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Impact of Primary Care Provider Knowledge, Attitudes, and Beliefs about Cancer Clinical Trials: Implications for Referral, Education and Advocacy

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Abstract

Primary Care Providers (PCPs) can be instrumental in helping to prepare patients for referral to cancer treatment. It has been suggested that PCPs can have an important impact on priming patients about the possibility of receiving care within a cancer treatment clinical trial (CCT). However, little is understood about how to effectively engage primary care providers in educating patients about trials.

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Conflict of Interest

Among the seven authors of the article, six have no conflicts of interest. Author Natasha Blakeney served as an independent contractor for ENACCT and is owner of a for-profit health and wellness service.

Ethical Standards

The human studies presented in this paper have been approved by the appropriate ethics committees and were performed in accordance with the ethical standards as outlined by the 1964 Declaration of Helsinki and its later amendments.

Data were collected as part of two qualitative research projects about primary care providers' role in referral to treatment and to CCTs. Participants were 27 PCPs who agreed to take part in qualitative face-to-face or telephone interviews and serve predominantly underserved, minority populations.

Interviews identified a number of factors influencing referral to oncologists, including patients' insurance coverage, location and proximity to treatment facilities, and the strength of ongoing relationships with and/or previous experience with a specialist. PCPs overwhelmingly expressed disinterest in discussing any treatment options, including CCTs. Misconceptions about quality of care received through trials were also common, presenting a deterrent to discussion.

PCPs need targeted, evidence-based educational interventions to appropriately address their concerns about cancer clinical trials, enhance provider communication skills, and alter patient referral behavior. Steps must also be taken to strengthen communication between oncologists and referring PCPs.

Keywords

primary care; cancer; clinical trials

Introduction

Patient access to cancer treatment clinical trials (CCTs) is a key measure for delivery of quality cancer care [1]. A recent Institute of Medicine (IOM) committee stated that the "therapies offered through CCTs should ideally be considered the preferred treatment choice for physicians and patients, if they are available" and recommended that all oncologists should "strive to make participation in clinical trials a key component of clinical practice and to achieve… high accrual rates of 10 percent or more"[2]. The Commission on Cancer [1] has increased its minimum percentage of cancer patients participating in CCTs for institutions seeking its accreditation. Despite these guidelines and recommendations, current US adult trial participation remains under 5 percent [2]. Participation is even lower among patients who are from racial or ethnic minority groups, are 65 or older, and/or who live in rural areas [3, 4, 5, 6]. The vast majority of cancer patients are not informed about the option of receiving cancer treatment through a CCT [7, 8, 9]. Even at major cancer centers, oncologists may not approach all eligible patients about participation[10], and patients from minority groups or who are 65 or older may be less likely to be approached, regardless of eligibility [11, 4, 12, 13].

In light of these low accrual rates, Primary Care Providers (PCPs) – who are often a well-known and trusted source of information -- can play an important role in providing information about and encouraging participation in appropriate trials [14, 15]. In a 2000 report, The Institute of Medicine recommended enhanced coordination between specialists and primary care providers to ensure cancer patients' health needs are met though a seamless delivery of care [16].

Despite these recommendations, studies show that PCPs are unaware that clinical trial participation may be an option for their patients and do not mention clinical trials when

preparing patients for the oncology referral [17]. Effective educational outreach to PCPs has been recommended by a number of experts [14, 18]; yet, only a few educational interventions have been shown to have a positive effect on PCPs' attitudes and behaviors. For example, a study conducted by the Education Network to Advance Cancer Clinical Trials (ENACCT) found that PCPs who attended an education program about clinical trials had a statistically significant increase in knowledge about the training content and an increase in positive attitudes about the role of a PCP for CCT referrals [19]. Similarly, a survey conducted by investigators at Michigan State University found that PCP attitudes and attendance at education sessions about CCTs consistently predicted referrals to treatment trials [20].

Although it has been suggested that PCPs and other referring providers can help to educate patients about clinical trials, few studies have examined the issues that need to be addressed in order to do this in an effective manner. With the ultimate goal of designing an educational intervention to address this issue, we studied the knowledge, attitudes and beliefs of PCPs towards CCTs, and their perception about the relevance of CCTs to their patients and to referrals to specialists. The aim of this paper is to shed light on these issues, which is critical to: a) defining the important role PCPs and other referring providers can play in providing information about and encouraging participation in clinical research, and b) improving future educational initiatives around oncology referrals for these medical professionals.

Methods

Data for this study were collected as part of two sequential qualitative research projects about CCTs (henceforth study 1 and study 2), undertaken collaboratively by ENACCT and partners from the Cancer Support Community (CSC), Albert Einstein College of Medicine, City College of New York, and Memorial Sloan-Kettering Cancer Center. Both studies, funded by two separate federal grants, sought to explore the extent to which PCPs educate their patients about the option of receiving cancer treatment through a clinical trial. Topic areas in the interviews included: actions taken during diagnosis and referral; factors influencing referral to an oncologist; communication with specialists; knowledge, attitudes and beliefs about CCTs; communication with patients about treatment (particularly through a CCT); and involvement with patients during cancer treatment. The purpose of these research projects was to inform a larger quantitative study on the issues and to guide the development of an educational intervention for PCPs.

Participants and Recruitment

Participants were 27 PCPs who agreed to take part in face-to-face or telephone interviews. In study 1, participants were recruited in the New York City area, with a focus on PCPs who serve predominantly underserved, minority populations, including recent immigrants. Recruitment targeted physicians who: a) worked in settings that are part of the NYC Research and Improvement Networking Group, a large practice-based research network in the Bronx and Upper Manhattan organized through the Albert Einstein College of Medicine; b) were employed by the Institute for Family Health, a community health network with

multiple locations; and c) work at 14 Queens-Long Island Medical Group Offices. A total of 18 physicians were interviewed between June 2009 and August 2010.

In study 2, ENACCT project staff and Program Directors from three Cancer Support Community Affiliates in Philadelphia, the San Francisco Bay Area, and Cincinnati identified PCPs through their local community networks and through a booth at a regional primary care medical education conference (PRIMED, New York City, June, 2011). A total of nine individuals were interviewed between March 2011 and August 2011. Two of these were health care professionals but not PCPs, so they were eliminated from the analysis.

Interview Process

In study 1, participants were interviewed in person or via telephone by a trained qualitative expert. All participants signed an informed consent form prior to being interviewed. Interviews followed a semi-structured format, with 27 questions, approved by all participating institutions' IRBs. Interviewees were offered $75 as an incentive for their participation.

In study 2, participants were interviewed via telephone by two trained interviewers from CSC and ENACCT. Interviews followed a semi-structured interview guide composed of a subset of questions from those used in study 1; the guide was approved by an independent IRB. A copy of the interview guide was sent electronically to participants in advance of the call. Interviewees were offered a $25 gift card by mail as incentive for their participation, following completion of the phone interview. Participation on the calls was regarded as consent, and respondents gave their permission for the interviews to be audio taped.

Analysis

The data from both studies were treated as one data set, focusing on the parts of the transcripts that were central to the aims of this paper. Recordings were transcribed and reviewed using inductive thematic text analysis [21, 22, 23]. The interview transcripts were analyzed by three individuals on the research team using an iterative process of transcript review, interpretation, and consensus discussion. To begin, team members read each transcript, highlighting important content and recording reactions and reflections in the margins of the text [24]. Next, team members synthesized their thoughts about key findings in an analysis template. The analysis template included sections devoted to the key study aims as well as space for supporting quotations. Team members met to compare thoughts and resolve discrepancies in order to reach consensus for each transcript reviewed. During each team meeting, a consensus document was created reflecting the synthesized thoughts, findings, and supporting quotations for each group of transcripts reviewed. In the final phase of analysis, the team collaboratively reviewed all collective analysis templates, identifying recurring thematic findings across the qualitative data set.

Results

In the interviews, PCPs described a number of factors influencing referral to oncologists, but none concerned the range of available quality treatment options or access to clinical trials. In fact, PCPs were highly reluctant to outline or introduce any treatment options-including

CCTs and preferred to leave all such discussions to the specialist. Finally, PCPs held a number of misconceptions about trials, which seemed to contribute to their reluctance to mention them to patients. We explore each of these areas in more detail below.

Factors Influencing Referral to Oncology Care

Several factors featured prominently in influencing providers' standard referral practices, including: a) patients' insurance coverage; b) location and proximity to treatment facilities, and c) the strength of ongoing relationships with and/or previous experience with a specialist. The extent to which ongoing communication would take place was also of concern. Finally, a specialist referral was seldom based on availability of treatment options or access to clinical trials.

PCPs frequently cited insurance coverage as guiding the referral, noting that an uninsured patient has fewer options for care available. Providers who work for or maintain affiliation with a large hospital center utilize an internal referral system, making the assumption that if insurance covered the PCP visit, then the visit to the specialist would also be covered. Location and proximity to treatment centers plays a significant role in referral patterns. PCPs considered proximity in relation to patients' financial resources, physical ability to travel, and other factors when determining referral choice.

The issue of trust was often cited as a determining factor for referral. PCPs routinely send patients to specialists that they have used previously and/or whom they trust based upon years of working together, as the following quote exemplifies:

> "I've been here for 12 years, so we have a little network of each of the subspecialties. We have our friends in network. We can pick up the phone and say, 'Uh-oh, I have something, this is positive. Would you be able to set up the appointment for me as soon as possible?'…It's just, over time you start referring patients to them and they would build up a relationship with you."

For some PCPs, the extent, quality and consistency of communication and feedback from a specialist play important roles in referrals. For these physicians, refering to a specialist is based upon whether the specialist keeps him or her informed about the patient during treatment.

Less frequently occurring themes include factors related to patient well-being, patient feedback, and language. For example, one provider mentioned:

> "… is this someone who will make my patient feel respected and comfortable?"

Referral choice is also impacted by the reputations and recommendations circulating among other providers.

Reluctance to Outline Treatment Options upon Referral

When referring patients to oncology, the vast majority of providers refrain from educating patients about cancer treatment, frequently citing a lack of expertise in oncology care, and discomfort with discussions regarding diagnoses and specific treatment options. The quote below was a typical response:

> "…I don't feel like I do very much explaining about cancer treatment at all because it's just not my expertise."

A few providers did feel comfortable discussing treatment options, but using a more general approach, deferring specifics to the specialist, as exemplified in this account:

> "I kind of give a broad strokes overview of whether or not you'd be a surgical candidate…, I'll say the oncology group is going to be kind of the go-to-person… to discuss those treatment options in more detail…I don't have a whole lot of background knowledge in it, to be honest, in terms of all the various options based on the type of cancer they have."

Like cancer treatment in general, the vast majority of providers refrain from patient discussion about the possibility of receiving cancer treatment through a CCT. Most believed this discussion was not part of the PCPs' role, and assumed if it were appropriate, it would be handled by the oncologist. In other words, they saw it as their role to triage patients to the specialist rather than to provide baseline information about treatment options.

> "I am not up on any cancer treatments… My role, as I see it, is to direct patients to reliable, quality institutions and or individuals who can guide them through that process."

> "…It's almost always going to be either the surgeon or the oncologist or the radiation oncologist in this area because the primary care provider, once they have that diagnosis, it's out of their hands. They simply don't have the time to deal with that discussion."

Very few PCPs believed it was their responsibility to take a more active role in educating patients about their treatment options, including receiving cancer treatment through a trial. These providers mentioned frequently discussing clinical trials with their patients as part of a general discussion of treatment options.

> "I usually do mention it. I do generally say, 'Sometime…sometimes there are clinical trial options too if that's something you're interested in', and I think I'll kind of have that in the back of my mind… 'Oh gee, I need to at least bring it up with patients.' So that's usually what I say is just kind of the broad strokes there may be a clinical trial option. That's something you can discuss with your, with the oncologist."

> "I think as a primary care provider…I would consider it part of my role. I mean, it's like I'm choosing a blood pressure treatment for the patient. I know all the blood pressure medications. I should be able to speak to potential clinical trials if they're available, because…it's part of the options for management."

Misconceptions shaping PCPs discussions around CCTs

Misconceptions about the nature of CCTs and their appropriateness for cancer care were common among PCPs and affected their motivation and interest to discuss them with patients. PCPs often erroneously viewed CCTs as suitable only for rare cancers, treatment

resistant or advanced stage cancers, stating that CCTs should only be considered as a treatment of last resort, as these excerpts show:

> "The only time when I probably would really consciously think about trials is in the patient with a particularly rare cancer…."

> "I think a patient for a clinical trial is somebody [whose]…tumor [has] recurred or … there's already a big tumor and [its] spread to other organs. The clinical trial may give them some hope because there's not much more you can do."

Providers also made erroneous assumptions regarding barriers to referral. First, there was a common assumption that trials only take place at major research centers rather than in the community setting. Second, some made the distinction that the "best places for treatment" were those sites offering a variety of treatment options, rather than those specifically offering clinical trials. Lastly, several believed that limited financial resources always preclude participation in a CCT.

> "So part of what's going on is, I'm not thinking, okay, is the best place of treatment for my patient going to be where all of the clinical trials are located or is it going to be where all the treatment options are located?"

> "…usually it has to be somebody who's really interested…But it also has to be somebody who has the financial resources and that means that their insurance has to be something that covers them well already. And then the last thing is they have to be physically able to travel to those trials. Some people who are dealing with cancers are not able to travel long distances."

Openness to Receiving Training about CCTs

Nearly all PCPs expressed some interest in participating in an educational training about CCTs and the PCP role. Providers were interested in a variety of training formats, including web-based training, grand rounds presentations, and training at a conference.

Some PCPs stressed the importance of a practical training that gives providers the nuts and bolts of accessing information about particular CCTs, including CCT availability, patient eligibility, discussing CCTs, and orchestrating a referral. Much of the PCPs' interest in training centered on patient selection issues, and recruitment for particular trials as opposed to the need for tips to have appropriate discussions with patients.

> "I think that for us it has to be very practical. It's, you know, how do I find out where? Who's appropriate for referral? And, once we identify who's perfect for referral, how do we do it? …Those simple, simple points are just key."

> "I think the issue more is sort of patient selection. You know, trying to figure out who's appropriate for trials and how to discuss them with patients."

A few providers expressed little interest in CCT training. These providers tended to view knowledge and discussion of CCTs as outside of their role as a primary care provider.

> "Because I see so many other things so much more frequently that with the little bit of free time I have, I'd rather increase my knowledge about something that I see

frequently versus infrequently…So the answer to that question is no. I wouldn't be interested because I would be, you know, as a general rule I would work with the oncologists that I work with and I would want them to be the people to make the referrals."

"…I would want to know more about standard of care, which is something which I would be more closely involved in, or my patients would more often get that. So cancer trials, you know, uh, no not really. I wouldn't wanna know—that's, that's twice removed from what I'm doing, so I think that's beyond the level of expertise for a primary care physician."

Discussion

PCPs and other referring providers are an important untapped resource for introducing the concept of clinical trials as an option to newly diagnosed cancer patients. They have an ongoing, established relationship with patients and are likely to be seen as trustworthy sources of information [15]. This study explored a number of challenges facing PCPs who could play a role in educating and priming patients about participating in cancer research, helping to shape the design of two educational interventions for PCPs on the topic.

First, it is clear that PCPs need targeted, evidence-based educational interventions to appropriately address their concerns and challenges. Misperceptions held by PCPs regarding the nature and role of CCTs were quite common. These misperceptions clearly affect the interest and inclination of PCPs to engage in a discussion with their patients. Further, most PCPs did not see the relevance of CCTs to the care they provide patients.

Second, while continuing education of PCPs is critical, it is also important to introduce the concept of clinical trials to physicians in training. We need to foster a paradigm shift in medical education to normalize the educational role of the "non-participating" referring provider in promoting clinical research participation. Offering clinical trial education programs to nurses and allied health professionals may also play an important role in helping to educate patients. As we move more towards the Patient Centered Medical Home model [25], such education is becoming even more important. Additionally, the purpose of any medical education must be to improve the patient care experience and outcomes by enhancing provider communication skills, changing prevailing attitudes about clinical research, and altering referral behavior. In this case, the results of our study could be used to better design courses for referring providers to bring about these changes. For example, respondents indicated that they would have discussions about treatment if they were aware of the latest treatment options, including having easy access to information about open clinical trials in their geographic area.

Third, it is clear that the role of the referring provider in improving CCT participation needs to be appreciated and addressed by oncologists participating in clinical trials, thereby reinforcing the value of this role. Relatively few PCPs in our study identified themselves as having a role in helping to prepare patients for their upcoming visit with the oncologist; most PCPs assumed if it were appropriate, a CCT would be mentioned by the oncologist.

Trusted PCPs can underscore the importance of quality care received through CCTs and better prime patients for that critical discussion with the oncologist.

Finally, oncologists and the referring PCP have a critical relationship that needs to be strengthened, particularly in terms of expected quality of communication following referral [16] and the advent of the patient-centered medical home. It is also worth noting that the interviews showed that providers' referral behaviors were largely shaped by the level of trust they had in the specialists to whom they referred patients and that the feeling of trust was at least in part due to the quality of communication they had with the oncologist.

Limitations

This study was composed of two small convenience samples. It was extremely difficult recruiting referring providers to participate in this study. Despite generous gifts cards and extensive outreach, we were only able to recruit a limited number who were willing to take part in somewhat lengthy qualitative interviews. The providers interviewed may have been more open to considering cancer research than other providers. Moreover, the majority of providers practice in one geographic area – New York City. The views and experiences of these providers and the others interviewed may differ from the general population of PCPs nationally.

Conclusion

This qualitative study, in addition to informing the development of educational interventions, laid the foundation for a quantitative survey of a larger sample of PCPs in New York City who treat minority, low-income patients. While PCPs and other referring providers can play a role in providing information about and encouraging participation in clinical research, it is clear that much more needs to be done to improve the knowledge, attitudes and beliefs of PCPs towards CCTs as a quality option for treatment.

Further research is needed to understand the issues for PCPs nationally, including the variation in beliefs and practices that may occur based on physician training, geography, and populations served, particularly among a range of underserved groups. In addition, there is a need to begin a dialogue about cancer clinical trials and the PCP's role during the medical education process, in order to affect the practice of both future PCPs and oncologists. These efforts are essential if we are to succeed in increasing patient access to clinical trials and state of the art care.

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