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Abstract
Purpose of study Knowledge about information sharing among primary care clinicians, oncologists, and their cancer patients is critical given its importance in facilitating the delivery of quality care to the increasing number of cancer survivors. The purpose of our study was to provide a better understanding of the nature of interactions among primary care clinicians, patients, and oncologists throughout the cancer care continuum to better understand the transition to survivorship.
Method Twenty-one qualitative in-depth interviews were conducted with 11 primary care physicians and 10 nurse practitioners. Themes were identified using content analysis.
Results The following themes emerged from the data including: (1) a visit is worth a thousand written reports—primary care clinicians described the importance of patient visits during cancer treatment; (2) community vs. cancer center oncologists—primary care clinicians described differences in information sharing with community oncologists as compared with those in academic centers; (3) correcting for information deficits—primary care clinicians, unable to obtain regular progress reports directly from oncologists, developed indirect strategies to obtain information; (4) the deficiencies in post-treatment follow-up care plans; and (5) the panacea of electronic medical records and survivor care plans.
Conclusions The themes that emerged from this work describe in detail the absence of systematic information sharing among primary care clinicians, patients, and oncologists that is needed to support quality survivorship care in the primary care setting. The descriptions by primary care clinicians contribute to a deeper understanding of the daily challenges that both interfere and/or support primary care clinicians in their care of survivors of cancer.
Implications for cancer survivors Managing the complex care of cancer survivors often requires the expertise of a number of skilled providers. Information sharing among these individuals is one of the most fundamental aspects of ensuring effective transitions in care. Our results indicate that systematic information sharing among providers caring for cancer survivors is lacking. Identifying strategies to enhance information sharing among and between providers is essential to facilitating the delivery of high-quality survivor care.

Keywords Information sharing • Primary care clinicians • Oncologists • Care coordination • Cancer care • Survivor care

Introduction
Survivors of cancer often require the expertise of multiple clinicians to manage the complex care needs that result from their illness which include: (1) surveillance for disease recurrence, (2) management of late long term treatment sequelae, and (3) promotion of healthy lifestyle behaviors, particularly those that are associated with decreasing cancer risk [1]. The number of people surviving cancer continues to grow, creating an urgency to develop strategies for clinicians from different disciplines to work together more effectively to enhance survivorship care [2]. A variety of models of survivor care have been developed including those where oncologists and primary care providers “share” care management of patients across the trajectory of cancer [3, 4]. Information sharing among providers is an area that remains challenging [3–5]; however, the importance of developing effective avenues for clinicians providing survivorship care to share information about their patients cannot be overstated.
There is substantial evidence in the nursing and organizational literatures that poor information sharing among healthcare providers has interfered with care quality and is responsible for serious and even lethal medical errors in hospital settings [6–11]. Furthermore, healthcare administrators and policy makers have made a point of identifying information sharing as an area for improvement to enhance patient safety [12, 13]. The survivorship literature also discusses the importance of information sharing among PCPs and oncologists, the primary clinicians who provide survivorship care [5, 14]; however, there are very few studies available that focus on this process. Most of the literature on survivorship care tends to address (1) which discipline is best equipped to care for survivors [15–18], (2) the comfort level primary care physicians in rendering survivorship care [19, 20], and (3) patient satisfaction with oncologists as compared to primary care physicians [20–22]. Developing knowledge and an understanding about information sharing practices among primary care clinicians (physicians and primary care nurse practitioners) and oncologists is critical to the design of effective interventions to improve the quality of survivor care.

We conducted in-depth interviews with primary care clinicians about information sharing with their cancer patients and their patients' oncologists where they described their interactions from the time of cancer diagnosis to the patient's transition into post treatment follow-up.

Our interview study included the experiences of nurse practitioners and primary care practice lead physicians, thus we refer to the participants as primary care clinicians (PCCs). We included nurse practitioners because increasingly, they provide primary care in the USA [23, 24] and yet, most previous studies focused on survivorship care have not included these providers in their samples [16, 21, 25].

Method

Sample

Participants included 21 PCCs, comprising a lead physician and a nurse practitioner from nine primary care practices (18 individuals) serving middle- to upper middle-income patients with health insurance, one lead physician from a large university-based practice, and one lead physician and one nurse practitioner from an inner city charity care clinic, all from New Jersey or Pennsylvania. Practices were selected based on the employment of a nurse practitioner and the agreement of both the nurse practitioner and lead physician to be interviewed. Saturation was reached for all themes and a charity care setting was selected later in the study along with the lead physician of a large practice within a university to provide the potential for contrasting findings when compared to the findings from the first nine practices [26]. However, the findings for these three individuals caring for patients from different socioeconomic groups did not differ from the other PCCs. All of the nurse practitioners provided care primarily to their own panel of patients and patients were referred to all the PCCs based on availability of encounter slots, area of expertise, and/or patient preferences. The PCCs had been in their positions for at least 2 years or more.

The participants were initially phoned by the coordinator of a practice-based research network and asked to participate in the study. The 11 practices in the network that employed at least one nurse practitioner were contacted followed by the clinicians from the charity clinic and the university practice. Two of the four clinicians from one of two practices declined to be in the study because they were moving within the timeframe suggested for their interviews and the nurse practitioner from another practice had only recently been hired which limited his experience in their practice setting.

Interviews

All participants were asked to read and sign the informed consent. The interview questions and the probes followed a qualitative interview format [27] and emerged from our interest in three areas including (1) information sharing among PCCs, patients, and oncologists at the time of diagnoses and during treatment; (2) information sharing among PCCs, patients, and oncologists during post-treatment follow-up; and (3) suggestions for how to improve information sharing. The interview began with the grand tour question, “Tell me about caring for a patient who is diagnosed with cancer?” The question was left open to encourage exploration of the process of caring for patients with cancer. Interviews were conducted by BDB and RC from March 2009 until March 2010. All interviews took place at the primary care site where the participant worked in a private room during a predetermined time. Interviews lasted from 1.5 to 2 h.

Data analysis

Interviews were recorded, transcribed verbatim, and entered into an ATLAS ti qualitative software program. The investigators then conducted a content analysis contrasting and comparing the different segments of the interview text. Content analysis refers to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meaning [28]. The investigators developed codes to identify recurrent content which they then grouped into themes. Data analysis began when the third interview was concluded, two
with physicians and one with a nurse practitioner. The authors BDB and RC reviewed the data, developed preliminary codes, and used memos to track analysis decisions. This process was repeated for the next six interviews. BDB analyzed the next eight interviews, reviewed the analysis with RC, reached consensus on codes and themes, and then analyzed the final four interviews. Lastly, the investigators individually re-reviewed all 21 interviews to confirm their agreement with the analysis [26, 28].

Results

The themes reported below reflect the sentiments of the PCCs whether they were nurse practitioners or physicians, or whether the patients they served were from a higher or lower socioeconomic group. One of the surprises that emerged from this analysis was that the nurse practitioners and the PCPs had very similar responses when describing their experiences with patients and oncologists. The limitations section addresses this finding more completely. Therefore, the data analysis does not distinguish between these groups. Double quotation marks within the paragraph represent exact quotes taken from the recordings, as do the indented paragraphs for larger quotations. Single quotation marks represent the statements made by the clinicians when quoting their patients.

The themes that emerged are as follows: (1) a visit is worth a thousand written reports, (2) community vs. cancer center oncologists, (3) correcting for information deficits, (4) the deficiencies in post-treatment follow-up care plans, and (5) the panacea of electronic medical records and survivor care plans.

Themes

A visit is worth a thousand written reports. Our findings suggested that, consistent with the literature, PCCs expressed frustration with the lack of interaction with patients undergoing cancer treatment. The importance of these patient visits is highlighted by one of the few physicians who experienced them:

A visit from the patient as compared to e-mails or oncologist reports is very important at this time. Of course the other stuff [oncologist reports and lab test results] is important, but the visits are too. A visit is worth a thousand of those...even just one...things come up such as relationship issues with other family members, for example, fear of death, sexual health, what to [tell] others...I can also get a sense of how they are doing when I see them. When we are face to face it [makes] a difference for when they come back.

PCCs described how their care differed philosophically from that of the oncologist and, the importance of "balancing" the oncologists approach. A common refrain was that PCCs were "oriented toward the whole person," rather than focusing "just on their cancer." They described themselves as providing "psychological and social support" which was important to continuity when the patient returned for regular primary care visits. PCCs distinguished themselves from oncologists such as when they described oncologists as "liberal with antibiotics" while they were more conservative because of their concern with long term ill effects of antibiotic overuse. Additionally, PCCs thought that the oncologists excluded them because they might be less aggressive in prescribing cancer treatments especially when patients had a "poor prognosis." A nurse practitioner shared her thoughts about being excluded from decisions about patients by stating, "Probably [the oncologist] doesn't want my opinion...[because] it might be different [from theirs]."

PCCs cited their efforts to maintain good relationships with patients as the reason that some of their patients visited them during cancer treatment, but perhaps unfairly, they also blamed oncologists when patients did not visit them. They attributed this to the oncologist "swallowing up" the patient by providing primary care as well as oncology care based on the oncologists "comfort level" and "willingness" to give care within the domain of primary care. PCCs complained that some patients visited them only because the oncologist "refused" to perform a procedure such as a pap smear which left them feeling "used" and "shut out."

A contradictory theme expressed by almost all PCCs was their empathy for their patients who they knew might be too "busy" to make an appointment, and yet, in contrast to most of the interviewees, a few PCCs were included in decision making about cancer treatment because their patients chose to include them, as expressed by this nurse practitioner,

I would say a lot of them do come back [for primary care while receiving cancer treatment]...with questions like 'where do I go? You know they told me I should see this person. Is this the person you would recommend?' A woman who was treated for breast cancer was on Arimidex® and was questioning 'is this really what I should be on or not?' Sometimes I'll do a follow-up blood test monitoring...and touch base with the oncologist. [I'll ask] What's the statistical benefit? Are these side effects or not? Is it worth taking or not? So I will play a role in guiding [the patient] and it might be that I may not know the exact statistical benefit and I'll just call the oncologist and ask them...

Community vs. cancer center oncologists. All PCCs reported that some oncologists and surgeons provided "very poor" or "inconsistent" feedback while others were "good" or "very
good.” Our analysis determined that oncologists and surgeons working in the community usually provided “high quality” feedback, while those working in large academic centers generally did not. One physician captured the expressions of other interviewees when she described the local oncologist as “great about getting back” to her. She added that when information was not forthcoming or she had a question about a patient, she would just call and either talk to the oncologist directly or would leave a message. This request was usually answered within the day. Another PCC described leaving a message for the local oncologist who was out of the office. The covering oncologist, “made it their business” to talk with him that day. And yet, when PCCs referred patients to the large academic cancer centers, they described feedback from oncologists as “poor” or “non-existent.” This pattern was described for ongoing treatment reports as well as final summaries. One physician provided a description of the comprehensive work that she had done to prepare a patient for their referral to a center:

A [patient] had enlarged lymph nodes. We worked for two hours in the office, first it’s the diagnosis, and the suspicion is lymphoma and all that, very complex, family’s here...it’s just very emotionally difficult,...but you want to help him, and they’re so... distraught, they can’t even think straight. We try to get their appointments set up and everything like that. So I send [the patient] to the [Cancer Center] and he needs to have a biopsy...And I never hear anything again. We’re [referring] our patients, we’re presenting them, and there’s very little feedback. We set the patient up, gave [the oncologists] all the medical information, gave all the insurance information, [they] don’t even have to look it up...And, the least [they] could do is just call us and say, ‘Hey, this is what I did for the patient, this is what we’re doing,’ it would be nice.

Interestingly, when PCCs were asked if they shared information with oncologists when they made changes to a patient’s care plan, they responded as did this physician who had recently treated a patient with severe hypertension.

I should have sent an e-mail to let [the oncologist] know about the medication changes. I’m figuring that they just really want to work on the treatment of cancer. In fact, I saw a patient last week and prescribed quite a few medication changes and I realize that I never informed the oncologist. I didn’t even think of it. So, you know, it’s a quid pro quo. I mean I can’t resent not getting letters from them, unless they’re expecting letters from me too. So I think a little bit more communication on both ends would probably be useful.

Correcting for information deficits. PCCs used at least three different approaches to obtain clinical information when it was not provided by oncologists. The most direct strategy was to “help” the often “confused” patient to schedule tests ordered by oncologists. Then, the PCC had the results sent to them as well as to the oncologist.

Periodically...an oncologist [will] hand-write...a prescription, “patient needs bone scan,” and then give it to the patient who’s immediately confused as to what they’re supposed to do. They’ll bring it into the office and I have to arrange for them to have the testing done with the right forms and the right referrals... I help them along with that process...what I get out of that is next to nothing, except at least I’ll get results too.

The next less direct approach was described by a nurse practitioner who told her patients to be sure that whatever tests they had, that they make sure that her name was on the order, so that the results would also be sent to her. The final and least direct strategy was when PCCs simply counseled patients to keep their own records of lab test results by informing them that “communication” between oncology and primary care was “very unreliable.” PCCs would then rely on the patient’s own records to obtain clinical information to guide their care.

The other information deficiency described by PCCs was obtaining information about a patient when they have not heard from them for a very long period of time. One physician described how he would call the patient directly “to get any clinical information I can” to keep track of his patients’ progress. And yet, the act of directly calling patients about their clinical progress also created a concern for several PCCs, as stated by a physician:

It’s hard, because it seems like you’ve been dismissed. And you don’t know if you’ve been dismissed by the patient or you’ve been dismissed by the oncologist, or both. You’ve formed a relationship with this person, sometimes long term...and yet, on the other hand, you don’t want to pressure somebody...[They may have] decided to choose another PCC. So am I supposed to call somebody that I haven’t heard from in six months and say, “hi, are you still seeing me or not?” So what if Mrs. Smith got scared and just stopped going to see the oncologist too and they haven’t been to see me either. How do I know that they’re actually receiving any sort of follow-up care for whatever it is they came in for? The least I could do is kind of nudging them into going back if I know that they’re supposed to be [seeing the oncologist] and they haven’t been.

The deficiencies in post-treatment follow-up care. Again, PCCs reported that oncologists in the community provided
"good summary reports" once cancer treatment was completed, while those in large cancer centers often did not provide any summary information. One physician described the challenge of preparing patients for long term side-effects of acute cancer medications when she had no information about the treatments, "if I knew what they were, I could look them up." Another physician described a patient whom she had started seeing again after cancer treatment. She asked her about any recent lab work or films that had been done by the oncologist and "she didn't know...she just didn't know." A nurse practitioner stated that since oncologists were going to keep seeing patients for years, the lack of consultation probably "didn't matter."

In contrast, most PCCs including those who felt that they received adequate information about a patient's treatment indicated that they needed more guidance about follow-up screening and side-effects of cancer treatments. This sentiment is captured by a physician caring for a patient with melanoma who recently returned for primary care. She had received updated information about the patient's treatment and prognosis, "but I needed some more information." She was interested in understanding the specific recommendations for post-acute care; she wanted to ensure that she was addressing those aspects of primary care that were critical for this particular patient.

Several PCCs spoke insightfully about respecting and preserving the relationship that the oncologist had developed with patients during the crises of cancer, after the patient had returned for their regular primary care visits; one nurse practitioner described it as follows:

"Most of the time the oncologist seems to want to see somebody on at least on a yearly basis, no matter...how far out their cancer has been...and people have formed a relationship with somebody once they've gone through an intense experience together. Yet, PCCs also expressed skepticism about the post treatment follow-up care provided by oncologists that extended years after their treatment to well patients with no cancer recurrence.

I don't know because I'm not really sure what actually goes on in the oncologist's office for those people in normal follow-up type of stuff. And you get their notes and they do seem to do like a regular physical exam. I'm not sure it's any different than what I do.

They also suggested that with adequate information sharing and consultation with oncologists, they would be poised to provide the best overall care for the patient because even as it related to cancer since PCCs "are screening for all cancers," not only a recurrence of the original cancer. Furthermore, several clinicians expressed the financial implications of otherwise well patients visiting oncologists for years with no cancer recurrence when a primary care visit would be far less expensive.

The panacea of electronic medical records and survivor care plans When asked about what would make post treatment follow-up better, the one recommendation agreed upon by all PCCs was the broad integration of electronic medical records (EMRs) even more than survivor care plans (SCPs). They all described the value of going online and seeing the tests, medications, and plan of care prescribed by cancer specialists for their patients. Those who used EMRs and were connected to a community in which patients cancer treatment records were already being shared spoke very well of the system. However, the PCCs that had good relationships with oncologists in their communities also stated that the EMR could not replace all verbal information sharing. Sometimes they just, "need to pick up a phone and talk to the oncologist or surgeon" about a particular case. Those PCCs who had readily engaged in conversations and consultations with oncologists and surgeons described the greatest satisfaction with the quality of care they were able to provide for their patients throughout their cancer treatment and during their post treatment follow-up care.

Discussion

Information sharing is one of the most fundamental aspects of ensuring effective care transitions and the delivery of high-quality care. As stated, the extant literature on information sharing and consultation between PCCs and oncologists focuses almost exclusively on the transition process of patients from cancer treatment to post-treatment follow-up, often described as the shift to the survivorship phase of care [4, 16, 20, 29, 30]. While this transition phase is a critical point of focus, our data suggests that a more consistent and thorough communication process may be even more beneficial. PCCs are clearly interested in sharing information and patient contact from the time that a patient is diagnosed with cancer until they return for regular PCC visits. Patient visits or telephone communications during cancer treatment provided PCCs with the opportunity to render much needed support to their patients, obtain important clinical information, assist patients in navigating the complex and often fragmented treatment process, and in maintaining a relationship that facilitated the delivery of high-quality post-treatment follow-up care. Information sharing is not only the responsibility of oncologists. PCCs were found to be negligent in sharing information with oncologists and they also need to take an active role in ensuring that clinical information is transmitted in a timely manner. Our findings indicated that some patients insisted on integrating their PCCs into their cancer treatment
program; as such, oncologists could consider recommending that patients visit their PCCs during this period to ensure continuity of care for when the patient resumes regular PCC visits during the post-acute period. An ongoing and comprehensive communication process can ensure the value of long-term care for cancer survivors.

Another finding from our study was that community oncologists were better at sharing information with their primary care colleagues, than were academic oncologists; to our knowledge, this has not been addressed in the literature. Community PCCs are often the gatekeepers for referrals to specialists within a certain geographic area. Clinicians may get to know one and support one another through a referral process. In contrast, a cancer center is in itself, a large specialized setting that often serves as a magnet for patients with cancer from broad geographic areas; therefore, referrals to cancer centers are not dependent on a discrete number of primary care clinicians from a specific locale. It is possible that one outcome of creating cancer centers, where all the providers are cancer specialists and the definition of the community is not geographically limited, is the lack of incentive to integrate community PCCs into the care of cancer patients by communicating with them during cancer treatment and during the survivorship phase of care. Thus, although the volume of cancer patients at cancer centers may result in improved outcomes for patients [31], there may be less incentive for oncologists to share information about the patient’s progress with their patient’s PCCs in the community.

The identification of strategies by PCCs to obtain information when it was not available included relying on their patients for clinical data that contributed to clinical decision making. Although there is literature that supports the notion of having patients maintain their own healthcare records [32, 33], the idea is fraught with potential problems. This may be especially true for cancer survivors because they are often receiving care at a time when they rightly perceive that their lives are at risk. The anxiety associated with this reality may likely interfere with the capacity of patients to understand and keep track of all their own clinical information, to say nothing of the complexity of the care that many cancer patients receive. Furthermore, the efficacy of this arrangement has not been evaluated.

Although the PCCs in this study were very positive about the role of EMRs in improving their access to information about their patients, EMRs and SCPs are associated with numerous challenges [34–38]. The notion that an EMR is the silver bullet that can correct poor information sharing between primary care offices and specialists in different networks and settings is unlikely. Unless PCCs and oncologists practice within the same network or system (and sometimes even when they do), they may not be able to readily access the information that would be most beneficial to them. PCCs interviewed in this investigation indicated that EMRs were of limited value in this particular context. The value of SCPs have also been suggested as a strategy to communicate specific surveillance and care recommendations for patients transitioning back to primary care after the completion of acute cancer treatment [36–39]. In a 2006 report on survivorship care transitions, the Institute of Medicine recommended that all cancer patients receive an individualized plan outlining guidelines for monitoring and maintaining their health [40]. Since this time, many organizations and groups have developed templates for this information transfer, but adoption rates of this strategy have been relatively low. A recent investigation indicated that PCCs support the IOMs SCP platform; they often report needing more information [41]. Moreover, current evidence on the effect that SCPs have on patient outcomes is limited. In addition, completion of SCPs requires a substantial time commitment and presently, this care is not reimbursable.

Limitation of this study

The data collected for this investigation were limited to interviews and did not include observations of interactions nor did they include the perceptions of oncologists. The sample included nurse practitioners who had their own panel of patients which gave them status as autonomous providers within their practice. Thus, the similarities of experiences of the nurses and physicians observed in these practices might not occur in other practices. The participating practices were located in two Mid-Atlantic States, so the regions in which the practices were situated could limit transferability of the findings to other regions of the country.

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