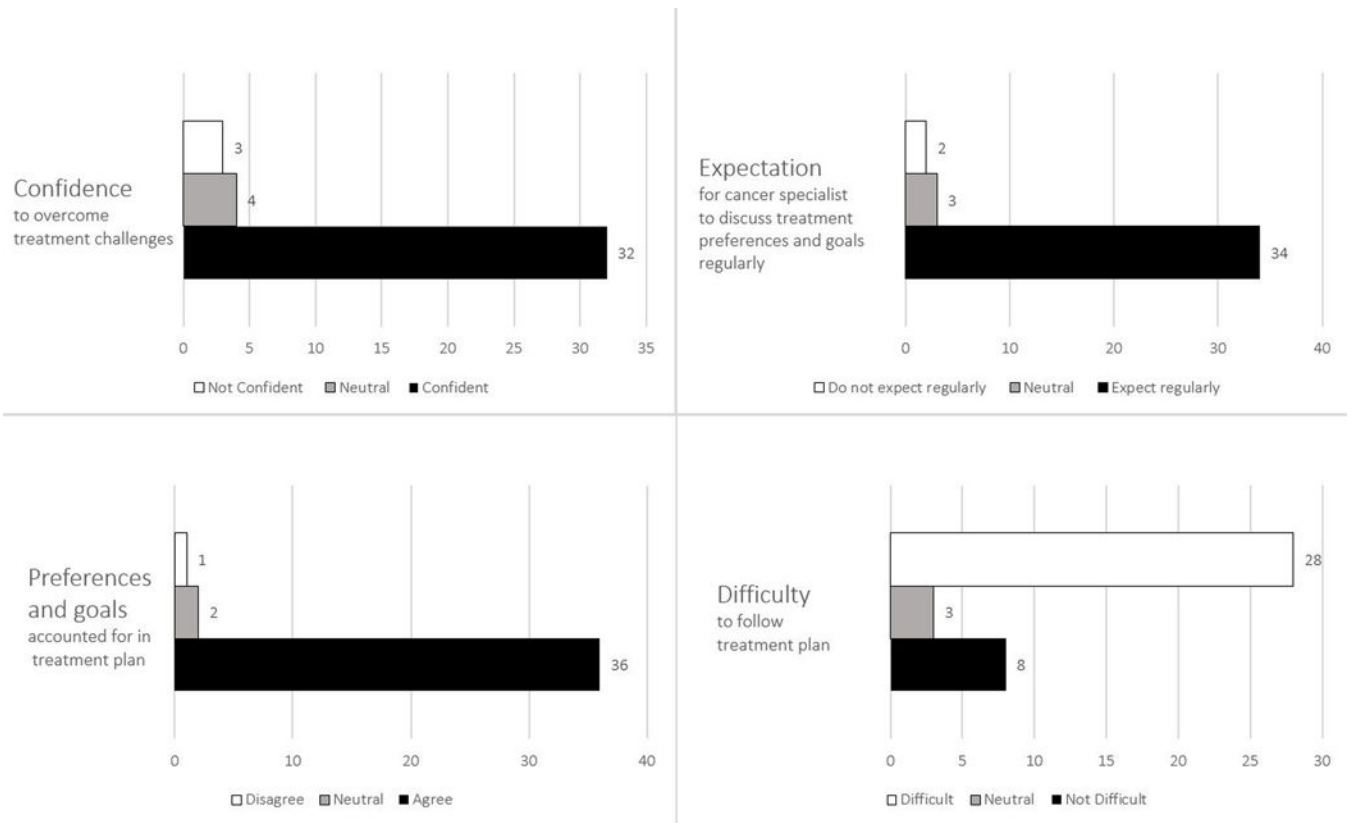


Fig. 1.
Cancer Treatment Perceptions

Table 1.

Participant Characteristics

Demographics	Proportion of Sample (N=39)
Gender (n, %)	
Female	29 (74%)
Male	10 (26%)
Age (n, %)	
Under the age of 65	22 (56%)
Over the age of 65	17 (44%)
Education (n, %)	
High School Graduate	1 (3%)
Some college	3 (8%)
Associate's degree (2 years)	6 (15%)
Bachelor's degree (4 years)	15 (38%)
Postgraduate degree	14 (36%)
Race/Ethnicity (n, %)	
White or Caucasian	34 (86%)
Hispanic/Latino	1 (3%)
Asian/Pacific Islander	1 (3%)
Other	3 (8%)
Community Type (n, %)	
Ovarian Cancer	7 (18%)
Kidney Cancer	14 (36%)
Lung Cancer	9 (23%)
Breast Cancer	8 (24%)

Table 2.

Themes and subthemes for patient goals with illustrative quotations

Thematic Domains	Subthemes	Illustrative Quotes
Physical Well Being and Symptoms	Overall Physical Activity (including functional activities)	“He wants to be able to go elk hunting.” “I want to continue to function well enough to take care of myself and maintain independence and remain in my home.” “I want to recover the strength, endurance, and muscle tone that I lost since undergoing surgery and chemo so that I can go hiking and enjoy other physical activities.”
	Pain	“He wants to remain off pain medications.” “I want to be able to jog daily without pain in my hips.”
	Sleep and Rest	“I want to be able to sleep without taking drugs.”
	Strength/Fatigue	“I want to be able to stay out late without worrying about my energy levels.”
Psychological Well Being	Anxiety	“I want to live without thinking about cancer so much.” “I want to manage my anxiety related to my disease, treatment side effects, and how any genetic components of my cancer could affect my son.”
	Cognition/Attention	“I want an attention span like I used to have so that I can return to my lifelong voracious reading habit.” “I want to continue to function well enough cognitively to manage my own financial affairs and able to make decisions about my own healthcare.”
	Control	“I want to form my own opinions about research, treatments, and disease management.”
	Depression	“I want to have a life with less anxiety, fear, and sadness.”
	The distress of Diagnosis/Control of Treatment	“I want to avoid going through chemo or other treatments again, and definitely don’t want my loved ones to have to endure it again.” “We want to understand likely life expectancy if we decided to stop treatment.”
	Enjoyment/Leisure	“I want to be able to travel ad-lib with my husband all over the country in our RV.” “I want to be well enough to stay around the farm and watch the chickens.” “I want to be able to go to a restaurant without worrying about what I eat.”
	Fear of Recurrence	“I want to maintain my emotional and spiritual well-being despite the fears associated with knowing I was already treated for invasive cancer.”
	Social Well Being	Affection/Sexual Function
Enjoyment		“I want to travel freely with my husband anywhere we feel like we can afford to go.” “I want to be able to care for my grandchildren for the summer at our island cottage without their parents.” “I want to keep up with my book club books each month.”
Finances		“I want to see to it that there are sufficient funds in place so that my daughter will be financially secure after I’m gone.” “I want to continue to function well enough cognitively to manage my own financial affairs and able to make decisions about my own healthcare.” “I want to get back into the workforce as quickly as possible with each episode or treatment, to curtail the escalating financial damage cancer is causing me.”
Roles and Relationships		“I want to finish the unfinished business in my life, such as completing the ancestry projects that were started by my mother.” “I want to feed and love my husband, to bring joy to my children, and spend time with family and friends.” “I want to be treated normally, not as sick or terminal.”
	Work	“As for the financial impact of illness, and the accompanying employment discrimination, only popular awareness, and pressure, plus politics, will make a difference. It’s not much, but I do what I can.” “I want to have a more productive life, like when I was a personal fitness trainer.” “I want to get back into the workforce as quickly as possible with each episode or treatment, to curtail the escalating financial damage cancer is causing me.”

Thematic Domains	Subthemes	Illustrative Quotes
Spiritual Well Being	Inner Strength	“I want to turn into an old man who can look back on cancer as a hurdle that I made the conscious decision to take on, fight, and beat.” “I want to live what life I have left with grace and dignity.”
	Religiosity	“I want to have the gumption to fight for my health each day and have the grace to understand when acceptance is warranted.” “I want to fully participate in the life of my church, attending worship, Sunday school, Bible studies, and mission trips.”
	Transcendence	“I want to live a stress-free, purposeful, and gracious life that contributes in a positive way to the well-being of others, using my challenges for good use.”

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Table 3.

Themes and subthemes related to goal-sharing with illustrative quotations.

Thematic Domains	Subthemes	Illustrative Quotes
Negative Attitude Towards Goal Sharing	Providers' lack of interest in goals	<p>"If I thought they had true interest... or if they had the ability or willingness to do anything about it."</p> <p>"I don't think he or she is interested in discussing these issues; I don't think he or she can help me with these issues; I don't think these issues are relevant to my cancer specialist, I should discuss them with others; Since I refuse to have regular mammograms there is not much else to discuss unless I am experiencing some pain."</p> <p>"Nothing. These were personal lifestyle goals. My cancer team is there to help cure me. Their job is medical."</p>
	Logistical concerns related to goal sharing	<p>"I don't think he or she has time; I don't think he or she is interested in these issues, I should discuss them with someone else."</p> <p>"Oddly enough, I haven't really thought about telling my oncologist what my goals are. He is always running behind when I see him so I feel I shouldn't take up more of his time than necessary since he has patients worse off than me."</p>

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