



Searching for cures: Inner-city and rural patients' awareness and perceptions of cancer clinical trials



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ARTICLE INFO

Article history:

Received 21 June 2016

Received in revised form

22 November 2016

Accepted 12 December 2016

Available online 18 December 2016

Keywords:

Clinical trial

Cancer

Health communication

Knowledge

Behavior

Attitudes

ABSTRACT

Fewer than 5% of cancer patients participate in clinical trials, making it challenging to test new therapies or interventions for cancer. Even within that small number, patients living in inner-city and rural areas are underrepresented in clinical trials. This study explores cancer patients' awareness and perceptions of cancer clinical trials, as well as their perceptions of patient-provider interactions related to discussing cancer clinical trials in order to improve accrual in cancer clinical trials. Interviews with 66 former and current inner-city and rural cancer patients revealed a lack of awareness and understanding about clinical trials, as well as misconceptions about what clinical trials entail. Findings also revealed that commercials and television shows play a prominent role in forming inner-city and rural patients' attitudes and/or misconceptions about clinical trials. However, rural patients were more likely to hold unfavorable views about clinical trials than inner-city patients. Patient-provider discussions emerged as being crucial for increasing awareness of clinical trials among patients and recruiting them to trials. Findings from this study will inform communication strategies to enhance recruitment to cancer clinical trials by increasing awareness and countering misconceptions about clinical trials.

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1. Introduction

The need for high-quality scientific evidence to support clinical and policy decisions has steadily increased over the last century, and is currently highly demanded by patients, providers, insurers, the pharmaceutical and medical equipment industry, and policy makers [46]. Clinical trials are still the golden standard by which the efficacy of any clinical intervention is assessed [30]. According to the [6]; cancer is the second leading cause of death in the United States, and significant material and human resources are dedicated to finding a cure or to improve the quality of life of patients. Nevertheless, when it comes to search for novel cancer therapies, participation in cancer clinical trials is very limited, with less than five percent of U.S. adult cancer patients enrolled in clinical trials [4]. Even within that small number, patients living in inner-city and rural areas are underrepresented in clinical trials, most likely due to

the limited availability of trials at the medical centers serving their communities and to patients' minimal interest in participating in these studies [36]. In contrast, suburban areas have been found to have the highest level of clinical trial participation [40]. The current state of cancer clinical trial participation reveals a critical need to increase recruitment in inner-city and rural areas.

Patients' awareness and perceptions of clinical trials, as well as attitudes of physicians, are some of the most important factors underlying low recruitment rates of patients into clinical trials [1,3]. There is a dearth of studies exploring awareness and perceptions of cancer clinical trials among patients in general, and among inner-city and rural patients in particular (see Refs. [23,27,31,50]). In addition, most of the limited number of studies conducted on these populations have either used quantitative methods such as surveys, thus limiting the depth and nuances of findings, or included mostly members of the non-diseased general population, thus limiting the voice of cancer patients.

Focusing on clinical trial investigators' perceptions of perceived barriers to clinical trial recruitment among rural and African-

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American communities, Tanner and colleagues urged that “future studies should qualitatively examine how African Americans, as well as rural residents, perceive the concept of medical research, in an effort to determine how best to move forward with appropriate CT [clinical trial] recruitment strategies” [44]; p. 93). Previous qualitative research exploring underserved populations’ perceptions of clinical trials were mostly exploratory due to the small sample size of cancer patients participating in them, usually about 20 participants total (e.g., [25,32,37]).

This study aimed to address these limitations by (1) focusing on inner-city and rural cancer clinics, (2) interviewing only current and former cancer patients, and (3) recruiting a larger number of participants than in previous qualitative studies. More specifically, this study explored patients’ awareness and perceptions of cancer clinical trials, as well as their perceptions of patient-provider interactions related to discussing cancer clinical trials. Findings from this study provide insight to the development of tailored regional communication strategies to improve accrual to cancer clinical trials among inner-city and rural patients. Indeed, as [25] recently stated, “the goal of future research should be to develop, apply, and refine theoretical and audience-based approaches to message design that will reduce the cancer health inequities of the medically underserved” (p. 1174). The present study represents a first step in that direction.

1.1. Barriers to participating in cancer clinical trials

Lack of trust and awareness are often cited as main reasons underserved populations do not participate in clinical trials [13]. Furthermore, physicians actively informing patients about and discussing the availability of clinical trials, as well as provider-patients interaction, have been identified as the most important factors promoting accrual [20,22]. While some patients may have a general cognizance of clinical trials, they may not be aware of clinical trials that are relevant to them. One national study of cancer patients reported that an astounding 85% of respondents were unaware that participating in a clinical trial was an option for them [42]. Other studies suggested that if patients were offered an opportunity to enroll in a trial, they would be inclined to participate [8] but that the complexity of research protocols and cost associated with participating in a clinical trial represented important barriers to overcome [49]. Recently publicized data from the Memorial Sloan Kettering Cancer Center states that only one in four Americans have a positive impression about clinical trials ($N = 1501$) and that over half of their surveyed physicians ($N = 600$) considered clinical trials only late in treatment [5].

For most research, increasing clinical trial study awareness for both oncologists and patients is one of the most recommended measures to improve the activation process and to promote accrual [10]. At community-based cancer centers, increased efforts need to be focused on educating and encouraging physicians, educating patients, as well as to increase the availability of clinical trials [17]. At a patient level, having the adequate information, presented in timely manner in an easy-to-understand, friendly format, may help decision making by increasing awareness and addressing some of the barriers related to low health literacy [11].

Several patient-provider centered factors have been also identified as affecting clinical trial accrual. While oncologists’ referral for clinical trials is essential for effective recruitment, many doctors may be reluctant to refer because they perceive clinical trials as an excessive administrative or financial burden to their practice [24] or because of assumptions about patient eligibility to enroll or concerns that a challenging social support system will adversely affect the patient’s ability to adhere to the study protocol [21].

Health communication has made impressive progress in the last

15 years and research on communication interventions have received significant support from the NIH, although studying accrual to cancer clinical trials has been ominously overlooked [38]. Nowadays, patients have a multitude of sources available from which to get information about health topics [16,39]. Nevertheless, cancer patients’ needs and interests present much variability, with only a minority of patients interested to learn as much as possible about their disease, and most of them depending on their physician for information [28].

As mentioned earlier, the purpose of this study was to examine inner-city and rural patients’ awareness and perceptions of clinical trials to support the development of a regional communication strategy to improve accrual to cancer clinical trials. To this end, this study aimed to investigate the following two main research questions:

RQ1. Where do current and former inner-city and rural cancer patients obtain information about clinical trials and what they know about them?

RQ2. How do current and former inner-city and rural cancer patients perceive clinical trials?

2. Method

Data were collected by conducting phone and face-to-face, semi-structured interviews with current and former cancer patients between June and August 2015. The research team recruited participants from an inner-city and a rural oncology clinic in the Midwest using a combination of network and convenience sampling techniques with the help of research nurses, who were part of the research team and who contacted potential participants by mail, phone and/or in person. Any current or former cancer patients from those two clinics were eligible to take part in the study, regardless of type of cancer or treatment, as well as prior participation in a cancer or non-cancer clinical trial. Current patients were recruited on site by the research nurses who told potential participants about the study. Former patients first received a letter in the mail about the study and were then contacted by phone by research nurses to see if they would be willing to participate in the study. Two research team members contacted the patients who agreed to participate to schedule a day/time for the interview. Participants provided consent twice: during the first step of the recruitment process and again before the interviews. The Institutional Review Board approved all recruitment documents (i.e., recruitment letter; phone call script) and materials (i.e., information statement; interview questions) related to the study.

A total of 100 current and former cancer patients agreed to participate and interviews were conducted with 66 of them (32 from the inner-city clinic and 34 from the rural one), as attempts to schedule or to conduct interviews with others were not successful, even after multiple attempts. Recruitment stopped when data collected from both groups of participants did not yield any new information, thus demonstrating data saturation, which refers to the idea that enough information has been collected to replicate the study [15]. While qualitative researchers recommend interviewing 20 to 30 participants as a broad rule of thumb [9], there is no formula or set number of participants to reach data saturation, as it depends on a study’s research questions. Therefore, data collection and participant recruitment continues until “depth as well as breadth of information is achieved” [35]; p. 3). All participation was voluntary and no compensation was provided as an incentive. The majority of the interviews ($n = 55$; 83.33%) took place by phone. Face-to-face interviews were conducted in private chemotherapy stations at the inner-city clinic. Two research team members

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