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How Oncologists and Their Patients with Advanced Cancer Communicate about Health-Related Quality of Life

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Abstract

Objective—To describe the content and frequency of communication about health-related quality of life (HRQOL) during outpatient encounters between oncologists and their patients with advanced cancer.

Methods—We coded for HRQOL talk in a subset of audio recorded conversations (each previously found to contain prognostic talk by the oncologist) from the Study of Communication in Oncologist-Patient Encounters (SCOPE) Trial, a randomized controlled trial conducted from 2003 to 2008 in two large U.S. academic medical centers and one Veterans Affairs Medical Center.

Results—Seventy-three encounters that involved 70 patients and 37 oncologists. Patients were more likely to be female (53%), white (86%), married (78%), and possessing some college education (62%). Most oncologists were male (78%) and white (78%). Mean ages were 59 years for patients and 44 years for oncologists. Every encounter included some talk about HRQOL and HRQOL discussions made up, on average, 25% of the visit time. HRQOL segments described symptoms (50%); general HRQOL (27%); and the following concerns: physical (27%), functional (22%), psychological (9%), social (7%), spiritual (1%), and other (28%). Topics included treatment (56%), disease (14%), and testing (3%), and conversations focused on past (44%), present (68%), and future HRQOL (59%).

Conclusions—HRQOL discussions between oncologists and patients are common, but the emphasis is often on treatment (e.g., side effects) and symptoms (e.g., pain) even in patients with advanced disease. Given the often intense emotional experience of patients with advanced cancer, oncologists may need to pay more attention to psychological, social, and spiritual HRQOL concerns.

Keywords

cancer; communication; oncology; patient-provider relationship; qualitative research; quality of life

INTRODUCTION

Cancer is generally associated with multiple symptoms, diminished functional status, and adverse changes in a patient's health-related quality of life (HRQOL) [1]. HRQOL is a complex, abstract, and multidimensional concept that is difficult to define and measure [2–5], which may be confusing to health care providers [6]. Given that the World Health Organization defines health as "not merely the absence of disease or infirmity" but as a concept that incorporates notions of well-being or wellness in all domains of life [7,8], HRQOL might best be defined as how an illness interferes with an individual's satisfaction or happiness with life in the domains that he or she considers important [2,9]. Because clinical trials involving cancer patients have shown that HRQOL predicts survival duration and other clinical outcomes [10–13], HRQOL has become a particularly important concept in cancer care [14,15].

Several randomized trials have shown the feasibility, as well as the benefits of, assessing HRQOL in clinical settings [6]. Unfortunately, many health care providers lack familiarity with the clinical utility of HRQOL and a lack of understanding of how to apply it specifically to clinical practice [6]. HRQOL has been shown to be a useful predictor of patient treatment response and survival; it has been argued that HRQOL data sometimes has even more predictive power than traditional clinical factors [6]. HRQOL can also affect decision making about therapeutic options [6]. In clinical decision making, HRQOL can be useful in (1) determining whether a new therapy is preferable to the standard therapy; (2)

comparing two standard therapies with similar survival outcomes; (3) determining the balance between positive and negative effects of therapy; (4) identifying the need for supportive care; and (5) facilitating communication in clinical practice [6].

In terms of communication in clinical practice, documentation of high levels of psychological and mental health problems in cancer patients have highlighted the importance of fostering open and active communication between patients and their health care providers [16,17]. Indeed, studies have indicated that effective doctor-patient communication is related to increased patient concordance, satisfaction, and trust, as well as improved biomedical outcomes (e.g., fewer symptoms) and improved psychological outcomes (e.g., better coping abilities and less anxiety) [18–21]. Because HRQOL is important to patient outcomes, it is important to know how it is discussed in patient-provider encounters.

Although existing data suggest that physician-patient communication could be improved [22] and that outcomes vary [10–13], U.S. data have not often included actual conversations or direct observation of interpersonal aspects of care. More specifically, it is currently unclear how much attention HRQOL receives in actual doctor-patient encounters. Our study was designed to describe the content and frequency of communication across multiple domains of HRQOL during outpatient encounters between oncologists and patients with advanced cancer. Because HRQOL information is largely obtained through patient self-report and issues related to HRQOL data collection exist for those using HRQOL within their clinical practice [6], we chose to focus our analysis on the amount of HRQOL talk, who initiated discussions, and content (topic, tense, and domain) of those discussions.

PATIENTS AND METHODS

Setting and Participants

The data analyzed came from the Study of Communication in Oncologist-Patient Encounters (SCOPE) Trial. This randomized controlled trial was conducted from 2003 to 2008 at the Durham Veterans Affairs (VA) Medical Center and Duke University Medical Center (Durham, North Carolina) and the University of Pittsburgh Medical Center (Pittsburgh, Pennsylvania).

As described in detail elsewhere [23], the SCOPE trial recruited medical, hematologic, gynecologic, and radiation oncologists and their patients who had advanced cancer and were thought to be likely to die within a year. We defined advanced cancer as the patient having a Stage IV malignancy that might limit their life to 1 year or less. To identify patients who had advanced cancer, we asked oncologists or their mid-level provider staff to identify patients with a Stage IV malignancy whom they “would not be surprised if they were admitted to an intensive care unit or died within one year.” This appeared to guarantee a significant burden of disease without the patient being referred so late in their disease progression that they were too ill to be enrolled in the study. We assured oncologists and providers that this information would not be conveyed to patients. Therefore, participating patients may or may not have known they were “terminally ill.”

The participants provided written informed consent to have their visits audio recorded and analyzed. The institutional review boards (IRBs) at each study site approved the overall project, which included a total of 415 baseline audio recorded encounters involving 59 oncologists and 281 patients, as well as this subset analysis.

Data Coding and Analysis

For the current analysis, we used standard techniques of content analysis [24] to code and describe the content and frequency of communication about HRQOL during the encounters. Initially, we gathered the subset of audio recordings that were found to contain prognostic talk by the oncologist [23]. These had been defined in an earlier analysis [25]. Prognostic talk by the oncologist was defined as comments about the expectations of the disease that refer to the likely course of the cancer or what the outcome might be (e.g., chances of survival). One hundred and five out of 415 baseline encounters were found to contain prognostic talk by the oncologist.

We chose to analyze visits that contained prognostic talk by the oncologist because we were interested in capturing oncologist-patient discussions of the disease in relation to the patients' past, present, and future HRQOL. In particular, given that these visits included talk of prognosis, we wanted to examine conversations about HRQOL in relation to future treatment decisions and goals of care.

This subset consisted of 105 encounters that involved 44 oncologists and 98 patients. From the 105 encounters, one coder randomly selected 5–10 audio recordings per week to assess whether the recording included any conversation about HRQOL and to determine the themes of the conversation. The coder and site-principal investigator met weekly to discuss the coding process and make any necessary changes to the codebook. When disagreements about coding arose, we developed rules to distinguish the appropriate codes. In qualitative studies, saturation is the main principle that guides sample size [27]. This process of random selection was continued until we reached theoretical saturation [26], the point at which we were no longer finding new themes discussed in the encounters. The process narrowed our subset to 73 encounters. Because the creation of the coding scheme was an iterative process, transcripts coded prior to finalizing the codebook were re-coded to reflect any changes in the coding scheme.

The codebook defined HRQOL talk as any talk about quality of life as it related to cancer. We defined a segment of talk as any conversation in which the oncologist, patient, or both spoke about HRQOL for any period of time. Within a segment of talk, we categorized the topic (treatment-related, disease-related, or testing-related), the tense (past, present, or future HRQOL), and the domain (symptoms; general HRQOL; or physical, functional, psychological, social, spiritual, or other HRQOL concerns) (Table 2). A given segment could include one or more codes from each category.

All conversations were analyzed by one coder and a random 20% were co-coded independently by the site-principal investigator to establish inter-rater reliability. In these 15 conversations, we reached 100% agreement on selection of units of analysis, or segments of talk. We established reliability of the coding system for each type of code by calculating an inter-rater reliability coefficient (kappa statistic) [28]. Because we allowed for multiple codes for each segment, we calculated separate kappas for each type of code. We achieved a kappa value of greater than 0.80, or "almost perfect" [29], on the codes for the HRQOL topics, tenses, and domains.

RESULTS

Encounters, Patients, and Oncologists

The 73 encounters in our final sample involved 70 patients and their 37 oncologists. The number of encounters per oncologist ranged from 1 to 8, with an average of 2 encounters per oncologist (SD = 1.7). Of the 70 patients, 67 had only 1 encounter audio recorded, and the remainder had 2 encounters audio recorded.

Most of the patients were female (53%), white (86%), married (78%), had some college education (62%), and self-classified their general health status as “restricted in strenuous activity but able to do light work” (54%) (Table 1). The mean age was 59 years (range, 27–83 years). The patients were diagnosed with hematologic cancer (39%), breast cancer (14%), lung cancer (11%), colon or gastrointestinal cancer (9%), brain cancer (3%), and other types of cancer (24%). Treatments for patients at time of this visit included chemotherapy (includes monoclonal antibody therapies) (49%), endocrine therapy (5%), radiotherapy (5%), surgery (1%), and other types of treatment (11%). Twenty patients (25%) were not receiving any treatment at the time of this visit. When asked their chances of being cured, most patients (56%) said they had 50% chance or less of “living a normal life span without this cancer.” Most patients (52%) had only known their oncologist for less than 6 months.

Of the 37 oncologists, most were male (78%) and white (78%) (Table 1). Their mean age was 44 years (range, 31–58 years), and, on average, they were 14 years post-oncology fellowship. The oncologists spent a mean of 24 hours per week on patient care and specialized in medical oncology (65%), hematology-oncology (22%), gynecologic oncology (8%), and radiation oncology (5%).

Conversation, Topics, and Tenses

All 73 encounters (100%) included talk of HRQOL. In 17 encounters (23%) the first mention of HRQOL was by the patient, typically in relation to symptoms (24%), physical (18%), functional (18%), psychological (18%), or other concerns (24%). In 56 encounters (77%) the first mention of HRQOL was by the oncologist, most often relation to generalized feelings (54%), symptoms (27%), or physical concerns (18%)—for those initially focused on generalized feelings (e.g., “How are you feeling?”), 8 (27%) were then directed by the oncologist toward a discussion of physical, functional, or other concerns, and 16 (53%) were directed by the patient toward a discussion of symptoms, physical, functional, or psychological concerns.

In the 73 encounters, HRQOL talk occurred in a total of 603 conversation segments. The average HRQOL segment length was 40 seconds (median=20 seconds; SD=58 seconds). The minimum segment length was 3 seconds, while the maximum length was 10 minutes (range=9 minutes, 57 seconds). For the 73 patients, the overall visit length ranged from 6 minutes 45 seconds to 85 minutes 20 seconds, with the average visit lasting 25 minutes 51 seconds. HRQOL discussions within these conversations ranged from 27 seconds to 18 minutes 27 seconds, with the average HRQOL discussion lasting 5 minutes 33 seconds. To compare the discussions between patients, the raw discussion length was standardized into a percentage of the total conversation. Therefore, HRQOL discussions ranged from 3% to 75% of the total conversation, with the average HRQOL discussion taking up 25% of the total conversation.

Of the 603 HRQOL talk segments, an analysis of topics showed that 56% concerned treatment, 14% concerned disease, and 3% concerned testing. An analysis of tenses showed that 44% focused on past HRQOL, 68% on present HRQOL, and 59% on future HRQOL. In 70 of 73 encounters (96%), treatment was discussed in relation to HRQOL, sometimes coupled with the goal of increased quantity (length) of life. Most segments that mentioned treatment were discussions of treatments in the future tense (245 of 377 segments, or 73%). Table 2 provides numbers, percentages, and examples of quotations about the topics and tenses.

Domains of Health-Related Quality of Life

Of the 603 segments, 50% discussed symptoms, 27% discussed general HRQOL, and many segments discussed specific domains of HRQOL that were coded as physical (27%), functional (22%), psychological (9%), social (7%), spiritual (1%), and other (28%). Examples are discussed below and also provided in Table 2.

Symptoms—Symptoms were discussed in 50% of segments. Symptoms were defined as talk about a sign or an explicit indication of the disease or treatment of the disease, especially when experienced as a change. In most cases, symptoms related to the disease or treatment were discussed in generic terms (e.g., as “symptoms,” “problems,” “getting sick,” or “having flu-like symptoms”), rather than in specific terms. For example, in a description of radiation treatment, one oncologist stated, “It’s really symptomatic control.… It’s trying to control the lymph nodes if they start to cause problems.” In a description of chemotherapy, another oncologist said,

> We can treat [the tumor] with chemotherapy to slow down its growth and to prevent you from becoming symptomatic. In this particular case, it is what we call palliative chemotherapy. It’s not that we are curing the cancer; it is just that we are slowing the growth. And the benefits are somewhat intangible, but we hope that it will make you feel better, that it will make you have a longer period of time in which you don’t develop symptoms.

When specific symptoms were discussed, they most often were symptoms related to pain (24% of segments); gastrointestinal problems such as diarrhea, vomiting, nausea, or constipation (22%); fatigue or other changes in energy level (20%); or skin problems such as rashes, irritation, itching, or sores (9%). With regard to gastrointestinal and dermatologic problems, for example, one oncologist stated:

> [Although we want the treatment] to attack the cancer, it may attack you.… That would be seen as a sunburn, [and you would probably] shed your skin if it causes real severe, crampy, painful diarrhea or liver failure. And about 20% of people would have some catastrophe like that.

In addition, some discussions involved talk of “tolerating” treatment (20%). For example, one oncologist said to the patient, “I believe that it was difficult for you tolerating the medicine. Is that right?” The patient responded, “It was a trip to hell and back.”

General Health-Related Quality of Life—Talk about general HRQOL occurred in 27% of the segments. It usually took the form of discussing HRQOL in relation to how a patient’s “body” was generally doing (46%). When one patient stated that “I feel good,” for example, the oncologist’s response was that “I can imagine you don’t feel 100%.” But it sometimes took the form of talking about general HRQOL in relationship to prognosis (36%). In several cases, it focused on the possibility of having to forgo short-term HRQOL to improve the long-term prognosis. For example, one exchange about prognosis and general HRQOL went as follows:

> *Oncologist:* And what’s your goal in terms of treatment?
>
> *Patient:* What do you mean?
>
> *Oncologist:* I mean, how hard should we push in getting rid of this lymphoma?
>
> *Patient:* Well, now, I can’t tell you that.
>
> *Oncologist:* How much work [would you be willing to do]? Would you be willing to get really sick from treatment?

In other cases, discussions of general HRQOL and prognosis focused on trying to maximize the quantity of life. These discussions included phrases about gaining a "longer period of good quality of life" and "giving the best quality of life we can for the longest period of time." As one oncologist stated, "We're not going to get away from the mission of curing you, but at the same time we want your quality of life to be good."

Somewhat less common were discussions that focused on HRQOL and potential "success" of treatment (14%). For example, when one patient said that radiation made him "feel worse and apparently didn't do...a whole lot of good," the oncologist responded that there are treatments "that have a good chance to help [and] would prolong quality of life and, when we get to the transplant phase, potentially cure you."

Physical Health-Related Quality of Life—Physical HRQOL was defined as "biomedical talk" about health status and physical conditions or physiological changes not explicitly attributed to the disease or treatment of the disease during the discussion. As such, concerns about diet and nutrition were solely coded as physical concerns. This talk occurred in 27% of the segments. Physical HRQOL talk was sometimes general in nature (19%), but it frequently focused more specifically on physical concerns about pain (30%), fatigue or energy loss (15%), weight loss or gain (15%), and gastrointestinal problems (11%). For example, in reference to pain, one patient stated "I don't want to go through unnecessary pain." Also, the following exchange occurred regarding a concern about a patient's recent weight loss:

> *Oncologist:* Are you eating?
>
> *Patient:* Not like I should.
>
> *Oncologist:* Okay, but is it slowly getting better than it was?
>
> *Patient:* Well, I weighed 92 today, so I don't think it's getting that much better.

Functional Health-Related Quality of Life—Talk about functional HRQOL or functional status occurred in 22% of the segments. It most frequently took the form of discussions about either maintaining or failing to maintain levels of general activity or general "functionality." The discussion sometimes concerned recreational, social, leisure, or hobby activities (33%), and it sometimes concerned fitness, strength, flexibility, hand functioning, weight bearing, balance, stability, mobility, the need for assistance (wheelchair, walker, or cane), and performance testing or performance status (28%). It less often concerned strenuous exercise activities such as weight training, biking, jogging, or running (11%).

In particular, many patients had concerns about how the disease or treatment might inhibit walking. As one patient, for example, emphasized: "I want to get feeling better.… I want to walk. I want to get a life back." In response, her oncologist replied, "I hear you" and "we're going to do the best we can."

Somewhat less common was talk of the impact of disease or treatment on a patient's ability to work (17%). As one patient lamented, "I just want to get well.… I'm used to working, you know. I'm used to getting out there and working, and I'm not used to being sick."

Psychological Health-Related Quality of Life—Talk of emotions, mental health, and psychological HRQOL was introduced into the conversations more frequently by patients than providers (59% vs. 41%) and occurred in only 9% of the segments. When psychological concerns were discussed, they centered on topics of cognitive functioning and decision-making ability (18%), the onset of depression (16%), increases in fear (12%), increases in stress (10%), and negative body image related to hair loss, changes in weight, or less attractive general appearance (10%). During an appointment with the oncologist, one patient frankly stated, “Damn. I look like shit.” Another patient complained that a family member accused her of “getting fat” and then asked the oncologist, “Does my stomach look big?” The oncologist responded reassuringly, “No, sweetie. I mean you have that big mass there in your abdomen, so it’s not really a matter of gaining weight.”

Social Health-Related Quality of Life—Concerns about social HRQOL took the form of discussions about relationships and social interactions, contacts, and roles. Discussions of social concerns were more frequently introduced into the conversations by providers than patients (59% vs. 41%) and occurred in only 7% of segments. In most cases (80%), they concerned the impact of the patient’s disease on the patient’s family, particularly the spouse, children, grandchildren, and parents. In one discussion, the oncologist gently reminded the patient:

> You have to prepare [your family members] for the fact that you’re not likely to make it. They need to know that. They need to know that you haven’t lost hope and that you’re going to keep trying, but they also need to know that you realize that this could not end happy, and it’s probably not going to end happy. Make sure they recognize that, because they’re the ones that ultimately have to deal with it.

In another discussion, the oncologist said, “We’ll give you a break [from treatment] for a few weeks.… I don’t want to give you anything. I just want you to get better.” The patient’s response was, “Good. My husband will love this. We’ll have a great time at the beach.”

Some discussions focused on advance care planning and included mention of social support systems, such as families, hospital infrastructure, and support groups to help patients cope. Other discussions focused on social interactions. In some cases, the patients were concerned about their weakened immune system and felt that they needed to decrease their social interactions to protect themselves from infections.

Spiritual Health-Related Quality of Life—Spiritual HRQOL was introduced into the conversations more frequently by patients than providers (75% vs. 25%) and discussed in only 4 segments (1% of all segments). For purposes of coding, we defined it as HRQOL related to beliefs about the meaning of life, about religion and religious activities, or about an individual’s sense of peace, purpose, or connection to others.

A few patients mentioned an increase in praying or reading the Bible to help them cope, and one mentioned the adoption of tai chi to help him cope. Another mentioned a decrease in church attendance because of fear of contamination. In a case in which a patient said that she had “good faith,” the oncologist responded, “Okay, I think that’s really important, because what I’ve found is that people who have a strong faith feel more comfortable with, when that time comes, letting go.”

Other Health-Related Quality of Life Concerns and Domains—When talk of HRQOL could not be coded according to the categories listed above, we coded it as other HRQOL talk. Within this category, other concerns were mentioned in 28% of the segments. Discussions of time were most common (37%) and included talk about the onset and duration of symptoms, disease, or treatment and discussions about life expectancy. Mentions of place were also common (31%) and typically revolved around whether patients would receive care as inpatients or outpatients. For example, one oncologist warned a patient that the treatment would be “a very long, tedious procedure,” and another said that it would have “a pretty large impact on your quality of life because you go to the doctor’s office for a few hours three times a week for three months.”

Less common was talk of decision making (12%), including discussions of treatment options, whether to continue treatments, and whether to pursue aggressive versus supportive treatments. One patient, for instance, said, “I know [the cancer] is not going to go away, but in order for me to at least have some kind of a life, without being sick, I don’t want to take that chemo.” In another case, although the patient confessed that he “hates drugs,” the oncologist responded that “we give you lots of things to help you try to prevent nausea.”

DISCUSSION

Although research shows that most physicians perceive HRQOL to be important, some argue that in routine clinical practice, physicians may perceive HRQOL data collection to be unnecessary [6]. However, in our study, when we analyzed the content of 73 routine ambulatory encounters between oncologists and patients with advanced cancer that contain prognostic talk by the oncologist, we found that discussions about HRQOL occurred in 100% of the conversations. HRQOL discussions ranged from 3% to 75% of the total clinic visit conversation. In 56 encounters (77%), the first mention of HRQOL was by the oncologist. In the 73 encounters, we coded 603 segments of HRQOL talk, and the vast majority were about symptoms (e.g., pain) and treatment (e.g., side effects from chemotherapy) in the past, present, and future. This major emphasis on symptoms and treatment may indeed be appropriate and warranted, as 49% of patients were undergoing chemotherapy.

Talk of general HRQOL and physical and functional HRQOL was frequent, but talk of psychological, social, and spiritual HRQOL concerns was infrequent. It has been noted that, over the years, physicians have been conducting informal HRQOL assessments by asking “How have you been lately?” [6]. However, this approach does not often address important dimensions of HRQOL such as psychological, social, or spiritual functioning. A patient may or may not voluntarily reveal concerns about these areas. Further, physicians may not discuss them due to embarrassment, time and resource constraints, or other barriers, such as attitudes of skepticism about the clinical relevance and value of psychosocial information in patient care [6,30].

In 96% of encounters, we found that oncologists and patients discussed HRQOL in relation to treatment or proposed treatment. Sometimes patients were asked to sacrifice their current HRQOL for the possibility that treatment might improve their future quality or quantity (length) of life. Other studies have noted the importance of assessing both the quality and the quantity of life, particularly in association with various cancer therapies [31]. Further, our finding that patients and their oncologists focus on symptoms and other physical domains of HRQOL is in keeping with findings that symptom relief is highly valued by patients and is usually associated with improvements in general functioning and overall HRQOL [32].

Our finding that discussions of psychological and spiritual concerns were more frequently initiated by patients than oncologists (59% vs. 41% and 75% vs. 25%, respectively) is consistent with the results of a study showing that the most prevalent HRQOL concerns of patients were existential concerns, spiritual concerns, and family concerns, followed by physical symptoms and emotional concerns [33]. Patients may have been more likely to initiate discussions of psychological and spiritual concerns because oncologists have been shown to be unaware of patient psychological distress [6].

Although our study involved more participants than most qualitative studies concerning doctor-patient communication, it included only a relatively small sample of oncologists and patients, and the oncologists practiced in the facilities of only two academic medical centers and one VA Medical Center. Moreover, our study did not address many other variables that shape a consultation, such as the use of nonverbal communication. These factors limit the generalizability of our results. However, we believe that insights into how oncologists and patients with advanced cancer talk about HRQOL can help break down the barriers to discussing difficult topics.

It has been argued that the more HRQOL is addressed in clinical practice, the more its usefulness will be realized [6]. HRQOL information can play an important role in clinical care, contributing to decision making, targeting problems, and improved physician-patient communication [6]. The goal of all health care is to enhance the well-being of patients [6] and using HRQOL data in clinical practice should allow providers to work toward that end.

It is clear from earlier studies that ineffective communication with health care providers causes distress to cancer patients and their families [34]. Prior studies have also found that cancer patients often want more information than physicians give them [18,35–38]. Although our study shows that oncologists and their patients routinely address the effect that cancer has on patients’ HRQOL, it also shows that the emphasis is on physical and functional issues, even though the patients have advanced disease and are unlikely to live for more than a year. Despite the fact that patient concerns have been shown to be largely psychosocial and spiritual in nature [33], it appears that outpatient encounters may play a minimal role in detecting or addressing such HRQOL concerns. This finding is consistent with physicians being more comfortable addressing biomedical versus psychosocial concerns [34]. Our results may point to the need for additional attention to psychological, social, and spiritual HRQOL concerns during outpatient encounters between oncologists and their patients with advanced cancer. Further research is needed to determine the reasons for infrequent psychological, social, and spiritual HRQOL discussions, such as referrals to psychological, social and spiritual support, and whether, most importantly, patient preferences are being met.

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Table 1

Sociodemographic and Clinical Characteristics of the Patients and Oncologists Whose Discussions Were Analyzed*

Characteristic	Patients (n=70)	Oncologists (n=37)
Age, years, mean (SD)	59.3 (12.4)	44.3 (7.6)
Gender, number (%)		
Male	33/70 (47)	29/37 (78)
Race, number (%)		
White	54/63 (86)	29/37 (78)
African American	8/63 (13)	0/37 (0)
Other	1/63 (2)	8/37 (22)
Patient’s marital status, number (%)		
Married	49/63 (78)	
Patient’s educational status, number (%)		
High school diploma or less	24/63 (38)	
Some college	18/63 (29)	
College diploma or more	21/63 (33)	
Patient’s financial situation, number (%)		
After paying bills, have enough money for special things	33/61 (54)	
Enough to pay bills but little spare money for special things	11/61 (18)	
Money to pay bills but only by cutting back on things	13/61 (21)	
Difficulty in paying bills, no matter what	4/61 (7)	
Patient’s self-reported general health status, number (%)		
Fully active	10/43 (23)	
Restricted in strenuous activity but able to do light work	23/43 (54)	
Ambulatory but unable to carry out any work activities	6/43 (14)	
Capable of only limited self-care	2/43 (5)	
Completely disabled	2/43 (5)	
Patient’s cancer diagnosis, number (%)		
Hematologic cancer	27/70 (39)	
Breast cancer	10/70 (14)	
Lung cancer	8/70 (11)	
Colon or gastrointestinal cancer	6/70 (9)	
Brain cancer	2/70 (3)	
Other cancer	17/70 (24)	
Treatment at time of this visit,† number (%)		
Chemotherapy (includes monoclonal antibody therapies)	39/70 (49)	
Endocrine therapy	5/70 (6)	

Characteristic	**Patients (n=70)**	**Oncologists (n=37)**
Radiotherapy	5/70 (6)	
Surgery	1/70 (1)	
No Treatment	20/70 (25)	
Other	9/70 (11)	
Patient’s self-reported chances of being cured (Living a normal life span without this cancer), number (%)		
0%	9/70 (13)	
1–10%	6/70 (9)	
11–20%	4/70 (6)	
21–30%	2/70 (3)	
31–40%	1/70 (1)	
41–50%	5/70 (7)	
51–60%	2/70 (3)	
61–70%	2/70 (3)	
71–80%	2/70 (3)	
81–90%	2/70 (3)	
100%	13/70 (19)	
Uncertain	6/70 (9)	
Missing	16/70 (23)	
Patient’s visits with the oncologist, number (%)		
0–2	26/63 (41)	
3–5	8/63 (13)	
6 or more	29/63 (46)	
How long patient has known current oncologist, number (%)		
Less than 6 months	33/63 (52)	
6 –12 months	10/63 (16)	
1–3 years	11/63 (18)	
More than 3 years	9/63 (14)	
Oncologist’s specialty, number (%)		
Medical oncology, solid tumors		16/37 (43)
Medical oncology, solid and liquid tumors		8/37 (22)
Hematology-oncology, liquid tumors		8/37 (22)
Gynecologic oncology		3/37 (8)
Radiation oncology		2/37 (5)
Years since oncology fellowship started, mean (SD)		14.2 (8.0)
Number of patient care hours per week, mean (SD)		23.5 (13.9)

[*] Because of missing data and rounding, not all percentages add to 100. Means were based on the full study sample, with one exception: for oncologists, the mean age was based on only 36 responses. SD indicates standard deviation.

[†] Because some patients were receiving more than one treatment at the time of this visit, counts total more than 70.

Table 2

Frequencies and Examples of Talk about Health-Related Quality of Life (HRQOL) during 73 Encounters between Oncologists and Their Patients, Coded in Terms of Themes Discussed during 603 Segments of Conversation[*]

Codes	Number (%) of the 603 Coded Segments	Examples of Quotations
Codes by topic		
Treatment-related	337 (56)	“The major risk is acute toxicity—nausea, vomiting, feeling lousy, the potential for infection.” (oncologist)
Disease-related	87 (14)	“You have a great quality of life, it sounds like. The disease isn’t causing a negative impact on your daily life.” (oncologist)
Testing-related	17 (3)	“So, we’ll give you some pain killers in preparation for the bone marrow test.” (oncologist) “When they draw blood, can they, you know, do it all at one time, without having to be stuck two or three different times?” (patient)
Codes by tense		
Past HRQOL	266 (44)	“I already made up my mind that I don’t want it to be like it was before.… I don’t want to go through unnecessary pain…because I did go through a lot.” (patient)
Present HRQOL	407 (68)	“I can’t do any [of that]. He [my husband] does all the cooking. He does all the cleaning up in the kitchen. I’m not used to that.… To get in the car, go to the store if I want to—I can’t do any of those things.” (patient)
Future HRQOL	353 (59)	“[There are treatments] that have a good chance to help [and] would prolong quality of life and, when we get to the transplant phase, potentially cure you.” (oncologist)
Codes by HRQOL domain		
Symptoms	300 (50)	“Those high doses can also damage the body, though. So you will feel bad from the chemo like you have a bad flu for a few weeks.” (oncologist)
General HRQOL	163 (27)	“The question is, What maximizes our chances for the longest quality of life?” (oncologist)
Physical HRQOL	163 (27)	“I don’t eat very much. I just don’t have the appetite.” (patient)
Functional HRQOL	134 (22)	“I want to walk. I want to get a life back.” (patient)
Psychological HRQOL	51 (9)	"I’m really angry. I’m angry because I didn’t ignore my condition and it wasn’t found before it got bad.” (patient)
Social HRQOL	44 (7)	“So as long as you’re not in front of someone coughing and sneezing and having a huge infection in front of you, it’s okay to go out and have fun and enjoy your life right now.” (oncologist)
Spiritual HRQOL	4 (1)	“We’re Catholic. We go to church. And holy water—I won’t even use the holy water because, I don’t know, [there might be] bugs or whatever swimming in that water.” (patient)
Other HRQOL concerns	169 (28)	“[The treatment will have] a pretty large impact on your quality of life because you go to the doctor’s office for a few hours three times a week for three months.” (oncologist)

[*] Visits included 70 patients and 37 oncologists. A given segment of conversation could include one or more codes from each category.