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Communication between oncologists and lymphoma survivors during follow-up consultations: A qualitative analysis

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Abstract

Cancer survivors often experience both short- and long-term challenges as a result of their cancer treatment. Many patients report feeling “lost in transition” following cancer treatment. The oncologist plays a key role in helping the patient to transition to survivorship. The purpose of this paper is to provide a descriptive understanding of the clinical care delivered during follow-up visits for lymphoma patients transitioning from active therapy into survivorship. We used thematic text analysis to identify themes in transcripts of audio recordings of 21 physicians and their patients in follow-up visits within 3 years of completing lymphoma treatment. Conversations between oncologists and patients during follow-up visits addressed a variety of themes, including specific health concerns, follow-up care, health promotion, prior treatment and test results, overall health status, emotional communication and affective tone, post-treatment rehabilitation, discussions occurring in the patient’s physical examination, and social issues. However, the frequency with which these themes were discussed varied. In addition, there did not appear to be a consistent framework for these visits. The varied nature of the follow-up visits analyzed in this study suggests the need for increased structure in survivorship-care consultations.

Keywords

doctor-patient communication; lymphoma; survivorship

Introduction

New and more effective cancer treatments, together with an aging population, are leading to a growing number of cancer survivors in the United States. There are over 14 million cancer survivors in the US, and this number is expected to grow to 18 million by 2022 (de Moor et al., 2013). Survivors often experience both short- and long-term challenges as a result of their cancer treatment, including fatigue, pain, sexual dysfunction, psychosocial concerns, and socioeconomic issues. Late effects can arise years after treatment, including secondary malignancies, lung damage, and cardiovascular disease. Consequently, cancer survivors also experience increased healthcare utilization and healthcare costs (Yabroff et al., 2014).

A further challenge for survivors is the decline in frequency of visits with their oncologists and treatment teams once treatment ends, even as sequelae of therapy persist or are yet to emerge. Many patients report feeling “lost in transition” after treatment, a phrase used by the Institute of Medicine (IOM) in their 2005 report to describe the lack of guidance survivors receive in adjusting to post-treatment care. As such, the IOM recommended survivorship-care plans for all patients completing treatment in order to help manage and coordinate their follow-up care (Committee on Cancer Survivorship: Improving Care and Quality of Life, 2005).

With a growing number of survivors requiring follow-up, healthcare providers often struggle with how best to implement survivorship care. Oncologists rarely provide survivorship-care plans, and healthcare providers frequently fail to have discussions with cancer survivors to ensure effective management of survivorship care (Blanch-Hartigan et al., 2014). A shortage of oncologists requires that the healthcare system adapt by sharing care provision with other healthcare providers (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007; Yang et al., 2014), many of whom may not be confident in their ability to meet the complex needs of survivors (Potosky et al., 2011). Ideally, survivorship-care plans would be implemented within existing care structures and ultimately promote dialogue between oncologists and survivors. However, currently, little is known about the content of consultations of survivors with their oncologists after treatment ends.

The current study represents a qualitative investigation of the conversations that occur during follow-up visits for lymphoma patients who are transitioning from active therapy into survivorship, and is intended to offer a descriptive understanding of the care delivered in this clinical setting.

Methods

Participants

This qualitative study is part of a larger randomized study to test the efficacy of a novel survivorship planning consultation for patients with Hodgkin lymphoma (HL) or diffuse large B-cell lymphoma (DLBCL) completing treatment with curative intent (Parker et al., 2016). Participating patients were treated by oncologists at one of four major cancer centers across the US. In the study, the sites were randomized to have their oncologists either receive a communication skills training intervention and conduct a survivorship-focused

office visit or provide a time-controlled, manualized consultation known as “Wellness Rehabilitation” focused on imaging test results and healthy nutrition and exercise as rehabilitation postchemotherapy. The study was approved by the Institutional Review Boards at all four cancer centers ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT01483664) NCT01483664).

The goal of this exploratory qualitative study is to describe the content and nature of current communication habits during HL and DLBCL patient follow-up visits within the patients’ first 3 years of survivorship. These assessments occurred before the oncologists were randomized to one of the two arms described above. Participating oncologists’ follow-up visits with two patients were audio-recorded to evaluate these baseline communication behaviors. These analyses included 40 patient visits with 21 oncologists from 2 of the 4 sites. Eligible oncologists were those who treated patients with HL and DLBCL. Eligible patients had a diagnosis of either HL or DLBCL, had a complete remission after completing chemotherapy and/or radiation therapy within the last 3 years, were at least 18 years old, were fluent English speakers, and were capable of offering informed consent.

Procedure

Oncologists initially first received a letter of introduction, and subsequently additional face-to-face information, from study investigators. Oncologists provided written informed consent. A total of 21 oncologists were approached across the two cancer centers; all consented to participate. Nineteen physicians had two follow-up visits, and two physicians had one follow-up visit, all visits were audio-recorded. As such, the total data set included audio recordings from follow-up visits with 40 patients. For this study, we randomly selected for evaluation one recording per oncologist for a total of 21 recordings.

Patients eligible for audio-recording assessment were approached, and interested patients were then consented into the study. Across the two sites, 44 patients were approached during the 7 months of recruitment. Two patients were subsequently deemed ineligible and two patients declined participation, one due to discomfort being recorded, and one due to emotional distress.

The oncologists were not prompted to address any specific topics or issues with consented patients during these visits, so as to capture communication content that the oncologists naturally and routinely discussed at such visits. Research staff set up the audio recorder prior to physicians’ entering the room, and collected recording equipment after the conclusion of the consultative visit.

Qualitative analysis

We formed a four-person team to assist with the coding and analysis of the data. We reviewed and interpreted the discussion content using thematic text analysis with an inductive, data-driven approach (Bernard, 2011; Boyatzis, 1998; Creswell, 2013). The qualitative analysis software ATLAS.ti was used to manage coding (Frieze, 2014). Consistent with this method, each team member independently read through the consultation transcripts and developed codes to represent the underlying meaning of key content within the narratives. The research team then met regularly to compare codes and achieve consensus about code names, meanings, and assignment to relevant content in the

transcripts. We ultimately created a codebook consisting of 38 descriptive codes. Our codes described distinct phenomena identified throughout the coding process. Once coding was complete, we grouped these codes into the following eight categories based on their conceptual similarity: (1) assessment of current or future health; (2) emotional expression; (3) follow-up care; (4) health promotion; (5) physical exam; (6) post-treatment rehabilitation; (7) review of prior treatment and tests; and (8) social issues. We generated quotation reports from ATLAS.ti that contained all narrative content coded with these categories.

We subsequently divided responsibility for identifying and describing the themes in the content coded with these categories between two teams of two members each. Each of these team members read the narrative content, synthesized and interpreted the data, and identified illustrative quotations for each theme. Team members met to reach consensus on and describe themes regarded as novel and salient. Rigor in our qualitative analysis was derived from successive rounds of iterative consensus work among multiple team members who analyzed the discussion transcripts (Morse, Barrett, Mayan, Olsen, & Spiers, 2002).

Results

Table 1 presents demographic data for participating oncologists, and Table 2 presents demographic data for patients. Discussions that emerged during follow-up appointments between oncologists and lymphoma patients were categorized into nine themes and several subthemes (Table 3). The themes are ordered according to frequency with which they presented in the data. We describe each discussion content area and communication strategies below.

Specific health concerns

Specific health concerns raised were both cancer-related and non-cancer-related and were discussed separately from cancer follow-up. For many concerns, neither the oncologist nor the patient discussed the relationship between the presenting symptom and the patient's cancer history, and oncologists did not proactively inform the patient whether current health issues were connected to their cancer history. Overall, there were more discussions of non-cancer-related health concerns than cancer-related issues.

Discussions of specific health concerns fell into three broad content areas: cancer-related current health issues, non-cancer-related current health issues, and patient uncertainty regarding relation of current health issues to cancer history. Oncologists typically asked about cancer-related late effects or post-treatment toxicities using a list of closed questions, with their inquiries focused on the patient's physical signs and symptoms. The topics included platelet recovery, fertility, neuropathy, menstruation, family planning, bruising, pain, chemo-brain and memory, muscle tension, varicosity, leg heaviness, nail quality, and hair recovery. There were few discussions regarding current functional status, e.g., "are you walking?" and within these discussions, neither the oncologist nor the patient discussed how functional status was affecting the patient's broader life.

Discussion of current health status at times overlapped with current health promotion efforts, such as diet, exercise, or vitamin use. Discussion of dietary issues typically focused on what types of foods patients could eat or tolerate, or discussions of vitamins. For example, an oncologist strongly suggested a patient who had bariatric surgery visit a nutritionist to follow up on recommendations for vitamins and supplements.

Oncologist: Do you think you can see a nutritionist that specialized in bariatric surgery? Please? And check your vitamin levels and everything else? You're cured-you're probably cured of your lymphoma, and you are controlling your overweight. Don't let this little thing of taking vitamins destroy your life.

With regard to non-cancer-related current health status, oncologists often asked about comorbid conditions (e.g., hypertension or diabetes) and how those were being managed. This included discussions of which other providers the patient had seen, and the process of consulting with other providers about managing these conditions. There was limited in-depth discussion regarding treatments the patient had received for these conditions, and generally the oncologist focused more on ascertaining whether appropriate follow-up care with other providers was in place. Patients and oncologists also discussed minor health issues such as symptoms of allergies.

Discussions involving patient uncertainty regarding cancer-relatedness of current health status focused on patients seeking normalization of current health problems. Patients presented a physical symptom and asked whether it was related to prior treatment, whether it was "normal," and whether they should be concerned by such symptoms. Oncologists often assuaged the patient's concerns.

Overall, oncologists did not inquire proactively about any psychological effects of cancer and did not ask patients about how physical symptoms had impacted their quality of life, functional status, or psychosocial status.

Follow-up care

Oncologists almost always raised future scans and visit schedules during these consultations. They often discussed the gradual lessening of follow-up care in a congratulatory and celebratory manner. Comments about the differences between CT and PET scans, and which scans are regarded best for the patient, often emerged during communication about ongoing follow-up. Many oncologists mentioned the 5-year mark post-treatment as the time when a patient would be deemed "cured" and considered for transitioning to a primary-care provider. At the same time, oncologists did not provide premature reassurance and often mentioned that they could never be 100% confident the cancer would not recur, but that it was highly unlikely, especially after 5 years of remission.

Oncologists often discussed the need for routine follow-up care with other providers such as the importance of women seeing a gynecologist for routine pap smears and mammograms, the need for colonoscopy at a certain age, and vaccinations (most often for influenza) from primary-care providers. The following exchange illustrates exemplary communication regarding such issues.

Oncologist: And for your regular healthcare, it's very important for any cancer patient, but particularly patients with lymphoma, to make sure that you're getting your regular screenings so you're on top of the mammograms, you're on top of the colonoscopies, and you'll want to see your doc just for a regular checkup once a year, make sure there

Patient: Mammogram has to be once a year, right?

Oncologist: Mammogram should be once a year.

Patient: Okay. I do that.

A number of oncologist–patient interactions included more complex discussions about management of comorbid health problems such as diabetes, hernias, and obesity. Family-planning conversations occurred in relatively few visits; such discussions were primarily raised by women concerned about fertility and when it would be safe to conceive after treatment.

Health promotion

Discussions regarding health promotion frequently arose; however, physician recommendations tended to be reactionary, rather than a systematic and organized element of the patient visit. Patients often volunteered information regarding engagement in physical activity or dietary practices without being prompted. Oncologists provided very few specific health promotion recommendations during the visit, and instead imparted more general statements regarding the importance of healthy diet and physical activity. They rarely offered specific assistance or referrals to other providers, sought to partner with the patient in pursuing healthy lifestyle change, or made reference to health behavior guidelines for cancer patients.

In general, oncologists were very encouraging and enthusiastic when patients described success in dietary change, weight loss, or physical activity engagement. Occasionally, oncologists engaged with their patients around this topic, discussing the ability for a cancer diagnosis to prompt positive change and the importance of lifestyle behaviors in the context of survivorship. The following narrative illustrates such communication.

Oncologist: You know, life doesn't give us a lot of good times to make those kind of big changes. There's always something going on, there's always some stress and it's hard to do that.

Patient: Yeah.

Oncologist: It's hard to sort of change course or make a big commitment to do something, and sometimes you need something to push you. That's pretty typical, but obviously you used that to your advantage and have made some great changes to get yourself healthy.

Prior treatment and test results

Discussions about prior treatment and recent tests included five domains: (1) results of recent scans and ongoing disease surveillance with imaging; (2) prior treatment received and

its ongoing effects; (3) results of recent blood work; (4) status of vital signs; and (5) patient questions about recent scan and blood work results. Oncologists typically began such discussions by communicating positive impressions, and subsequently framed messages to patients with reassurance if the patient had concern about the results from recent scans or blood work.

Communication about results of recent scans and ongoing imaging needs were most prevalent. Oncologists provided an overall assessment of the scan results, whether they were normal, looked “good,” or whether they showed slightly abnormal results. In some instances, oncologists embedded expressions of congratulations if results suggested that the patient was in remission. Oncologists also spoke of the prognostic meaning of the scan results, and how they can be predictive of long-term outcomes; for example, if scans at the end of treatment showed encouraging results, then the likelihood of cure is high, and the overall importance of ongoing scans for disease monitoring and management. The following exchange illustrates the nature of these discussions.

Oncologist: They talk in here-remember last time we did a scan there was a little bit of lymph node in the chest that we said, what the heck, is that some inflammation? You didn’t have disease here to begin with. So “The mildly hyper-metabolic findings,” that means they were lighting up just a little bit, “are less conspicuous on this study.”

Patient: Okay.

Oncologist: So that the number they put on it-so if something that’s really, quote, “hot” on these scans would be around 20, 10 to 20.

Patient: Okay.

Oncologist: Your number was 3.6, not hot. Now it’s 2.6, so whatever-

Patient: Even less hot-

Oncologist: -whatever inflammation, you know, some type of reaction to an allergy or something that was there is even, even less reacting than it was before.

Patient: Okay.

Oncologist: So, great scan.

Patient: Sweet.

Oncologist: So we got what we wanted from this scan. This is the first step to being cured; being done with this is getting this first scan.

Patient: Okay.

Oncologist: So we’re very happy with that. Frame that, put that up on the fridge at home.

Oncologists discussed future scans that a patient would receive as part of their ongoing disease management, often in the context of overall care planning. They described how frequently scans would need to be performed; such content was occasionally spoken about within the context of explaining recent scan outcomes to the patient, including the likelihood of a remission or possible cure. Oncologists also explained the best, most useful type of ongoing imaging for the patient.

Second, oncologists described the patient's prior treatment and its effects. This included clarification regarding the specific type and scope of treatment the patient had received. Patients provided information regarding how they have managed past or current treatment side effects. Patients also asked whether any current health problems could be related to their treatment and sought guidance regarding whether such problems could be permanent. Oncologists often used such inquiries to guide discussion of the long-term effects of prior treatments, and to recommend follow-up care to manage the risks of such potential effects.

Oncologists also provided overall assessments of the patient's recent blood work results. Positive assessments were typically communicated simply as "it's fine" or "it's good," whereas oncologists discussed the need to repeat blood work if it revealed abnormal findings. Discussions regarding the patient's vital signs, such as blood pressure and weight, also occurred. Communication about the patient's weight included how the patient may be managing any weight fluctuations and the presence of any changes in weight since the patient's prior visit, which occasionally prompted the oncologist to discuss dietary and exercise recommendations.

Finally, patients asked about the meaning of findings from recent scans and blood work. Patients sought clarification about what their results meant clinically, whether their results were "normal" or not, with an underlying intention to obtain reassurance from their oncologists about the state of their present health.

Overall health status

Oncologists frequently initiated the discussion of current health at the beginning of the visit. They usually asked patients about their health with an open question, using phrases like "So, how are you feeling?" Some patients responded by discussing current health issues at length; others responded more casually with something like "Good, how are you?"

Patients initiated these discussions and seemed focused on terms such as "remission," "cure," and "recurrence." Patients also asked which of these they could use to describe their status to others. Oncologists did not offer premature reassurance and sought to control the expectations of patients with sensitivity. Oncologists often referred to 5 years of remission, often meaning normal scans, as a benchmark for being considered "cured," but at the same time, reminded patients that there was never 100% certainty the cancer would not recur. The following exchange illustrates this duality.

Oncologist: The type of lymphoma that you had-I'll use the past tense-is a very curable one, so we feel more comfortable in someone like you using that term earlier on, so I'd say that-

you know, let's, let's see a few more scans to have a bit more confidence, but I think that we could, in a preliminary fashion, say you're very likely to be cured.

Patient: Okay.

Oncologist: You know, of course we'll continue to watch this to double check that and confirm things, but I think that I can pretty confidently say that at least by the end of this upcoming year we could say exceedingly likely to be cured.

Patient: Okay.

Oncologist: You know, these things very rarely can come back later so it's very difficult to say with a 100% confidence. And what in life is 100% confident?

Patient: Nothing.

Oncologist: Nothing is.

Finally, oncologists discussed the likelihood of a recurrence during patients' first 5 years of follow-up. In what appeared to be an effort to alleviate patient anxiety, oncologists noted both the prompt action that would be taken if signs or symptoms of recurrence were present and the availability of additional treatments.

Emotional communication and affective tone

Overall, the discussions between patients and oncologists were generally positive and upbeat. The oncologist seemed to set this general tone and, in some cases, appeared more upbeat than the patient. This tone was set in four distinct types of expressions: congratulations, celebration, encouragement, and reassurance.

Three forms of expression of congratulations were present. The first were messages of congratulations regarding positive gains in health promotion, such as weight loss or quitting smoking. In these cases the oncologist commented on the patient's overall physical appearance, telling the patient that they "look great" and that they should keep up the good work. In some instances, this communication corresponded with a lifestyle change or positive gains in health promotion. The oncologist conveyed that he or she was impressed with the positive changes the patient had made and praised successes to date. This was often accompanied by an acknowledgement that it is challenging to make behavioral changes. The oncologist often seemed more positive about health promotion efforts than the patients, who expressed modesty over their behavior changes and the desire to accomplish more.

Oncologists also made congratulatory statements regarding positive results from recent scans, pointing to these as a sign of real progress. They also congratulated patients on adjustment to life after treatment, praising their recovery after treatment or their ability to resume normal activities or work.

Expressions of celebration marked the length of time the patient had been in remission, treatment anniversaries, or graduations of time since completion of treatment. Oncologists

anticipated marking milestones in care with “big hugs” or patients “throwing a party” with family and friends.

Even when the topics discussed were not completely positive, oncologists maintained a positive tone through expressions of reassurance and encouragement. Expressions of reassurance were typically prompted by discussions about the patient’s prognosis, or when the oncologist discussed recent scan results that were questionable or less positive. Oncologists appeared to reassure the patients regarding the state of their disease, particularly if a patient expressed anxiety about outcomes of recent scans. For example, one patient expressed being nervous when coming for visits due to the uncertainty of scan results. The oncologist attempted to normalize the patient’s feelings about visits and reassured them not to worry. In another example, the oncologist advised the patient to not obsess over conducting breast self-examinations and encouraged the patient not to worry excessively about her breast cancer risk.

Additionally, oncologists offered encouragement about the patient’s long-term prognosis, the potential that the patient could indeed already be “cured,” and affirmation that the patient’s disease had not recurred to date. There was general encouragement to return to normal functioning and to focus on positive health promotion efforts. Overall there were more expressions of encouragement or congratulations than reassurance.

Post-treatment rehabilitation

Discussion of post-treatment rehabilitation addressed a number of topics critical in survivorship: family planning, the return to pre-cancer roles, and the lingering chance of recurrence. Oncologists addressed issues related to family planning with direct responses and reassurance. Further reassurance was provided in supporting the ability of patients to return to their premorbid state, with oncologists often noting that for some patients it may take time to “get back to normal.”

Oncologists were straightforward and effective in addressing frequent questions concerning recurrence and follow-up screening. Recognizing that anxiety and fear are commonly associated with this discussion, oncologists skillfully balanced the recognition that recurrence is always a possibility with provision of reassurance, noting the ability of follow-up screening protocols to monitor and facilitate treatment of such occurrences.

Discussions occurring during the patient’s physical examination

Visits frequently included a physical examination—Overall, four categories of discussion content emerged during the physical examination: (1) the patient’s present health; (2) health promotion; (3) follow-up care; and (4) personal life issues, either of the patient or the oncologist. Communication regarding the patient’s present health predominantly involved the patient sharing details about current physical symptoms, and the oncologist providing explanations as to what such symptoms may signify for the patient’s health. In some cases, these discussions included the patient’s concern that the symptoms (such as enlarged lymph nodes or the presence of nodules) may be a sign of possible cancer recurrence. Other issues included patient inquiries about recent blood work results, patient

recovery status including recovery from treatment, management of other comorbidities, and oncologist assessments of the patient's overall health.

Discussion of health promotion topics, such as the importance of sun protection, a healthy diet, and regular exercise, as well as recognizing the patient's recent efforts to improve their health, also emerged at certain points during the physical examination. For example, one oncologist inquired about the status of the patient's attempts at smoking cessation within the midst of his examination of the patient, which subsequently led to a dialogue about the nature of cancer serving as a teachable moment for positive health behavior change.

Other themes included follow-up care, such as the process of transferring medical records from the patient's primary oncologist to another provider, or communication about how often the patient should return to the clinic for examinations and scans. Finally, small talk regarding either the oncologist's or patient's personal life, such as issues surrounding family, work, or school, also tended to arise during the physical exam.

Social issues—Discussions of social issues were rare during these consultations and most often focused on work or general family situations. Overall, oncologists were responsive and curious about these social issues, and engaged with the patient during such conversation. The discussion often started with a question from the oncologist about the patient's work or family situation. The questions often indicated some prior knowledge on the oncologist's part about the patient's specific situation. Generally, the oncologist did not ask a specific question about the impact of cancer on social issues.

There were varying degrees to which patients' discussion of social issues involved their cancer; some discussions of work and family life did not revolve around or even mention cancer. Patients mentioned new work positions, retirement plans, and living situations. A few patients couched their answers in terms of the impact of cancer on social issues. For example, one patient discussed how the family had been through a lot as a result of his/her cancer and how the birth of a baby in the family had influenced the patient's follow-up care decisions.

Discussion

Conversations between oncologists and patients during follow-up visits addressed a variety of overarching themes, including specific health concerns, follow-up care, health promotion, prior treatment and test results, overall health status, emotional communication and affective tone, post-treatment rehabilitation, discussions occurring in the patient's physical examination, and social issues. However, the frequency with which these themes were discussed varied. In addition, there did not appear to be a universal framework for these visits. The visits varied greatly in terms of length of time and content of the conversations.

Some discussion of follow-up care with the oncologist and cancer team was evident in almost all consultations, but at no stage was there a sense of formal introduction to the concept of becoming a cancer survivor. Oncologists were successful at communicating the plan for the next 5 years in terms of both visits and scans, what might collectively be considered a monitoring plan. Though such a follow-up care plan is important and clearly

desired by patients, ideally patients will also have a plan for health promotion over the course of those 5 years and beyond. Conversations about sun protection, smoking cessation, healthy diet, exercise, and routine care from other health providers were not routinely discussed.

However, health promotion communication is important for cancer survivors, who may benefit from a broad range of prevention behaviors (Ballard-Barbash et al., 2012; Fong et al., 2012). In addition, patients report wanting discussions and resources about survivorship care and prevention (Berg, Stratton, Esiashvili, & Mertens, 2016; Jefford et al., 2008; Jones & Courneya, 2002). Communication may also lead to increased health behavior change. Survivors are more likely to change unhealthy behaviors if they see these as causing cancer or cancer recurrence (Rabin & Pinto, 2006). Research indicates that half of survivors report less than optimal communication around managing uncertainty (Blanch-Hartigan et al., 2016). Discussing prevention after cancer might help manage uncertainty or reduce fear of recurrence. Such teachable moments can lead to increased health promotion behaviors (Bluethmann et al., 2015; McBride, Emmons, & Lipkus, 2003). Survivors prefer these discussions to come from their oncologist and express concern about their primary-care providers' ability to address their unique needs (Mayer, Nasso, & Earp, 2017).

Although both oncologists and primary-care physicians recognize the evidence base on prevention in survivorship and acknowledge the importance of health promotion communication, the delivery and approach to these discussions vary greatly (Coa et al., 2015). Regarding overall health status, survivors were very concerned with labels such as *remission* and *cured*. These terms were often brought up by the survivors, and physicians should initiate discussion of these terms and explain them. A greater evidence base on the most effective approaches for delivery of these messages as well as standardization of training in the delivery of follow-up care may increase effectiveness of health promotion communication during survivorship visits.

Social issues were a theme that was discussed infrequently during these visits. However, many survivors experience major life changes as a result of a cancer diagnosis and treatment, including relationship issues, financial burden, and employment concerns (Yabroff, Lawrence, Clauser, Davis, & Brown, 2004). Many survivors do not receive psychosocial care as a routine part of survivorship care (Forsythe et al., 2013), and many oncologists and primary-care physicians report not providing psychosocial care (Forsythe et al., 2012). Developing a standard list of pertinent topics to guide discussions with cancer survivors could potentially improve the quality of follow-up visits and ensure that all relevant content areas are addressed. The utilization of a distress screening in addition to assessing patients' psychosocial needs has been suggested as the best assessment to determine who needs follow-up psychosocial care (Philip & Merluzzi, 2016).

One important limitation of this study is the variance among consultations in time from completion of treatment. In conjunction with our choice of a qualitative method, this study did not allow us to provide a quantitative description of what is happening in a first consultation after treatment. Instead, our aim was to describe general themes that are discussed in post-treatment visits. A further limitation is that we did not elicit the patients'

perspectives on the communication with their doctor, which we would recommend as a component of future research. Relatedly, we did not collect data about the details of the visit or about the physician participants.

The varied nature of the follow-up visits analyzed in this study suggests the need for increased structure, something survivorship-care plans are designed to provide. The survivorship-care plan ideally will address all the key areas for survivorship and allow the patient to leave with a written document that can be reviewed and shared with family members, friends, or other healthcare providers. This reduces the need for the patient to rely solely on their recall of the conversation with the doctor. The provision of written survivorship-care plans by oncologists may also facilitate increased conversations between cancer survivors and primary-care providers about survivorship issues (Blanch-Hartigan et al., 2014).

However, there is still mixed evidence about the effectiveness of survivorship-care plans (van de Poll-Franse, Nicolaije, & Ezendam, 2017). Future research should continue to assess how survivorship-care plans impact the communication between survivors and oncologists, as well as patient outcomes such as knowledge and health system utilization. Receipt of a survivorship-care plan is associated with increased patient-centered communication reported by cancer survivors (Blanch-Hartigan et al., 2015). Yet, more work is needed to effectively implement survivorship-care plans or improve models of survivorship care in a way that promotes effective communication between survivors and their team of healthcare providers.

Patients make a complex transition at the end of therapy given with curative intent, moving from active therapy to a state of survivorship. Follow-up visits offer a key opportunity for oncologists to address the challenges survivors face regarding future routine health care, emotional issues resulting from treatment, and overall health promotion. While our analysis of the communication during follow-up visits indicates that many oncologists and survivors discuss some of these themes, the breadth and depth of such communication were highly variable, and often failed to address one or more key domains.

Communication variability identified in this study suggests that not all survivors are receiving information about key issues in survivorship. Just as there are standards of care for treatment, survivors may benefit from standards of care for survivorship visits. A more universal framework for communication between oncologists and survivors in these visits is a potential strategy to ensure that survivors receive all pertinent information about both their current health status and their future care. The present study suggests that such a framework should include more emphasis on social issues, health promotion, and emotional concerns. The clinical goal of an enhanced survivorship visit framework or standard of care would be to incorporate these topics into the discussion with patients in a way that promotes survivor health, addresses their psychosocial needs and concerns, but does not increase burden or replace important follow-up planning. Oncologists may, therefore, benefit from increased training and education on how to effectively discuss psychosocial and health promotion topics during survivorship visits.

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References

- Ballard-Barbash R, Friedenreich CM, Courneya KS, Siddiqi SM, McTiernan A, Alfano CM. Physical activity, biomarkers, and disease outcomes in cancer survivors: a systematic review. *Journal of the National Cancer Institute*. 2012; 104(11):815–840. [PubMed: 22570317]
- Berg CJ, Stratton E, Esiashvili N, Mertens A. Young adult cancer survivors' experience with cancer treatment and follow-up care and perceptions of barriers to engaging in recommended care. *Journal of Cancer Education*. 2016; 31(3):430–442. [PubMed: 25948413]
- Bernard, HR. *Research methods in anthropology: Qualitative and quantitative approaches*. Lanham, MD: AltaMira Press; 2011.
- Blanch-Hartigan D, Chawla N, Beckjord EI, Forsythe LP, de Moor JS, Hesse BW, Arora NK. Cancer survivors' receipt of treatment summaries and implications for patient-centered communication and quality of care. *Patient Education and Counseling*. 2015; 98(10):1274–1279. [PubMed: 26146237]
- Blanch-Hartigan D, Chawla N, Moser RP, Finney Rutten LJ, Hesse BW, Arora NK. Trends in cancer survivors' experience of patient-centered communication: results from the Health Information National Trends Survey (HINTS). *Journal of Cancer Survivorship*. 2016; 10(6):1067–1077. [PubMed: 27193357]
- Blanch-Hartigan D, Forsythe LP, Alfano CM, Smith T, Nekhlyudov L, Ganz PA, Rowland JH. Provision and discussion of survivorship care plans among cancer survivors: results of a nationally representative survey of oncologists and primary care physicians. *Journal of Clinical Oncology*. 2014; 32(15):1578–1585. [PubMed: 24752057]
- Bluthmann SM, Basen-Engquist K, Vernon SW, Cox M, Gabriel KP, Stansberry SA, Demark-Wahnefried W. Grasping the 'teachable moment': time since diagnosis, symptom burden and health behaviors in breast, colorectal and prostate cancer survivors. *Psychooncology*. 2015; 24(10):1250–1257.
- Boyatzis, RE. *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage Publications; 1998.
- Coa KI, Smith KC, Klassen AC, Caulfield LE, Helzlsouer K, Peairs K, Shockney L. Capitalizing on the "teachable moment" to promote healthy dietary changes among cancer survivors: the perspectives of health care providers. *Support Care Cancer*. 2015; 23(3):679–686. [PubMed: 25160494]
- Committee on Cancer Survivorship: Improving Care and Quality of Life. From cancer patient to cancer survivor: Lost in transition. 2005. Retrieved from Washington, DC
- Creswell, JW. *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage Publications; 2013.
- de Moor JS, Mariotto AB, Parry C, Alfano CM, Padgett L, Kent EE, Rowland JH. Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. *Cancer Epidemiology, Biomarkers & Prevention*. 2013; 22(4):561–570.
- Erikson C, Salsberg E, Forte G, Bruinooge S, Goldstein M. Future supply and demand for oncologists : challenges to assuring access to oncology services. *Journal of Oncology Practice*. 2007; 3(2):79–86. [PubMed: 20859376]
- Fong DY, Ho JW, Hui BP, Lee AM, Macfarlane DJ, Leung SS, Cheng KK. Physical activity for cancer survivors: meta-analysis of randomised controlled trials. *BMJ*. 2012; 344:e70. [PubMed: 22294757]
- Forsythe LP, Alfano CM, Leach CR, Ganz PA, Stefanek ME, Rowland JH. Who provides psychosocial follow-up care for post-treatment cancer survivors? A survey of medical oncologists and primary care physicians. *Journal of Clinical Oncology*. 2012; 30(23):2897–2905. [PubMed: 22778322]

- Forsythe LP, Kent EE, Weaver KE, Buchanan N, Hawkins NA, Rodriguez JL, Rowland JH. Receipt of psychosocial care among cancer survivors in the United States. *Journal of Clinical Oncology*. 2013; 31(16):1961–1969. [PubMed: 23610114]
- Friese, S. *Qualitative data analysis with ATLAS.ti*. London: Sage Publications; 2014.
- Jefford M, Karahalios E, Pollard A, Baravelli C, Carey M, Franklin J, Schofield P. Survivorship issues following treatment completion—results from focus groups with Australian cancer survivors and health professionals. *Journal of Cancer Survivorship*. 2008; 2(1):20–32. [PubMed: 18648984]
- Jones LW, Courneya KS. Exercise counseling and programming preferences of cancer survivors. *Cancer Practice*. 2002; 10(4):208–215. [PubMed: 12100105]
- Mayer DK, Nasso SF, Earp JA. Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. *The Lancet Oncology*. 2017; 18(1):e11–e18. [PubMed: 28049573]
- McBride CM, Emmons KM, Lipkus IM. Understanding the potential of teachable moments: the case of smoking cessation. *Health Education Research*. 2003; 18(2):156–170. [PubMed: 12729175]
- Morse JM, Barrett M, Mayan M, Olsen K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*. 2002; 1:1–19.
- Parker PA, Banerjee SC, Matasar MJ, Bylund CL, Franco K, Li Y, Kissane DW. Protocol for a cluster randomised trial of a communication skills intervention for physicians to facilitate survivorship transition in patients with lymphoma. *BMJ Open*. 2016; 6(6):e011581.
- Philip EJ, Merluzzi TV. Psychosocial issues in post-treatment cancer survivors: Desire for support and challenges in identifying individuals in need. *Journal of Psychosocial Oncology*. 2016; 34(3):223–239. [PubMed: 26939620]
- Potosky AL, Han PK, Rowland J, Klabunde CN, Smith T, Aziz N, Stefanek M. Differences between primary care physicians' and oncologists' knowledge, attitudes and practices regarding the care of cancer survivors. *The Journal of General Internal Medicine*. 2011; 26(12):1403–1410. [PubMed: 21785923]
- Rabin C, Pinto B. Cancer-related beliefs and health behavior change among breast cancer survivors and their first-degree relatives. *Psychooncology*. 2006; 15(8):701–712. [PubMed: 16302292]
- van de Poll-Franse LV, Nicolaije KA, Ezendam NP. The impact of cancer survivorship care plans on patient and health care provider outcomes: a current perspective. *Acta Oncologica*. 2017; 56:1–5. [PubMed: 27846757]
- Yabroff KR, Guy GP Jr, Ekwueme DU, McNeel T, Rozjabek HM, Dowling E, Virgo KS. Annual patient time costs associated with medical care among cancer survivors in the United States. *Medical Care*. 2014; 52(7):594–601. [PubMed: 24926706]
- Yabroff KR, Lawrence WF, Clauser S, Davis WW, Brown ML. Burden of illness in cancer survivors: findings from a population-based national sample. *Journal of the National Cancer Institute*. 2004; 96(17):1322–1330. [PubMed: 15339970]
- Yang W, Williams JH, Hogan PF, Bruinooge SS, Rodriguez GI, Kosty MP, Goldstein M. Projected supply of and demand for oncologists and radiation oncologists through 2025: an aging, better-insured population will result in shortage. *Journal of Oncology Practice*. 2014; 10(1):39–45. [PubMed: 24443733]

Table 1

Sample demographics of oncologists.

Characteristic	Total (N = 21) N (%)
Gender	
Male	13 (62.0)
Female	8 (38.0)
Age (mean, <i>SD</i> , min–max)	51, 10.3, 35–68
Race	
White	18 (86.0)
Asian/Indian	2 (10.0)
Black	1 (4.0)
Ethnicity	
Non-Hispanic	18 (86.0)
Hispanic	3 (14.0)
Number of years in practice ^a (mean, <i>SD</i> , min–max)	17.8, 10.7, 1–36

^a *n* = 20. One oncologist did not provide years in practice.

Table 2

Sample demographics of patients.

Characteristic	Total (N = 21) N (%)
Gender	
Male	11 (52.0)
Female	10 (48.0)
Age (mean, <i>SD</i> , min–max)	54.2, 10.7, 21–87
Race	
White	16 (76.0)
Asian/Indian	3 (14.0)
Black	2 (10.0)
Ethnicity	
Non-Hispanic	20 (95.0)
Hispanic	1 (5.0)

Table 3Key follow-up visit discussion themes.^a

Discussion content themes	
Specific health concerns	<ul style="list-style-type: none"> • Specific health concerns were both cancer-related and non-cancer-related, were discussed separately from topics regarding cancer follow-up, and discussions of non-cancer-related issues were more prevalent than cancer-related issues. • Included three content areas based on their relationship to the patient's cancer history: cancer-related current health issues, non-cancer-related current health issues, and patient uncertainty regarding cancer-relatedness of current health issues. • Patients asked oncologists whether their presenting physical symptoms were related to their prior cancer treatment. • Few discussions occurred regarding the patient's current functional status. • Discussions at times overlapped with current health promotion efforts. • Oncologists often asked about comorbid conditions and their management. • Discussions involving patient uncertainty regarding cancer-relatedness of current health status focused on patients seeking normalization of current health problems.
Follow-up care	<ul style="list-style-type: none"> • Oncologists brought up the need for future imaging and visit schedules and often discussed the gradual lessening of follow-up care in a very congratulatory and celebratory manner. • Oncologists mentioned the 5-year mark post-treatment as the time when a patient would be considered "cured" and transition to their primary-care provider, yet mentioned that they could never be 100% confident the cancer would not recur. • Oncologists often discussed the need for routine follow-up care with other providers.
Health promotion	<ul style="list-style-type: none"> • Discussions regarding health promotion frequently arose, but were random and passive by nature, rather than a systematic and organized element of the patient visit. • Oncologists were very encouraging and enthusiastic when patients described success in dietary change, weight loss, or physical activity engagement. • Oncologists provided few specific health promotion recommendations, and instead imparted more general platitudes regarding diet and physical activity. • Oncologists may have missed opportunities to communicate regarding health promotion more comprehensively.
Prior treatment and test results	<ul style="list-style-type: none"> • Discussions included recent scan results and ongoing disease management with imaging, prior treatment received and its ongoing effects, results of recent blood work, status of vitals, and patient questions about recent scan and blood work results. • Communication about scan results and ongoing imaging needs were most prevalent. • Oncologists began discussions by communicating positive impressions, and then framed messages with reassurance if recent scans or blood work were atypical or abnormal. • Oncologists embedded expressions of congratulations if results suggested that the patient was in remission and also spoke of the prognostic meaning of scan results. • Discussions included clarification regarding type and scope of treatment and management of treatment side effects. • Patients inquired about the meaning of findings and sought clarification about what their results meant clinically.
Overall health status	<ul style="list-style-type: none"> • Oncologists frequently discussed current health at the very start of the follow-up visit, and usually asked about health very generally using phrases like "How are you feeling?" • Discussions involved patients trying to understand their current disease status, their general health outlook, and cancer status moving forward. • Oncologists did not offer premature reassurance regarding possibility of cure and sought to control the expectations of patients with sensitivity.

Discussion content themes

Emotional communication and affective tone

- Discussions were generally positive and upbeat in tone.
- Oncologists set affective tone through expressions of congratulations, expressions of celebration, expressions of encouragement, and expressions of reassurance.

Post-treatment rehabilitation

- Discussions addressed family planning, the return to precancer roles, and the lingering chance of recurrence.

Discussions occurring in the patient's physical examination

- Discussions that emerged within the context of the patient's physical examination included the patient's present health; health promotion; follow-up care; and personal life issues, either of the patient or the oncologist.
- Present health discussions involved the patient sharing details about current physical symptoms, and the oncologist providing explanations as to what such symptoms may signify for the patient's health.
- Discussion of health promotion topics included the importance of sun protection, a healthy diet, regular exercise, and recognition of the patient's recent efforts to improve their health.
- Follow-up care discussions included the process of medical records transfer or frequency needed for follow-up visits.

Social issues

- Discussions were minimal and related to either work issues or general family situations.
 - Often started with a question from the oncologist about the patient's work or family situation.
 - There were varying degrees to which patients' discussion of social issues involved their cancer; some discussions did not revolve around or even mention cancer.
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^a Although the content areas are ordered according to the frequency of endorsement in the transcripts, the specific bulleted conclusions are not ordered by frequency.