Original Article

Giving Voice to Patient Values Throughout Cancer: A Novel Nurse-Led Intervention

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Abstract

Context. Optimal advance care planning allows patients to articulate their values as a touchstone for medical decision making. Ideally, this occurs when patients are clinically stable, and with opportunities for iteration as the clinical situation unfolds.

Objectives. Testing feasibility and acceptability in busy outpatient oncology clinics of a novel program of systematic, oncology nurse-led values discussions with all new cancer patients.

Methods. Within an institutional initiative integrating primary and specialist palliative care from diagnosis for all cancer patients, oncology nurses were trained to use specific questions and an empathic communication framework to discuss health-related values during outpatient clinic visits. Nurses summarized discussions on a template for patient verification, oncologist review, and electronic medical record documentation. Summaries were reviewed with the patient at least quarterly. Feasibility and acceptability were evaluated in three clinics for patients with hematologic or gastrointestinal malignancies.

Results. Oncology nurses conducted 177 total discussions with 67 newly diagnosed cancer patients (17 with hematologic and 50 with gastrointestinal malignancies) over two years. No patient declined participation. Discussions averaged eight minutes, and all patients verified values summaries. Clinic patient volume was maintained. Of 31 patients surveyed, 30 (97%) reported feeling comfortable with the process, considered it helpful, and would recommend it to others. Clinicians strongly endorsed the values discussion process.

Conclusion. Nurse-led discussions of patient values soon after diagnosis are feasible and acceptable in busy oncology clinics. Further research will evaluate the impact of this novel approach on additional patient-oriented outcomes after broader dissemination of this initiative throughout our institution. J Pain Symptom Manage 2019;58:72–79. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Advance care planning, cancer, communication, patient participation, nursing

Introduction

No measure of the quality of cancer care is more important than the concordance of care with the patient's core health-related values (i.e., what is important and means most in life).[1–3] As focus on "patient-centeredness" sharpens,[2] failure to align treatment with values is viewed as a medical error.[1] Cancer poses challenges to patients' basic identity and dignity[4,5] and necessitates discussions about the relative burdens and benefits associated with various treatment options. Exploration of values is essential to affirm patients' "personhood," learn how they define living well, and provide a touchstone for

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shared medical decision making throughout cancer.[6–8] Patients want clinicians to discuss their values and plan treatment accordingly.[9,10]

However, patients' values are infrequently and inadequately addressed.[9,11,12] If at all, values discussions typically occur only at end stage, when incapacity may prevent patients from participating directly and leave clinicians and surrogates struggling to make patient-centered decisions.[13] Advance directives can denote end-of-life preferences, but a broader discussion of values early in the treatment trajectory is necessary to inform ongoing decision making.[3,14,15] Insufficient attention has been given to work processes and tools to facilitate these discussions.[16] Many clinicians lack adequate training for eliciting values.[17] Although physicians generally lead discussions about prognosis and treatment plans, oncology nurses may be well positioned to engage patients early in values discussions,[18] which fall within the permissible scope of nursing practice and help patients continue to find meaning in life and inform "authentic" care decisions.[19]

To address these unmet needs and opportunities, we developed and piloted a novel, nurse-led intervention to normalize, systematize, and thereby ensure discussion of each patient's values from diagnosis.[20] Our prior work has shown that assessing values is acceptable to patients with advanced cancer.[8,21] We believed that normalizing these discussions for all patients would result in less apprehension for patients, their loved ones, and clinicians. We therefore hypothesized for this study that routine discussion of values from the start of cancer care, decoupled from stage or prognosis, would be feasible[22] and acceptable for oncology nurses to incorporate into their clinic workflow.

Methods

Study Design

This study was reviewed by the Memorial Sloan Kettering (MSK) Institutional Review Board, who waived informed consent based on minimal risk to participants, and was conducted as a preplanned component of an institutional quality improvement initiative, the MSK "1-2-3 Project."[20] This initiative integrates primary and specialist palliative care from diagnosis for all medical oncology patients receiving care at MSK, regardless of stage or prognosis. In addition to systematic assessment of symptoms, information and decision-making preferences, and illness understanding, patients also participate in structured discussions of their values with their oncology nurse.

Setting and Participants

MSK is the largest private dedicated cancer center in the world. Patients receive outpatient oncology care in clinics in New York City and the metropolitan region that are each staffed by an attending oncologist and one or two registered oncology nurses. For this study, eligible patients were 21 years or older, English-speaking, with a new diagnosis of cancer made or confirmed at MSK, establishing care at MSK (defined as a return for at least one follow-up visit after the initial visit, but not more than two visits before project participation).[20] Screening for participants included weekly review of preclinic schedules in three medical oncology clinics: a myelodysplastic syndrome (MDS) clinic and two gastrointestinal (GI) medical oncology clinics. Implementation was phased, beginning with MDS patients in 11/2016 and extending to the GI oncology clinics in 5/2017 and 4/2018. For this report, we analyzed data relating to patients enrolled in the project through December 2018.

Nurse Training in Eliciting Core Patient Values

Oncology nurses were trained to lead values discussions by MSK palliative care nurse practitioners (NPs) in two 45-minute sessions using a small-group approach (two NPs, two nurses). An NP first reviewed (and provided a printed handout summarizing) essential principles of clinician-patient communication and specific questions in the protocol for the values discussions (Appendix). Training then focused on use of a communication framework using strategies (acknowledgment, normalizing, and partnering) for empathic nurse responses to patient emotions (e.g., fear, sadness) that might arise in these discussions and others. NPs used role-play to model communication skills in a hypothetical clinical scenario, after which nurse learners practiced skills through role-playing and received feedback from the NPs. Thereafter, oncology nurses had access to designated palliative care NPs for informal "coaching" to address challenging patients or clinical situations, while the oncology team could also request formal consultation from these specialists.

Values Discussion Materials and Process

At the second clinic follow-up visit, patients received a one-page "Getting to Know You" handout inviting them to participate at the subsequent visit in a brief discussion exploring "who you are as a person and what you most value." This handout included three of the questions to be discussed (What should we know about you as a person to take best care of you? Facing cancer, what gives you strength? What does living well mean to you at this time?), and encouraged patients to consider them, discuss with family, and make notes, in the interim. At the following two visits, the nurse used our evidence-based[7,8,21,23,24] protocol (Appendix) to guide these two-part discussions, which focused (both parts) on values. At the beginning of the second values discussion, the nurse briefly highlighted the values stated by the patient during the first discussion. The final item of the second values discussion offered patients an opportunity to discuss specific preferences for intensive interventions/end-of-life care, such as CPR preference. (The item did not ask, "what are your preferences?", but asked whether the patient wished to discuss them at that time. If so, the nurse explored the preferences directly.). Nurses asked patients whether they had shared thoughts on these topics with a loved one. If not, the nurse inquired about the patient's plans to do so and offered to facilitate. On occasions when a values discussion was not possible during the scheduled clinic visit (e.g., the nurse was away), the discussion was rescheduled for the next visit.

From contemporaneous notes, nurses prepared a templated "Values Summary" of the discussions (combining Part I and Part II), which were verified by the patient at the next clinic visit. Any patient-requested modifications were incorporated. The Summary was securely e-mailed to the patient's oncologist for further discussion, as appropriate, with the patient and the interdisciplinary clinic team. At quarterly intervals thereafter, and/or if a patient or clinician wanted to readdress sooner (e.g., if there was an important change in clinical status, such as disease progression or hospitalization), the Values Summary was again reviewed with the patient and updated as needed. The nurse recorded the duration of each values discussion and the time required for documentation.

Evaluation of Feasibility/Acceptability

Based on established criteria for assessment of feasibility,[22] we collected data on implementation and practicality. We also evaluated acceptability using three items (found it helpful [very/somewhat/not], felt comfortable participating [very/somewhat/not], recommend to others [Y/N] in similar situation) rated by patients on a Likert scale.[21] Patients who answered "not" or "no" to any of these questions were classified as finding the intervention "not acceptable." This survey focused on the clinic that saw the highest volume of study patients per day among the three participating clinics. In that clinic, 31 patients were accrued into the study during the period of observation and all such patients completed the acceptability items. In addition, a research assistant used a written guide to interview these 31 patients and all project clinicians ($n = 7$) about the experience of participating in the intervention and recorded responses in real-time handwritten notes.

Results

Study Participants and Values Discussion Characteristics

Among 73 consecutive patients who were approached to participate in the two-part values discussions, none declined to participate. Characteristics of these patients are in Table 1. In addition to MDS, many GI cancers were represented, in both early- and late-stage diseases. Sixty-seven (92%) patients participated as scheduled, completing a total of 177 discussions (67 Part I and 58 Part II discussions; 35 discussions reviewing the Values Summaries prepared by the nurses; and 17 quarterly discussions revisiting the previous Values Summary with 13 patients). Fewer than 15% (9/62) declined the opportunity to discuss their end-of-life care preferences with the nurse. The most common reasons for not completing discussions were as follows: patient died or transferred care to another clinic (e.g., MDS patient referred for bone marrow transplantation) before discussion time point (Visit 3 for Part I, Visit 4 for Part II). Median time to patients' Part I values discussion differed between the MDS (68 days) and GI (28 days) patients due to differences in the frequency of their clinic visits.

All patients reviewing a Values Summary ($n = 35$; this component was incorporated in the protocol in a later phase of the study) confirmed its accuracy in reflecting their values; six of these patients requested minor modifications (clarification of values, elaboration on answers, and/or minor wording revisions) before confirming. Of patients who reached the four-month interval for re-review of the Values Summary ($n = 17$), three patients revised their initial Summary.

The median duration of each values discussion (each of the two parts) was eight minutes (Part I = 7, Part 2 = 9; range 5–20). Nurse preparation of values Summaries took eight minutes on average. Initial review of Summaries by patients averaged five minutes, as did quarterly interval reviews. Although referral to specialists was an option, the oncology clinic teams felt able to address emotions arising in the discussions without seeking additional assistance.

Appendix includes selected examples of patient statements in these structured values discussions.

Acceptability of the Values Discussions Sequence

All 31 patients receiving the Likert acceptability questionnaire provided responses. All but one (97%) reported that the values discussions and documentation were helpful, and they felt comfortable with the process and would recommend it to others in a similar situation.

Table 1
Characteristics of Patients[a]

Demographic	GI Cancer (n = 50)	MDS (n = 17)	All (n = 67)
Age, yrs, mean (range)	56 (35–87)	69 (36–90)	63 (35–90)
Gender, n (%)			
Male	33 (66)	10 (59)	43 (64)
Female	17 (34)	7 (41)	24 (36)
Malignancy type, n (%)		N/A	
Colorectal (or small bowel)	22 (44)		
Pancreatic	15 (30)		
Cholangiocarcinoma and gallbladder	6 (12)		
Gastroesophageal	5 (10)		
Neuroendocrine	1 (2)		
Unknown primary	1 (2)		
Stage, n (%)		N/A	
I	1 (2)		
II	7 (14)		
III	16 (32)		
IV	26 (52)		
Race/ethnicity, n (%)			
White	36 (72)	15 (88)	51 (76)
Asian	7 (14)	0 (0)	7 (10)
Black/African American	4 (8)	1 (6)	5 (7)
Other	2 (4)	1 (6)	3 (4)
Unknown	1 (2)	0 (0)	1 (1)
Marital status, n (%)			
Married	33 (66)	10 (59)	43 (64)
Single	11 (22)	4 (24)	15 (22)
Divorced	3 (6)	2 (12)	5 (7)
Widowed	3 (6)	1 (6)	4 (6)
Religion, n (%)			
Roman Catholic	17 (34)	2 (12)	19 (28)
Other Christian	11 (22)	6 (35)	17 (25)
Jewish	3 (6)	6 (35)	9 (13)
Muslim	1 (2)	0 (0)	1 (1)
Hindu	1 (2)	0 (0)	1 (1)
Unknown	1 (2)	0 (0)	1 (1)
None	16 (32)	3 (18)	19 (28)

GI = gastrointestinal; MDS = myelodysplastic syndrome.
[a] At time of recruitment into the study.

Implementation and Practicality Characteristics of the Values Discussions Process

Clinic volume (ranging from 15–35 patients/day before this intervention) was maintained in each of the participating clinics. Fig. 1 shows how many patients were scheduled for Values Discussions or review of Values Summaries per clinic day as a proportion of the total number of patients participating in the project in that clinic. Nurses were able to complete discussions as scheduled for most patients; rescheduling captured nearly all remaining patients (Fig. 2).

In structured interviews, participating oncologists (n = 3) and oncology nurses (n = 4) universally endorsed the values discussion process as valuable for patient care and gratifying for them as cancer care professionals. All felt that although the values discussions might have involved additional time with some patients early in the disease course, the process ultimately improved efficiency as well as quality of care by normalizing such discussions and establishing a framework for shared decision making going forward, including end-of-life care decisions. Clinicians also perceived patients as responding positively to the opportunity to share more about themselves as people, be heard, and identify their core values. Nurses conducting these discussions described their perception that patients found them "thought-provoking," "informative," inclusive, person-centered, and caring. Regarding the nurse's own experience, one nurse commented that these values discussions give patients "the space to actually reflect … and the patient then feels empowered to discuss what their wishes and goals are." Nurses did suggest that with a high volume of clinic patients, the process might be more practical in terms of workflow if all topics were covered in a single values discussion rather than a sequence of two.

Discussion

Past efforts promoting advance care planning have concentrated primarily on specific preferences for end-of-life interventions and achieved limited success among cancer patients.[25] In this pilot study, we evaluated a novel, nurse-led intervention to normalize, systematize, and thereby ensure discussion of each

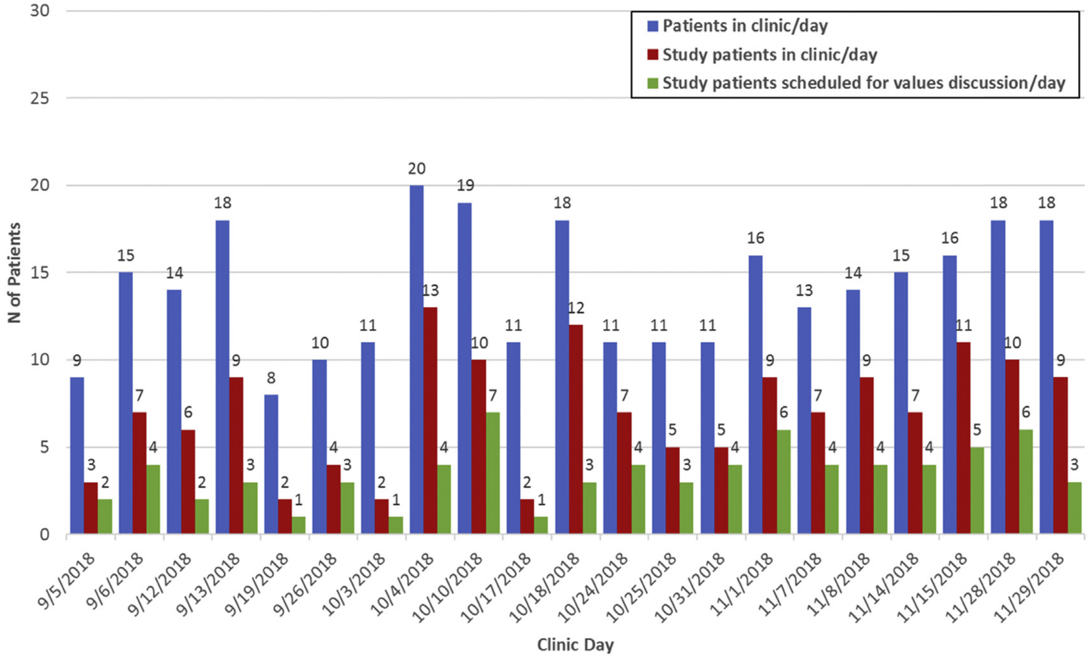

Fig. 1. Volume of patients and values discussions in gastrointestinal oncology clinic. This clinic saw the highest volume of study patients per day (median 7, range 2–13) among the three participating clinics. Volumes shown are for a three-month timeframe from September 2018–November 2018).

cancer patient's core health-related values from the time of diagnosis. Oncology nurses explored patients' values and summarized responses for verification with the patient, review with the oncologist, and documentation in the electronic medical record (EMR). Values Summaries demonstrated the richness and depth of the discussions, although brief, and the relevance and importance of the values statements they captured. We found that this process was feasible for implementation in hematologic and solid tumor oncology clinics, acceptable to patients, and perceived as valuable and practice-enhancing by the clinicians. Nurse training was completed in less than two hours.

Our intervention introduced several innovations. First, these discussions were initiated at the beginning of cancer care for all patients, regardless of stage

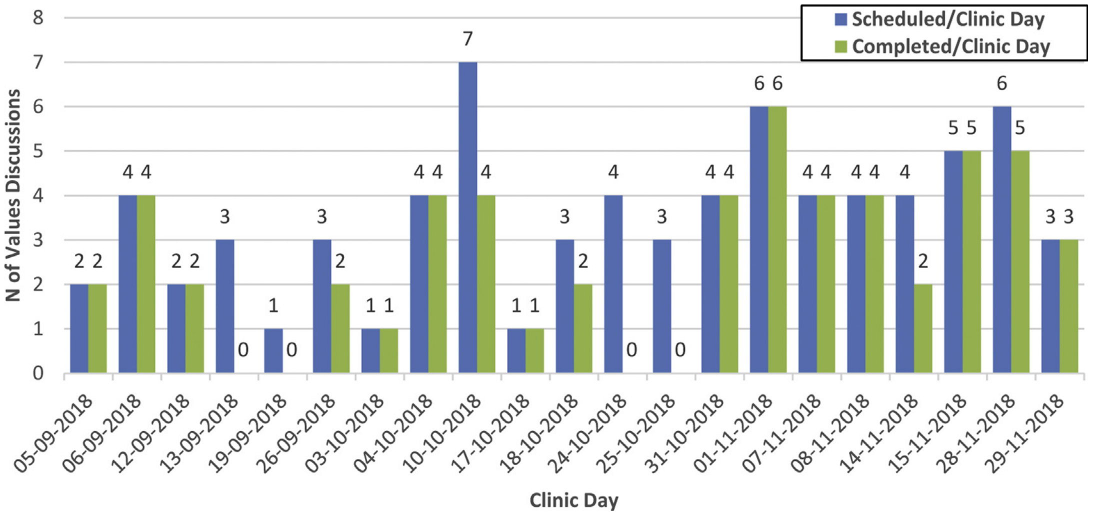

Fig. 2. Completion of values discussions in gastrointestinal oncology clinic. This clinic (same as in Fig 1) saw the highest volume of study patients per day among the three participating clinics. Volumes shown are for a three-month timeframe from September 2018–November 2018. Reasons for non-completion/postponement: trained nurse was away ($n = 10$); nurse was too busy ($n = 8$); discussion was deferred by clinician and/or patient ($n = 3$). Of 21 discussions that were not completed as originally scheduled, eight were completed within the following month.

(although most of the patients in our study had advanced disease because this stage distribution is common in patients with these malignancies), prognosis, or treatment intent, and included patients with hematologic malignancies as well as those with solid tumors. By normalizing the process for all patients, the new intervention builds on our prior work promoting elicitation of patients' values,[8,21,26] which focused on patients with advanced cancer. Second, the intervention was embedded in the oncology clinic routine. As a result, patients seemed less apprehensive than if discussions had been linked to poor prognosis or deferred until disease-directed treatment had failed. In addition, early discussions of values provided a framework for ongoing decision making, whereas even detailed advance directives cannot anticipate the countless clinical scenarios that arise as the illness and treatment course progress.[14,15,27] Third, the focus of discussions was on values rather than end-of-life preferences, which are known to be unstable and may not actually reflect underlying values.[28] In articulating their priorities, patients could identify both longer life and comfort, whereas past initiatives have typically asked patients to prioritize one over the other,[29] although they need not be mutually exclusive. Fourth, the discussions were led by oncology nurses, who are well positioned for this role. Patients spend the most time with nurses and feel comfortable talking with them about issues they may hesitate to discuss with physicians or family; nurses are the nation's most trusted professionals.[30] An ongoing study is also testing a nurse-led primary palliative care intervention in oncology clinics, but it is limited to patients with advanced solid tumor malignancies and is delivered by specially selected nurses who require a much longer period of training and do not carry a regular clinic workload.[31,32]

Our intervention gives concrete form to recent recommendations for more communication research,[33] as well as to a multidisciplinary Delphi panel's recommendation that advance care planning refocus on preparing for "in-the-moment" decision making through ongoing communication about values rather than specific preferences.[14] It also meets proposed best practices,[34] targets clinicians' desire for systematic integration into clinical care,[35] and adds to the advance care planning interventions (prompts, templates, and order sets) recently described for use in modern EMRs.[36] Workflow of clinical teams was accommodated and the process we piloted did not reduce clinic volume.

In addition, this approach incorporates recommendations to improve palliative care at the primary level (i.e., by clinicians who care for patients with serious and complex illness but who are not palliative care specialists).[37,38] Although the availability of palliative care specialists has expanded significantly in hospital settings, most outpatient clinics across the U.S. still lack access to these specialists.[39] Perhaps more importantly, primary palliative care is the responsibility of all physicians, nurses, and others caring for patients with cancer and is an integral part of comprehensive cancer care.[40] Treatment decisions are made by the oncology team, who must understand the patient as a person and what the patient values most in life as a prerequisite for patient-centered, goal-concordant decision making. In addition, communication about values affirms personhood and strengthens therapeutic alliance with the primary team. Whereas discussion limited to code status focuses on death and tends to engender fear and avoidance, our values discussions focused on how patients wanted to live and were embraced by patients and clinicians alike.

Our study has limitations. For this pilot, we limited enrollment to three clinics caring for patients in two disease groups, MDS and GI cancer. However, implementation in the hematologic malignancy setting is a major step forward as prior research has identified unique barriers to palliative care improvement efforts in that setting.[41–43] GI cancers are both common and diverse, and often progress quickly, making it especially important to initiate early discussions of patient values. Although the number of clinics involved in our pilot study was small, these are busy clinics caring for a large volume of patients and thus provided an ideal opportunity to evaluate feasibility as well as acceptability of the intervention. We did not evaluate delivery of the intervention by other personnel, such as physicians alone, mental health professionals, or lay health navigators, as compared to oncology nurses. Because these nurses are an integral part of the primary team, are highly trusted by patients, learned the necessary skills with minimal training, embraced the role, and were successful in integrating the intervention into their workflow, we believe that they are ideally positioned for this work. A larger sample accrued and studied over a longer time frame is needed to rigorously evaluate effectiveness of the intervention on other outcomes of importance to patients, families, clinicians, and health care systems (such as goal concordance, quality of communication, patient centeredness, and advance care planning documentation). We are currently scaling up our intervention for institution-wide implementation.

Lessons from this pilot study have informed our ongoing work. First, we have now consolidated the two-part values discussion over successive visits into a single discussion at one visit. Although we have not yet formally compared outcomes of these two approaches, our early experience (14 completed so far, with positive feedback from patients and clinicians) indicates that the single discussion approach is more feasible in that it takes less overall time to conduct and document and is easier to integrate into clinic workflow, while still retaining the essential content and apparently preserving the patient experience. Patients as well as clinicians respond positively to this approach. Second, we have identified the need for improved access to documentation of patients' values in the EMR. This has prompted a collaboration with informatics experts in our institution to create a new "tab" (highly visible section in the EMR) that will centralize and optimize access to all documentation related to patients' values, goals, and preferences. Third, the goal of large-scale implementation requires a training program for thousands of nurses across many clinic settings. Our Department of Nursing, which fully endorsed this initiative, has collaborated to create a group of nurse champions from diverse disease groups and sites within our system who will facilitate the training of additional nurses and who will have standardized resources for this role. Based on our pilot experience, we believe that implementation of the intervention can be enhanced by several strategies including nursing team-based approaches that allow a second nurse (with appropriate skills training) to meet with the patient if the primary oncology nurse is unavailable; review of preclinic summaries for scheduling with optimal efficiency during the clinic day; involvement of administrative staff in clinic to facilitate integration of the intervention in workflow with day-to-day adjustments; and use of automated reminders and other tools to ensure maximal implementation and fidelity.

In conclusion, we have successfully pilot-tested a process for oncology nurse–led discussions of core health-related values with all cancer patients from the time of diagnosis, regardless of stage, prognosis, or treatment intent. This process is feasible even in busy oncology clinics and is acceptable to patients and the interprofessional teams who care for them. Each patient has a unique perspective on what is important, gives meaning, and defines an acceptable quality of life. This perspective is essential to elicit from all patients, including those with early and/or curable disease, as it allows patients to affirm their personhood while facing serious illness and provides the basis for medical decision making that is aligned with their values.

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Appendix

Appendix

Structured Discussion of Health-Related Values: Oncology Nurses' Guide and Examples of Patient Responses

Values Discussion Part 1	
Nurse Question	Examples of Patient Responses (Followed by Gender [M/F], Age [yrs], Cancer Type)
What should I know about you as a person to take the best care of you?	"I'm a pretty analytical and detail-oriented person. The more information I get the better, so I can make an informed decision. I also appreciate communication and openness." — M, 55, Pancreas "Above all, I am an optimist. While I have a positive attitude, I do not like things "sugar coated" so that I am not blindsided down the road. Honest, open communication is important to me." — M, 73, MDS
Facing cancer, what gives you strength?	"My cancer team — I have a team dedicated to me and that impresses me a lot. I think optimism is the key, which is helping my family and I stay stronger. After the initial diagnosis shock is absorbed, then you get the mentality to put up your dukes and fight." — M, 67, Pancreas "My faith and knowing that God has a plan for me. My family also is a great strength of support. I'm trying to stay positive, cherish the small moments, and working to keep the anger and frustration that comes with this experience out of my heart. I've also found strength in hearing survivor stories, that helps me." — M, 67, Pancreas
Facing cancer, what concerns you the most?	"Striking a balance between what makes me happy and what I need to do to be safe. Spending as much time as possible … with my daughter and grandchildren is a priority, but … I want to make sure I am doing everything I can for my health." — F, 74, MDS "Having my future stolen from me." — M, 37, Colorectal
What does living well mean to you at this time in your life?	"Spending as much time as possible with my girlfriend, getting back to my physical lifestyle, such as hitting the gym and eating well. Working consistently in my craft and being surrounded by my friends. Enjoying all that NYC has to offer—I love this city." — M, 40, Colorectal "Seeing my friends (I have a group of 14 close friends) – I hope to continue with our regular activities of shopping and going out to eat. Also, I want to do something meaningful with my life and help those less fortunate than me." — F, 71, Pancreas
What do you hope for most?	"A complete recovery. Good health is the starting point. From there, all else flows." — M, 78, Cholangiocarcinoma "For my health to be restored, but also for my family to be comfortable and for me to be able to help them like I've done before." — M, 75, Colorectal
What else are you hoping for?	"A miracle cure, but, honestly, I know it won't happen within my lifetime. But, I'm hoping the next generation will be cancer free. I see the St. Jude ads, which are just heartbreaking. I'm in my 70s, I've lived my life." — F, 74, Colorectal "I hope to be able to see my son reach some life goals. Senior prom, graduation, going to college, and graduating college. I want to see him get married and have babies." — F, 36, MDS
Did you discuss the questions with a loved one or other trusted person before this visit?	"Yes, we continue to have these conversations. I have been seeking professional help regarding financial planning. I am having conversations about the 'will' and 'trust funds.' I am doing this now to prevent future family conflict and misunderstandings. I have learned to be more pragmatic about these discussions. I used to be afraid and concerned about these matters, but not anymore." — F, 72, Colorectal
If yes→ what was that like?	"It was okay. [My son] isn't a very emotional guy, kind of business minded like me. We usually are too busy laughing to get into the nitty-gritty stuff. He likes to have a good time, just like me. But when I got this diagnosis, we talked about me moving up here, selling the condo, getting my affairs in order. I think it put his mind at ease to know that I was planning to not just dump everything on him, and that made me feel good." — M, 79, MDS
If no→ are you planning to talk about it with them now that the two of us have talked it through?	"No, my wife and I have our ups and downs. So, we haven't talked about it." M, 65, Colorectal "I don't have a problem with discussing my health with my daughters, but many times I still want to be their mother, so I tend to do a lot

(*Continued*)

Appendix
Continued

Values Discussion Part 1	
Nurse Question	Examples of Patient Responses (Followed by Gender [M/F], Age [yrs], Cancer Type)
	of listening to their needs and problems. When I need to, I will express all of my wishes to them. I have a geriatric counselor near my home that I have been talking with and this is helpful." — F, 74, MDS
Values Discussion Part 2	
Previously, We Talked About What Living Well Means to You. For Example, You Mentioned That: [Nurse Summarizes].	
At this point, what concerns you the most?	"I hope that chemo gives me more quality time, quality is more important that quantity. Obviously, we'd all like to live as long as possible, but I don't want to spend it lying in bed all the time." — M, 78, Pancreas "My father is sick with Parkinson's and my concern is not being able to have the financial means to go down to Florida to bury him when the time comes. Only my aunt and uncle are aware of my diagnosis. For now, I want the family attention and focus to be on my father. But, to be quite honest, our conversations have been a big help, because I've been able to talk aloud about how I'm feeling. Answering these questions has been very therapeutic for me." — M, 54, Colorectal
When we spoke earlier, you mentioned that you'd had/had not yet had a conversation with a loved one about your hopes and values. Have you talked about your goals, priorities, and wishes with your family?	"Yes. I … stayed with my daughter and her husband for a few weeks. It came up naturally in conversation. To be honest it is kind of strange that we never talked about these things before. I have had other cancers, and I am older. I guess I thought they knew what I would want." — F, 89, MDS "Yes, I have. I want a peaceful death. Ideally, I would want to pass in my sleep. But, avoiding pain as much as possible is very important. If I'm in pain all the time, I want to avoid that." — M, 85, Pancreas
For example, have you talked about what abilities are so critical to your life that you can't imagine living without them?	"If my mind is still active and I can still communicate. Those are the most important abilities for me. However, if I could communicate I'd still like to make the decisions. Only if I was unable to do so would I want my sister to make critical decisions." — M, 63, Colorectal
If yes → Can you share this with me also?	"Communication is everything. As long as I'm able to control everything from the neck up, I'm okay. Talking, walking, and of course spending time with my family are critical too. I need my mind to be able to think so I can still run my business." — M, 62, Pancreas
If no→ It can be helpful to begin this conversation with me. What are some of your priorities in this area?	"The ability to fully take care of myself and work out are really important to me. As I've mentioned in the past, I am a very active person. Even this morning, I was up early and had a nice workout. I enjoy exercising." — M, 42, Colorectal "It is important that my family is set financially, and they are. I want to be able to live normally. To eat, drink, walk, and talk without feeling sick." — M, 49, MDS
Some people want to be very clear about what types of treatment they would want in an unexpected crisis situation, like if they had a cardiac arrest or couldn't breathe or eat on their own. Do you want to talk more about that now?	"If I'm at the point where my situation is irreversible, then I wouldn't want to be on life support or other measures. Most importantly, I don't want my wife and kids to make those decisions. I don't want to burden them with that." — M, 56, GE Junction "No, I do not want to talk more about that. But, I know that I don't want to be a 'vegetable' at all." — F, 71, Pancreas
If hasn't already discussed with a loved one→ Now that we've talked about this, is there someone in your life you'd like to share these thoughts with?	"No, not really. We are staying positive and hoping for the best outcomes. I spoke to my sister about this." — F, 59, Pancreas "No, it's just me and a few close friends. I keep my circle small. They don't need to know about this, in that great of detail anyhow. A few of them know about my diagnosis." — F, 48, Pancreas
If yes→ Who? When might be a good time to talk to them? Do you want to talk now about how you might start off that discussion?	"My son. I guess I should have the conversation with him, we haven't really talked about it. I would want him to make decisions when the time comes. It comes for everybody, doesn't it? I don't want him to feel uncertain, or like he is doing the wrong thing. My sister and I discussed things before her passing and it made things easier for everyone." — F, 70, MDS "Obviously my wife, but she is back in Puerto Rico, and I don't want to discuss this right now because these topics make me very emotional." — M, 73, GE Junction