Preferences of Individuals With Cancer for Patient-Reported Outcome Measures

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PURPOSE: Symptom monitoring and management using patient-reported outcome (PRO) measures improves outcomes for individuals with cancer. The purpose of the current study was to provide a qualitative assessment of preferences of individuals with cancer for PRO measures.

PARTICIPANTS & SETTING: 15 patients receiving systemic therapy at the University of Texas MD Anderson Cancer Center.

METHODOLOGIC APPROACH: Participants completed three PRO measures. Qualitative interviews were conducted, and content analysis was used to identify relevant themes.

FINDINGS: Identified themes were the importance of communicating various aspects of the disease and treatment experience to the oncology team, the importance of systematic PRO assessments, congruence among PRO questionnaires and questions clinicians ask at clinic visits, concerns about the length of PRO questionnaires, the importance of the response options available in PRO questionnaires, and willingness to complete PRO measures frequently.

IMPLICATIONS FOR NURSING: Oncology nurses are critical facilitators of the systematic use of PRO measures across the cancer care continuum.

KEYWORDS patient-reported outcomes; quality of life; symptom burden; patient-centered care

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Cancer is associated with distressing disease-related symptoms and treatment-related side effects that affect functioning and quality of life (QOL) (Kim et al., 2009). When symptoms are not well controlled, they can result in emergency department visits, unplanned hospitalizations, delays in treatment, and lack of adherence to an effective treatment course (Basch et al., 2017; Boehmke & Dickerson, 2005; Dodd et al., 2010; Kayl & Meyers, 2006; Mooney, Beck, et al., 2017; Mooney, Berry, et al., 2017; Spoelstra et al., 2015; van Herk-Sukel et al., 2010; Whisenant et al., 2017). Although national guidelines provide management strategies for cancer-related symptoms, no known best practices for routinely monitoring symptoms and responding to symptoms during outpatient cancer care exist (Barbera et al., 2015; Basch et al., 2016, 2017; Berry et al., 2011, 2014, 2015; Cleeland et al., 2011; Mooney, Beck, et al., 2017; Mooney, Berry, et al., 2017).

At the initiation of therapy, strategies for the self-management of symptoms may be discussed with patients with cancer; patients should be encouraged to contact the oncology team if symptoms are not well controlled. However, patients with cancer tend to notify clinicians about moderate to severe symptoms less than 5% of the time (Mooney, Beck, et al., 2017). In addition, clinicians often underestimate the severity of symptoms and their interference with daily functioning and QOL during cancer care (Basch, 2017; Basch et al., 2009; Williams et al., 2016; Xiao et al., 2013). Evidence suggests that systematically monitoring the symptom experience using patient-reported outcome (PRO) measures during treatment for cancer can improve QOL, increase adherence to therapy, and decrease emergency department use, as well as increase overall survival (Barbera et al., 2015; Basch et al., 2016, 2017; Berry et al., 2011, 2014, 2015; Cleeland et al., 2011; Mooney, Beck, et al., 2017). However, adding PRO measures to routine clinical

care requires significant planning in regard to care delivery practices. In particular, use of a PRO measure in clinical practice must balance the added burden of measurement to the patient and to the clinical workflow with benefit to the patient.

Clinicians wishing to assess the symptom experience of individuals with cancer have many options related to their choice of PRO questionnaire. There are several health-related QOL instruments with multidimensional constructs that are used as symptom measures, as well as symptom-specific instruments. There is ongoing debate concerning which measure offers the most valid and clinically relevant information for optimal clinical management of disease-related symptoms and treatment-related side effects. What makes a good questionnaire can be subjective from either a clinician or patient perspective. However, there is a general consensus that an ideal instrument will have established psychometric properties in contexts similar to those of the clinical population (Aaronson et al., 2002). In addition, it should be valid, reliable, and responsive in its ability to register clinically important symptomatic changes over time.

In the context of symptom management, the subjective nature of the symptom experience requires that patients be the source for the evaluation of symptoms (Cohen & Botti, 2015). However, evidence of patient acceptability, perceived usefulness, and preferences for PRO use in clinical practice for monitoring symptoms is limited, with most assessments focused around whether completion of PRO measures enhances patient–provider symptom-related communication. Patients with cancer have described feeling that reviewing a PRO measure with their clinician can be helpful in discussing health issues and ensuring that important health issues are mentioned that may otherwise be missed (Detmar et al., 2002b; Stover et al., 2015). For example, when asked about the acceptability, perceived value, and comprehension of a PRO measure used to facilitate communication with an oncology provider during a clinic visit, patients with cancer described feeling that a summary of symptoms and functional status was helpful in discussing health issues with clinicians (Stover et al., 2015). In addition, when provided with scores and a graphic display of PRO measure responses during a clinic visit, 87% of individuals with cancer believed that use of the measure facilitated communication with their provider (Detmar et al., 2002b). Increasing frequency of symptom discussions during clinic visits has been reported with the use of PRO measures in routine clinical care (Detmar et al., 2002a; Kotronoulas et al., 2014; Taenzer et al., 2000; Todd et al., 2015; Velikova et al., 2004). In addition, individuals with cancer have described the need to coordinate the timing and scope of PRO measures to disease and treatment stages, suggesting that measures of various domains of QOL may be appropriate at varying times and intervals during the disease and treatment trajectory (Velikova et al., 2008).

Given the limited evidence concerning the acceptability of and preferences for PRO symptom measures among individuals with cancer for use in routine clinical care, the current authors' objective was to provide a description of preferences for PRO measures among individuals with cancer, with respect to factors that affect their responses and their willingness to complete PRO measures during clinical care. The current authors used the Symptom Management Model, which describes an interrelationship among the symptom experience, symptom management strategies, and patient outcomes, as a conceptual foundation for this study (Dodd et al., 2001). The symptom experience is the individual's perception of the dimensions of a symptom. Symptom management strategies refer to changing methods for coping with and decreasing the symptom and the symptom outcome, including communication with the clinical team about symptoms. The purpose of the current study was to provide a qualitative assessment of PRO instrument preferences among individuals with cancer for collecting disease- and treatment-related symptom data.

Methods

Individuals with cancer undergoing chemotherapy treatment completed three PRO measures commonly administered to individuals with cancer and participated in a single semistructured qualitative interview for the purpose of assessing preferences for PRO instruments. This study was approved by the institutional review board at the University of Texas MD Anderson Cancer Center.

Sample

Patients in the outpatient infusion center at MD Anderson Cancer Center in Houston, Texas, were screened for eligibility in the current study using the electronic health record system. Potential participants were purposively selected to ensure that a range of patient preferences was obtained. Potential participants were targeted for recruitment according to minimum desired percentages of characteristics

that could influence PRO preferences. These characteristics included gender (target of 40% male and 40% female), age (target of 40% aged younger than 60 years and 40% aged 60 years or older), and race/ethnicity (target of 40% White, 20% Black, and 20% Hispanic). Eligibility criteria were age of 18 years or older, English fluency, ability to read and complete the questionnaires on own, and diagnosis of advanced cancer, with ongoing treatment including at least one cycle of chemotherapy. Sampling continued to saturation, such that when themes related to PRO preference in this population were completely explored and no new information was found in at least three consecutive interviews, recruitment was stopped (Parse et al., 1985).

Procedures

After obtaining informed consent, study participants completed three hard-copy PRO measures. The order of the PRO measures was randomized, and participants were blinded to the questionnaire titles. The researchers (M.S.W., O.B.) documented completion time in minutes. Following PRO measure completion, individual semistructured interviews were conducted to allow the participants to relate impressions and preferences of the PRO measures. Demographic and clinical information from participants' medical records was collected by researchers (M.S.W., O.B.) using the REDCap web-based application.

Patient-Reported Outcome Measures

The MD Anderson Symptom Inventory (MDASI) is a brief PRO measure of the severity of 13 symptoms and 6 areas of symptom interference with daily life common to all cancer types (Cleeland, 2007). The concept of symptom burden provided the developmental framework for the MDASI (Cleeland, 2007). The MDASI has established validity and reliability for

FIGURE 1. Interview Guide

Introduction

I am going to ask you some questions about your experience completing these questionnaires (the interviewer should lay out the questionnaires in front of the participant in the order in which they were randomized at this time). We will refer to the questionnaires as A, B, and C, as indicated at the top of the forms. (Questionnaire A is indicated here, but repeat all but the last question for each questionnaire.)

Questions

- In sharing important information about your disease and treatment experience with your oncology team, how helpful do you feel questionnaire A would be?
  - Possible probe questions: How helpful was questionnaire A for reminding you of important things that you wanted to discuss with your oncology team? In communicating about how you are feeling, how helpful was questionnaire A? What suggestions do you have for making questionnaire A more helpful?
- Questionnaire A has a set of instructions at the top and then is divided into sections, with other instructions at the beginning of some sections. How helpful are the instructions?
  - Possible probe questions: Can you tell me more about that? How do you feel about the amount of time the questionnaire asked you to recall in answering the questions?
- Questionnaire A has X options, ranging from X to X, you can choose from for your answer. In addition, questionnaire A has words describing each option above the answer choices OR questionnaire A has words describing the lowest and the highest answer options. How helpful were the answer options?
  - Possible probe questions: Can you tell me more about that? How easy was it for you to answer the questions on the questionnaire using the answer options provided?
- Questionnaire A has X questions. How do you feel about the length of questionnaire A?
- Do you have concerns with any of the questions on questionnaire A?
  - Possible probe question: Are there any repetitive, redundant, or overlapping questions?
- How would you feel about completing questionnaire A before seeing your oncology team at each clinic visit?
- How would you feel about completing questionnaire A weekly at home between clinic visits? For what period of time would you be willing to do this?
- How would you feel about completing questionnaire A more than 1 time each week at home between clinic visits? For what period of time would you be willing to do this? Is there anything else important about completing any of these questionnaires that you would like to tell me? Do you have a preference for any of the questionnaires to communicate information about your disease and treatment experience to your oncology team? If so, why do you prefer that questionnaire?

Note. Interview should be conducted after participant has completed all 3 questionnaires.

use in multiple cancer diagnoses (Cleeland, 2007). The MDASI is scored by calculating a mean symptom severity score of all symptom ratings and a mean interference score of all interference item ratings.

The Functional Assessment of Cancer Therapy–General (FACT-G), version 4.0, is a validated QOL instrument that asks patients to respond to 27 items measuring general QOL associated with cancer. The FACT-G is divided into four primary QOL domains: physical well-being, social/family well-being, emotional well-being, and functional well-being. The total FACT-G score is obtained by summing the domain subscale scores, with higher scores correlating with a more favorable QOL. The FACT-G has established psychometric properties for use in populations of individuals with cancer (Cella et al., 1993).

The European Organisation for the Research and Treatment of Cancer QOL Questionnaire–Core 30 (EORTC QLQ-C30) is a validated 30-item QOL instrument for use with individuals with cancer. The EORTC QLQ-C30 is composed of a number of subscales representing health-related QOL dimensions: global health status/QOL, physical functioning, role functioning, emotional functioning, cognitive functioning, social functioning, fatigue, nausea and vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties (Aaronson et al., 1993). The EORTC QLQ-C30 has established reliability and validity (Aaronson et al., 1993).

TABLE 1. Sample Characteristics (N = 15)

Characteristic	$\bar{X}$	SD
Age (years)	58.1	10.5
Characteristic		**n**
Cancer type		
Breast		4
Uterine		3
Colorectal		2
Ovarian		2
Lung		1
Lymphoma		1
Prostate		1
Sarcoma		1
Education		
High school graduate		3
Some college or technical school		2
Undergraduate degree		4
Graduate school		6
Employment		
Employed full-time		8
Retired		4
Homemaker		1
Medical leave of absence		1
Unemployed		1
Ethnicity		
Hispanic		3
Non-Hispanic		12
Marital status		
Married or partnered		11
Divorced		2
Single, living alone		2
Race		
White		12
African American		3
Sex		
Female		10
Male		5

Qualitative Interview Procedures

Qualitative interviews containing open-ended questions were conducted in a private room in the infusion center at MD Anderson Cancer Center by trained research staff according to an interview guide (see Figure 1). Additional probe questions were asked if the trained interviewer felt that elaboration was required. Interviews lasted between 30 and 45 minutes, and they were digitally audio recorded and professionally transcribed. Only the interviewer and the participant were present in the room during completion of the PRO measures and the interview. After patient data collection was completed, the interviewer dictated or wrote a field note about the interaction with the participant during the interview. Once the transcription was complete, the interviewer verified the accuracy of the transcription.

Analysis

Descriptive statistics were used to describe the participant sample based on demographic, disease, and treatment characteristics and PRO measures' time to completion in minutes to understand whether perspectives about each PRO measure may be influenced by differences in time to complete each measure.

Content analysis of the transcripts was performed to describe the participants' perspectives (Parse et al., 1985). Two researchers experienced in qualitative research (M.S.W., O.B.) initially reviewed the

interviews and identified themes using descriptive exploratory analysis. For bias control and to ensure credibility and dependability in the analysis, two other members of the study team then reviewed the analysis results and confirmed or suggested modification (L.A.W., C.C.). All researchers involved in the analysis jointly met to review the analysis, revising themes as needed until all agreed on the final analysis from the qualitative interviews. Detailed notes of decisions, meetings, and emergence of findings were kept throughout the analysis process, and participant quotes describing each theme were extracted to demonstrate credibility and confirm findings.

Results

Participant demographic and clinical characteristics are summarized in Table 1. Mean patient age was 58.1 years (SD = 10.5); cancer diagnoses included gynecologic (n = 5), breast (n = 4), and colorectal (n = 2); and all participants were undergoing active chemotherapy at the time of the interview. All participants had at least a high school level of education. The number of items on each PRO questionnaire, mean time to completion with standard deviations, and ranges for completion time are presented in Table 2.

Qualitative Interview Results

Identified themes were the importance of communicating various aspects of the disease and treatment experience to the oncology team, the importance of systematic PRO assessments, congruence among PRO questionnaires and questions clinicians ask at clinic visits, concerns about the length of PRO questionnaires, importance of the response options available in PRO questionnaires, and willingness to complete PRO measures frequently.

Importance of communicating various aspects of the disease and treatment experience to the oncology team: Participants described the importance of clearly communicating different aspects of their disease and treatment experience, including their physical and emotional experience, to their oncology team and acknowledged that PRO instruments facilitated communication of their experience. A 49-year-old man, referring to the EORTC QLQ-C30, said, "I felt like it had more experience-specific questions, which is less an assessment of 'How do you feel about physical activity or your limitations?' [and] more like this one task: 'How did you perform doing this one task?'" A 49-year-old woman, speaking about the same instrument, said, "It's helpful information. It's a mixture of both physical and emotional." Referring to the FACT-G, a 75-year-old woman called it "very helpful, because they need to know just what's going on with me and how well I'm taking the treatment and accepting what's happening with my body and with my life." Of the MDASI, a 71-year-old man reported the following:

> The symptoms of how you're feeling with the treatment and this is something that's more of, "OK, this week did you have any of this?" where you're letting them know that, yeah, it made me sick. I was nauseous, I had trouble breathing, things of that nature.

Importance of systematic PRO assessments: Participants felt that systematic PRO assessments helped them communicate their concerns with care providers and reminded them of things they may have wanted to discuss with their care providers. A 65-year-old woman, in reference to the FACT-G, said, "There's certainly some that I think would remind you that, oh yeah, I do want to mention this to him, that this happened or I'm having a problem with this. It would remind you of certain things." Of the MDASI, a 62-year-old woman reported that "it had . . . topics that at least jogged my memory, about things that I may not have—that I should have mentioned that I didn't think about." Similarly, a 71-year-old man, also speaking of the MDASI, said, "It's hitting things that might've happened that you want to make sure and remember and tell them."

TABLE 2. Completion Time for Patient-Reported Outcome Measures in Minutes

Measure	Items	$\bar{X}$ Time	SD	Min Time	Max Time
EORTC QLQ-C30	30	3.36	1.16	1.78	6
FACT-G	27	3.08	1.21	1.67	5.38
MDASI	19	2.23	0.68	1.1	3.76

EORTC QLQ-C30—European Organisation for the Research and Treatment of Cancer Quality-of-Life Questionnaire–Core 30; FACT-G—Functional Assessment of Cancer Therapy–General; max—maximum; MDASI—MD Anderson Symptom Inventory; min—minimum

Congruence among PRO questionnaires and questions providers ask at clinic visits: Participants noted that many of the questions on the PRO measures were the same questions their care providers often ask at clinic visits, particularly the symptom-related questions. A 63-year-old man remarked as follows in regard to the EORTC QLQ-C30: "They do tell me to start off with how my constipation is or if I've got diarrhea or [am] short of breath. They do ask me all those questions." A 65-year-old woman, also referring to the EORTC QLQ-C30, said, "I think it probably helps a lot because these are things they ask me." Of the MDASI, a 48-year-old woman reported, "They ask me these same questions whenever I see them every three weeks. I guess it would just be an addendum to what they ask me already." Another participant, a 63-year-old man, said of the MDASI, "They ask those questions verbally and enter it into the computer just about every time I see them anyway." Also of the MDASI, a 48-year-old woman said, "They do ask a lot of these same questions. Maybe not necessarily your mood, but they do ask about your sleep, your nausea, your pain level, things like that. They ask every time I go see them."

Concerns about the length of PRO questionnaires: All three questionnaires were of acceptable length to participants, but participants mentioned that they would be more likely to complete shorter instruments. A 62-year-old woman said of the EORTC QLQ-C30 that she "thought it was absolutely fine" and "was not bothered by the length." Of the FACT-G, a 65-year-old woman reported that "it was fine. It was short, and it was to the point." A 59-year-old woman, referring to the MDASI, said that "it wasn't too long. . . . I was more likely . . . [to] do something short."

Some patients preferred a numeric scale for measurement response options, whereas others had reservations about the use of a numeric scale. For example, in reference to the MDASI, a 62-year-old woman said, "0, being not present, and 10, being the worse, or as bad as you can imagine, I thought was very, very clear." However, a 54-year-old woman also referring to the MDASI said, "I didn't like all those numbers as a choice as a pretty big scale. I think you could probably have 5 options instead of 10. . . . It just gives you an awful lot of in between." A 49-year-old man said of the MDASI that "he liked the variety": "Obviously, it's fairly subjective. Was I a 5 or a 6 or a 5.2, and which one do I put? To have that broad range allows you to more specifically detail your response."

Importance of the response options available in PRO questionnaires: Participants reported the use of descriptors as well as numbers on the measurement scale to be helpful and had varying opinions about acceptable ranges of response options. A 49-year-old man said of the FACT-G that "the range was broad enough, not too broad, not too narrow, and, instead of just 0, 1, 2, 3, 4, actually demarcating what those things mean made it a lot easier to pick them." Of the FACT-G, a 71-year-old man said,

> I do like the fact that not at all, a little bit, somewhat, quite a bit, very much—that puts some values to it, rather than a 1, 2, 3, 4, 5, 6. It's a little more descriptive. It's a little bit easier making a choice.

A 57-year-old woman, in reference to the EORTC QLQ-C30, reported she "would rather have there be a little more of a range. I think maybe even having a fifth option so you're kind of in the middle of the road" would be helpful.

Participants described a variety of preferences for recall time, but they preferred one week instead of just 24 hours. A 57-year-old woman, referring to the EORTC QLQ-C30, said, "I think a week is better than just the past 24 hours, because sometimes things happen during your week that may affect how you would answer that rather than just thinking back to . . . 24 hours." Similarly, a 59-year-old woman said this of the FACT-G: "I like a longer period of time better than just the 24 hours because a week gives you a pretty good time frame." Also of the FACT-G, a 54-year-old woman reported that "most people aren't going to remember two weeks out." A 49-year-old man said the following of the FACT-G:

> You can have a good day, and you can have a bad day if you look at one 24-hour period. If you look at seven days, you look at the mean of the experience, and it gives a much different picture.

A 59-year-old woman said of the MDASI that "it's a little bit short because just one day might be a particularly bad day, but it's not reflective of how I've felt for a long period of time."

Willingness to complete PRO measures frequently: Participants were willing to complete all three PRO measures prior to each oncology visit and the symptom burden measure as much as once weekly at home. When asked about willingness to complete the questionnaire prior to each clinic visit, a 59-year-old woman, in reference to the MDASI, said, "It would be helpful, especially if you could do it right then, and

you're supposed to fill it out and bring it with you, like homework." A 49-year-old man, of the FACT-G, said, "I think it would be a very productive thing to do," and a 59-year-old man, of the EORTC QLQ-C30, said, "I think the more they know, the better."

When participants were asked if they would be willing to complete the questionnaire at home in between clinic visits, participants were willing but indicated that they would prefer to do it electronically and no more than once weekly or once in between visits. A 62-year-old woman, of the EORTC QLQ-C30, said, "I could definitely do it weekly at home, especially electronically." Of the FACT-G, a 62-year-old woman said the following:

> I think I would be more likely to do it if it was sent to me electronically and I could answer it and send it right back. If it were something that were given to me paperwise and I had to remember to bring it back with [me], I'm not sure how reliable, with "chemobrain," I'd be.

A 57-year-old woman, in reference to the FACT-G, said, "If it's once a week, that would be fine," and a 62-year-old woman, in reference to the MDASI, said that "electronically would be ideal." However, a 57-year-old woman, referring to the MDASI, said, "In my situation, weekly would mean you'd be filling it out three times between visits. I'm not sure it would change all that much in three weeks. Maybe once during the in-between visits would probably be adequate."

Discussion

The current authors conducted a qualitative study to describe preferences for use of PRO measures among individuals with cancer for routine symptom monitoring in clinical oncology care, employing three commonly used measures of QOL and symptom burden to ground the qualitative interviews. After completing three PRO measures, participants described the importance of sharing symptom and QOL information with their oncology team. Participants in the current sample felt that systematic PRO assessments may help them communicate with their care providers. Previous evidence suggests that PRO assessments may support patient–provider engagement and help set priorities for patient–provider discussions during in-person and remote office visits (Lavallee et al., 2016; Stover et al., 2015; Todd et al., 2015). The use of PRO data to inform discussions during oncology encounters may facilitate patient–provider communication about domains of health-related QOL and encourage more frequent discussions of symptoms without prolonging encounter time (Detmar et al., 2002a, 2002b; Taenzer et al., 2000; Velikova et al., 2004).

Participants in the current study reported that completing PRO instruments may help to remind them of issues they want to discuss with their provider that may have otherwise been missed. The usefulness of PRO measures as triggers for memory of important health-related concerns has been previously cited (Stover et al., 2015). Completion of PRO measures may not only serve to trigger the individual's memory about a symptom experience but may also allow individuals with cancer the opportunity to reflect on their health and recognize areas that may warrant discussion with their oncology team (Greenhalgh et al., 2018).

The U.S. Food and Drug Administration (FDA, 2009) has suggested that choice of PRO measure for use in a clinical trial should consider respondent burden; attention should be paid to questionnaire length, formatting, font size, instructions, and questions that the patient may be unwilling to answer. Similar to consideration of the potential for missing data in clinical trials with inappropriate respondent burden, clinicians should consider the potential for missing assessments or missing data when selecting PRO measures for use in routine clinical care. Although the QOL questionnaires and the symptom burden questionnaire administered in the current study were acceptable to participants in length, formatting, font size, instructions, and questions, measures should be selected with care and at appropriate intervals to minimize patient burden and missing data.

Previous work has suggested that individuals with cancer prefer questionnaires that cover a broad range of concepts inherent to QOL, including common symptoms and problems, disease- and treatment-specific issues, and individual patient-specific issues (Velikova et al., 2008). Importantly, choice of PRO measure and timing of measurement should correspond to the unique disease-specific experience and treatment stage (Velikova et al., 2008). In the current sample, on average, the symptom burden questionnaire (MDASI) took less time to complete than measures of QOL (EORTC QLQ-C30, FACT-G), and participants reported a willingness to complete the symptom burden measure as frequently as once per week during treatment. In designing protocols for routine symptom monitoring during clinical care, attention should be given to participant burden, selecting the most narrowly focused

PRO measure that adequately captures the patient experience at the time of measurement. When to use symptom-specific measures versus other QOL measures should be considered. In the current sample, routine monitoring using PRO measures, as much as weekly, was acceptable to most participants.

Participants in the current sample reported various preferences for measurement recall time. Choice in recall should depend on the specific domain captured by a measure, as well as its variability, duration, frequency, and intensity; patient burden and ability to easily and accurately recall the requested information should also be considered (Norquist et al., 2012). Attention should be paid to choosing measures with a recall time that corresponds to the characteristics of the phenomenon of interest and the purpose of the assessment (Stull et al., 2009). Although some individuals in the current study preferred weekly recall times and others preferred 24-hour recall times, existing evidence suggests there is minimal difference between daily and weekly reports for symptom PRO measures (Mendoza et al., 2017).

Participants in the current study reported varying preferences in relation to response measurement scales and options. Decisions concerning whether to use a measure with descriptors labeling all points or having only anchors on each end of a numeric scale and whether to choose a measure with more or fewer response options should be carefully considered (FDA, 2009). Attention should be given to ensuring that the chosen instrument uses clear wording in response options, with a clear distinction between choices that are justified empirically; avoids potential ceiling or floor effects; and avoids causing bias to the direction of the responses (FDA, 2009). Particular emphasis should be placed on whether the item response options are appropriate for the intended population and whether instructions to individuals with cancer for completing items and selecting responses for the items are adequate (FDA, 2009). In the current sample, participants reported that the instructions provided were adequate across all three measures. In addition, although some participants preferred a specific response scale, all response scales were deemed to be acceptable for measuring QOL and symptoms from the perspective of individuals with cancer.

Strengths and Limitations

Given the limited evidence concerning the acceptability of and preferences for PRO symptom measures for use in routine clinical care among individuals with cancer, the current authors present a description of preferences for PRO measures with respect to factors that affect participants' responses and willingness to complete PRO measures during clinical care, obtained through qualitative interviews. Participants were purposively selected based on age, gender, and race/ethnicity to obtain a breadth of perspectives about PRO questionnaires. For convenience of completing interviews, participants in the current sample were recruited and interviewed in the infusion center while receiving systemic chemotherapy. Additional research is needed to determine whether preferences for PRO measures among individuals with cancer are transferable across treatment types and in the contexts of radiation therapy, surgery, transplantation, immunotherapy, and survivorship. In addition, the current sample size was fairly small; research with larger cohorts is needed to better understand the preferences of individuals with cancer concerning the systematic use of PRO measures in routine care.

KNOWLEDGE TRANSLATION

- Individuals with cancer indicated that it is important to share symptom and quality-of-life information with their oncology team.
- Individuals with cancer reported that systematic assessments help them to communicate concerns.
- Individuals are willing to complete questionnaires prior to oncology visits.

Implications for Nursing

Results from the current study suggest that oncology nurses should recognize the importance of communicating with individuals with cancer about the symptom and QOL experience, recognizing that systematic assessments may facilitate communication of concerns. Cancer-related symptoms are often managed by interprofessional teams that may be led by nurses; accordingly, oncology nurses are critical advocates for and facilitators of using systematic measurement of PROs across the cancer care continuum. Individuals with cancer may use systematic measurement of their symptoms and QOL as a method for recognizing areas that may warrant additional discussion with their oncology team. Nurses should take care to select and administer PRO measures in a way that reduces burden to individuals with cancer and missing data. Selected PRO measures should be appropriate to the construct of interest, as well as to the disease and/or treatment site patient population in which the measure will be administered.

Conclusion

Individuals with cancer feel that it is important to share symptom and QOL information with their oncology team. Routine symptom monitoring, as much as weekly, is acceptable to individuals with cancer. Given the variability in preferences for questionnaire recall time and measurement scale, additional research is needed, with larger samples, to describe the preferred presentation of PRO measures for routine use in research and clinical practice.

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