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

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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 in 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.

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

conducted about three-fourths of all interviews ($n = 49$; 74.24%) and a trained doctoral candidate with experience interviewing members of marginalized groups in the context of health communication conducted the other interviews ($n = 17$; 25.76%) when there was a conflict of schedule between the participants and the two research team members. The average interview time was about 18 min.

Participants answered a series of open-ended questions pertaining to their knowledge and perceptions of clinical trials in general and cancer clinical trials in particular. Participants also answered questions about their sources of and access to health information. The research team adapted questions from previous health communication studies exploring overall awareness of, attitudes towards, and (potential) participation in cancer clinical trials (e.g., [33,34,41,43,47]. At the end of the interview, participants answered demographic questions. All interviews were audio-recorded and transcribed using pseudonyms to protect participants' confidentiality. The data of the study amounted to 481 double-spaced pages of transcript.

The two research team members who conducted the interviews analyzed the data in ATLAS.ti (version 6.2), software that assists in organizing and making sense of qualitative datasets. Researchers first coded participants' answers in chronological order during the data collection period using a combination of "open coding," identifying relevant themes line by line, and "focused coding," searching for specific themes to group them into categories [7,14]. After completing all 66 interviews, the researchers also coded the data using "theoretical coding," more analytical codes to gain more insight about participants' knowledge, attitudes and beliefs of clinical trials [14]. Open and focused coding allow researchers to analyze the data while continuing the data collection in order to further explore the emerging themes/codes in subsequent interviews, while theoretical coding help make sense of participants' responses by exploring larger connections among codes and generating more conceptual codes linked to health communication theories. Researchers met throughout the data collection and analysis phase to compare notes and ensure that similar themes were coded in similar ways. They also shared codes with the research team to obtain feedback on interpreting participants' responses. The research team then compared the final codes that emerged from the data analysis based on their frequency for inner-city and rural participants.

2.1. Participants' demographics

Inner-city ($n = 32$) and rural ($n = 34$) study participants were equally divided in terms of gender, with 20 and 21 women, and 12 and 13 men, respectively. Table 1 presents participants' demographic characteristics based on place of residence. Inner-city participants included 16 African Americans, 14 White Americans and 2 Latino Americans. Their age ranged from 28 to 69 ($M = 54.77$; $SD = 10.66$). Rural participants were older; their age ranged from 37 to 89 ($M = 67.15$; $SD = 12.07$), and all were White Americans except for one African American. Most rural participants had received at least some college education ($n = 24$) and overall reported a median annual income between $20,001 and $40,000. Most inner-city participant had not gone to college ($n = 23$) and overall reported a median annual income between $10,001 and $20,000. The majority of participants ($n = 60$) had never taken part in a clinical trial (see Table 1).

Table 1
Participants' characteristics by place of residence.

	Inner-city participants	Rural participants
Gender		
Male (n)	12	13
Female (n)	20	21
Race/Ethnicity		
White-American (n)	14	33
African-American (n)	16	1
Hispanic-American (n)	2	0
Age		
Mean (standard deviation)	54.77 (10.66)	67.15 (12.07)
Range	28–69	37–89
Education		
Median	High school diploma	Some college
Annual Income		
Median	$10,001 - $20,000	$20,001 - $40,000
Previously participated in clinical trial		
Yes	4	2
No	28	32

3. Findings

The study's research questions dealt with where participants obtain clinical trial information and what they know about them (RQ1), and how they perceive clinical trials (RQ2). Table 2 presents the main categories and codes based on frequency and participants' place of residence. Differences among codes based on participants' demographic variables such as educational and income levels were also taken into account by isolating responses from inner-city participants and rural participants. No in-group differences were found among the codes based on those variables. In addition, participants' responses were also compared according to prior participation in clinical trials. Interestingly, participants who had been part of a clinical trial did not seem to have a better or worse understanding of clinical trials than participants who had never taken part in a clinical trial.[1]

The codes represent the main themes from the findings and are organized in two overall categories: awareness and perceptions of clinical trials. Findings are presented below based on category, code and participants' place of residence. Within each category, the codes/themes that emerged as common to both inner-city and rural participants are discussed first, followed by the codes/themes that were different between inner-city and rural participants. Findings are thus discussed in the order in which they are presented in Table 2. Each first mention of a participant's name in a new paragraph is followed with his/her place of residence in parentheses.

3.1. Awareness of clinical trials: similarities between inner-city and rural participants

Overall, inner-city and rural participants reported similar levels of awareness about clinical trials, mainly learning about them via the media and personal experiences. Inner-city and rural participants also reported overwhelmingly relying on doctors and nurses for information about their health. Lastly, about half of inner-city and rural participants mentioned searching for health information online.

3.1.1. Learning about clinical trials in the media

The most common source of information about clinical trials in general for both inner-city and rural participant was mediated advertisements for industry-sponsored trials. For instance, Patricia (inner-city) said that she sees "ads on TV on recruitment to clinical trials for other things [not cancer clinical trials] all the time." Similarly, Christopher (rural) stated, "every now and then I see in

[1] This may be because of the six participants who reported having been part of a clinical trial, only one was for a *cancer* clinical trial.

Table 2
Topic relevance of the two patient samples based on frequency and residence.

Categories and codes	Inner-city participants (n)	Rural participants (n)
Category: Source of information/Awareness		
Similarities between inner-city and rural participants		
Learning about clinical trials in the media	19	15
Learning about clinical trials from experience	9	11
Relying on doctors-health care practitioners for information	26	31
Searching for health information online	13	16
Differences between inner-city and rural participants		
Learning about clinical trials from hospital literature	9	2
Not discussing clinical trials with doctors	18	31
Category: Perceptions		
Similarities between inner-city and rural participants		
Not understanding clinical trials	17	15
Perceiving clinical trials as being a guinea pig	4	6
Differences between inner-city and rural participants		
Perceiving clinical trials as last resort	5	12
Understanding the usefulness of clinical trials	7	3
Perceiving clinical trials as good care	7	12
Worrying about placebo	1	8

the paper, the local paper here that I take, that there may be a clinical trial for somebody that, for example has sleep apnea." These advertisements may influence perceptions of clinical trials. Elizabeth (rural) described one of these advertisements, stating that, "laboratories want you to go in for, you know, a night or a week or something like that on the TV on commercials, and they will, you know, you're tested for different medicines and things."

Participants said that most of these studies dealt with smoking or being overweight, and emphasized the amount of dollars received for participation. Some advertisements even position participation in clinical trials as something to do "in between jobs" or when searching for a job. For instance, Helen (inner-city) noted that in one advertisement she viewed, you could "earn up to 1500 dollars to come to this place for three nights to participate in a clinical trial."

Inner-city and rural participants also heard about clinical trials in the media through TV shows. Melissa (rural) mentioned hearing about clinical trials in the TV show *House*. Helen (inner-city), who identified herself as "a big *Grey's Anatomy* fan," stated, "that's how I know mostly about clinical trials, is medical shows." She added that clinical trials are portrayed as a "last resort […] they've tried everything else, and they're on—they're basically on the dying list. And they're reaching for anything because they're not ready to give up." Mark (rural) also heard about clinical trials in TV shows and said that characters who participate in clinical trials "survive with bad consequences."

3.1.2. Learning about clinical trials from experience

The second most common way inner-city and rural participants reported learning about clinical trials was via personal or vicarious experience, such as "life experiences through different family members," as Jessica (inner-city) aid. Nancy (rural) stated, "my husband has had cancer three times, the first time around with lymphoma, and he had clinical trials then." Even if they did not know anybody who took part in a clinical trial, some participants said that they had learned about clinical trials because of their experience being a cancer patient for so long. For instance, Catherine (rural) stated, "I've been a patient for eight years. And so, just throughout the years, you know, just through patient navigators, pamphlets, readings, and discussions with my doctor […] the whole, I would say, oncology grapevine." This "oncology grapevine," as Catherine calls it, refers to discussions with various health care providers, other patients and possible exposure to hospital literature.

3.1.3. Relying on doctors-health care practitioners for information

Doctors represented the number one source inner-city and rural participants reported relying on to get information about their health/cancer. The following series of short quotes illustrate how much participants rely on doctors: "I get my information from my doctor" (Barbara, inner-city); "if I have a question, I usually ask the doctor" (Richard, inner-city); "here at the hospital" (Nicole, inner-city) "all that I know I have gotten from doctors" (Karen, rural); "just relied on the doctor and the nurses" (Linda, rural); "my physician, who I trust completely" (Amy, rural); "I normally ask my doctor or the hospital or something like that" (Donald, rural).

Participants explained that they trust and value the opinion of their doctors, who are usually also familiar with participants' relatives. For instance, Barbara (inner-city) stated, "the doctor, mostly because I go by what he tells me. He talks about different things because he knows those in the family who have had breast cancer since I had it." However, and as discussed further below, while participants in this study relied on their doctors for information related to their disease, the majority of them also said that they had *never* discussed clinical trials with their doctors.

3.1.4. Searching for health information online

Almost half of inner-city and rural participants mentioned using the Internet to search for health information related to their cancer. Richard (inner-city) stated, "I'll get on the Internet when I need certain answers." Carol (rural) was a little more detailed in her answer, stating, "if I'm taking a medication and I'm having a little bit of a side effect from that medication, I'll get on there [the Internet] to see what the side effects of that medicine are." Asked if she obtained health information from other sources than her doctor and the Internet, Lisa (rural) responded, "where else? That's about all. The Internet is the only thing." When asked if they visited specific websites, about half of these participants responded searching for information on WebMD, the Mayo Clinic, the American Cancer Society, the Susan G. Komen foundation, and the National Cancer Institute. Some participants mentioned one or two sources, while others said they started with a general Google search.

3.2. Awareness of clinical trials: differences between inner-city and rural participants

The main differences between inner-city and rural participants' awareness of clinical trials were related to their visit to their oncologist. Inner-city participants were more likely than rural participants to learn about clinical trials from hospital literature that they read while waiting to meet with their oncologist. Rural participants were more likely than inner-city participants to report that they did *not* discuss clinical trials with their oncologist.

3.2.1. Learning about clinical trials from hospital literature

About one third of inner-city participants learned about clinical trials by reading hospital literature. For instance, James (inner-city) stated, "when I walk into the doctor's office or in the hospital I see things on the wall, I pick them up and read them, they have magazines." Michael (inner-city) stated, "whenever I go to the doctor on my follow ups in those things I sit in, actually there are posters,

clinical trial posters saying how they help." On the contrary, only two rural participants reported reading hospital literature. Both clinics where the study took place had generic posters about participation in clinical trials displayed in the waiting rooms, but none had any pamphlets or handouts about clinical trials available to patients.

3.2.2. Not discussing clinical trials with doctors

Rural participants were much more likely to have reported *not* discussing clinical trials with their doctors. Sandra (rural) stated, "I just never ever; I have cancer and it's just a subject [clinical trials] we [patient-provider] never discussed. I was never around that type of thing, so I really never discussed this. I didn't even know it was an option." Most participants said that their oncologist only discussed their treatment, as William (rural) stated, "my physician just talked to me about how my treatment was going and how I was progressing until I was released from treatment."

3.3. Perceptions of clinical trials: similarities between inner-city and rural participants

Overall, inner-city and rural participants did *not* understand what clinical trials are. While they reported different misconceptions about clinical trials, as further discussed below, the only similar misconception inner-city and rural participants held about clinical trials was equating participation in a clinical trial to being a guinea pig.

3.3.1. Not understanding clinical trials

When inner-city and rural participants were asked how they would define or explain clinical trials, most of them could not answer. Most participants' responses resembled that of Patricia (inner-city), who said, "I don't know because I've never talked with anyone who has done that [a clinical trial]," or that of Robert (inner-city), who said, "I don't really know exactly what it [clinical trial] is, what it consists of." Even participants who reported being familiar with the term 'clinical trial' could not define or explain it. For instance, Christopher (rural) stated, "I've heard of the name, but I really and truly don't understand, you know, the scope or the depth of what a clinical trial is."

While most participants did not know what a clinical trial was, a few seemed particularly confused about it. George (inner-city) said he was not sure if he had participated in a clinical trial or not, stating, "I don't know if I'm still on the clinical trial, I know I've been doing this for a while." George was referring to his cancer treatment, but did not know if his treatment was part of a clinical trial. David (rural) thought that a phone interview could be a clinical trial.

3.3.2. Perceiving clinical trials as being a guinea pig

A smaller, but similar number of inner-city and rural participants perceived participating in a clinical trial as being a guinea pig in an experiment. For instance, Kathleen (inner-city) emphasized this point, stating, "it's experimental, you know, it's experimental, it's for study, and of course that would put one in the position of a lab rat." Similarly, Stephanie (rural) stated, "I think, in my opinion, people who are in a clinical trial are more of a guinea pig." Considering what would make him participate in a clinical trial, Daniel (rural) stated, "I'm not just going to be somebody's guinea pig."

3.4. Perceptions of clinical trials: differences between inner-city and rural participants

Inner-city and rural participants' differed in their perceptions of clinical trials. Rural participants were more likely than inner-city participants to perceive clinical trials as last resort treatments, while inner-city participants were more likely than rural participants to understand the usefulness of clinical trials. In addition, rural participants were more likely to perceive clinical trials as good care, yet they were also more likely to worry about receiving a placebo.

3.4.1. Perceiving clinical trials as last resort

The most common misperception about clinical trials pertained to being used only as a last resort. Rural participants were more likely than inner-city ones to hold the view that clinical trials are used when "there was absolutely no medicine that would help," in the words of Dorothy (rural). Mark (rural) said that a "clinical trial is probably the best last chance." When asked to elaborate, he answered, "well, when all the accepted methods have been tried, or ruled out, and there's not much left for you to do other than try a clinical trial." These participants also mentioned the idea of clinical trials as a last resort when responding to what would make them consider taking part in a clinical trial. For instance, Melissa (rural) stated, "if that's my only option, then, yeah, sure, I would be willing to try something. If it wasn't, you know, if I had other options, then I might not."

3.4.2. Understanding the usefulness of clinical trials

Inner-city participants were more likely than rural ones to perceive clinical trials as useful, as they commented on the significance of clinical trials. Patricia (inner-city) stated, "that medicine I'm taking, that's coming from people on trial […] someone has been in a trial process in order for these medicines to—for me to be able to take them." Elizabeth (inner-city) described clinical trials as benefiting all parties involved, as they help "research people find answers and it also helps the patient." In the same way, Deborah (inner-city) expressed her trust in and the value of clinical trials stating, "I think that that's how we're going to cure cancer one day is by a clinical trial."

3.4.3. Perceiving clinical trials as good care

Rural participants were more likely than inner-city ones to perceive clinical trials as good care. Karen (rural) stated, "I have had no earlier experience but I'm aware that as the medical practice goes, they're not going to do anything that's harmful to do." Even if something were to happen during the trials, these participants still perceived clinical trials as safe, as Carol (rural) explained, "if the pill, the medicine, don't agree with you they will take you off of it. So, you're not in any harm's way and you are under a doctor's care and they are very thorough making sure you are okay."

3.4.4. Worrying about placebo

Despite perceiving clinical trials as good care, rural participants were also more likely to report that they would worry about receiving a placebo instead of an alternative treatment if they were to participate in a cancer clinical trial. For instance, Edward (rural) stated, "the way I understand it [clinical trial], not everybody gets the real medicine. Some of them get placebos, and, you know, it seems like people are not getting the benefit." Similarly, Angela (rural) stated, "I would not want to be in a group where I was given, where I thought I was getting a drug for treatment and then given a placebo." Only one inner-city participant mentioned such concerned.

4. Discussion

Findings reveal many similitudes between inner-city and rural patients when it comes to sources of information and perception of clinical trials. Both reported similar levels of awareness about

clinical trials via traditional media (advertisements and TV shows), websites, and personal experiences. The only differences dealt with hospital literature and discussion with doctors. In both cases, inner-city participants reported more awareness about clinical trials from brochures and oncologists. However, it is important to keep in mind that regardless of these differences, overall, only a minority of inner-city and rural participants reported reading hospital literature, and the majority of participants in both groups reported *not* discussing clinical trials with their oncologists. This is particularly problematic because both inner-city and rural participants also reported relying on doctors and nurses for health-related information.

In the present study, patients not being told about the therapeutic option to participate in a clinical trial highlights one of the major problems facing accrual, in both inner-city and rural clinics. The number of participants who stated not having discussed clinical trials with their oncologist reflects what other researchers have reported. Exploring cancer clinical trial awareness [43], found that 78% of the patients they surveyed had not received any information about clinical trials from their general physicians, oncologists or nurses. In their survey of oncologists [2], found that 55% of them felt uncomfortable discussing the option of a clinical trial with their patients. This significant absence of patient-provider discussions about cancer clinical trials observed in the present study is highly problematic for the clinics' effort to recruit clinical trial participants, given that other studies have repeatedly emphasized the crucial role such discussions play in the enrollment of patients in cancer clinical trials (e.g., [12,19,26,45,48].

Regarding awareness about clinical trials, most studies found that the majority of patients are overall unaware of clinical trials [13,29,33]. However, one study found that 84% of surveyed patients were aware of clinical trials [51]. Our findings seem to support the observation that patients may have heard about, but are less likely to understand what clinical trials are. Three quarters of participants in this study had heard about clinical trials from one or several different sources. However, more than half of participants were unable to explain what clinical trials entail or displayed misperceptions about clinical trials. This may be related to having mainly heard about clinical trial via media sources, such as television shows and advertisements from large pharmaceutical companies, neither of which emphasizes what clinical are, but are more focused on the immediate financial benefits for the participants. Indeed, these advertisements have been identified as some of the many factors that contribute to low enrollments of patients in cancer clinical trials conducted as part of federally funded research studies. For instance [26], stated that, “of great concern are the large number of industry-sponsored trials which frequently siphon patients from CTCG [Clinical Trials Cooperative Group] trials and which usually offer much higher reimbursement rates.” (p. 1973). Findings support the idea that media contribute to participants' misunderstanding and misperceptions about clinical trials by only associating them with particular scenarios that usually do not apply to patients' experiences.

Participants' comments reveal how little they know about clinical trials, despite having been diagnosed with cancer, having met with doctors and nurses, and visited hospitals multiple times. In their survey of general public and cancer survivors [34], found “low scores on the measure of clinical trial understanding” and stressed that “public understanding of clinical trials needs to be increased substantially” (p. 91). Even though most participants could not explain how clinical trials work, some nevertheless held specific views and opinions about clinical trials. Inner-city and rural participants were as likely to perceive participating in a clinical trial as being a guinea pig in an experiment, even though such perceptions were only held by a minority of participants in both groups. Rural participants were more likely to perceive clinical trials as good medical care, but also as being used as a last resort and as potentially ineffective because of the chance of receiving a placebo Inner-city participants were more likely to perceive clinical trials as useful to find new cures.

While some studies have reported that cancer patients' fear and/or distrust of the medical system presents a barrier to clinical trial enrollment [13,33], most participants in this study did not express such concerns. On the contrary, the majority of participants clearly stated that they trust their doctors and health-care practitioners and mainly rely on them for information pertaining to their health. Other studies have reported that associating taking part in a clinical trial as being a guinea pig represents a major barrier to patient enrollment in cancer clinical trials [13,26]. However, in the present study, only a minority of participants expressed that idea. The most common perception inner-city and rural participants held about clinical trials dealt with receiving good medical care, thus reinforcing the trust participants have in the medical system.

4.1. Limitations

Results presented here need to take into account the study's limitations. Participants were recruited from only two cancer clinics in the Midwest. In addition, even though participants had achieved different levels of education and came from various socio-economic backgrounds, most of them were White Americans. The interviews addressed patient-provider discussions but these interactions were not observed. Similarly, oncologists were not interviewed to confirm what participants said. Future studies should address these limitations and further explore the relationship between media representations of clinical trials and patients' perceptions of clinical trials, as media represented the main source of participants' information about clinical trials.

5. Conclusion

The purpose of this study was to qualitatively explore inner-city and rural cancer patients' awareness and perceptions of clinical trials using patients' own words. As mentioned above, most previous studies either used quantitative methods such as surveys or mainly included members of the non-diseased general population. The present study thus contributes to communication efforts about cancer clinical trials by focusing on understanding what patients know and feel about clinical trials, and how they are similar or differ based on attending an inner-city or rural cancer clinic. Findings support previous studies' results regarding patients' serious lack of awareness and understanding about (cancer) clinical trials, and showcase the primordial importance of patient-provider interaction to help recruit patients in clinical trials. Findings also reveal that both inner-city and rural patients have limited awareness, low understanding of the concept of clinical trials, and are very passive in their engagement with information about cancer clinical trials, as they expect and rely on doctors and nurses to provide them with most of the health information they think they need.

Findings also shed light on the prominent role mass media, and especially commercials and television shows, play in forming patients' misperceptions about clinical trials. In addition, less than half of the participants used the Internet to search for health information. Such findings suggest that despite the almost ubiquitous use of online platforms in most communication efforts, changing perceptions about clinical trials will most likely require an offline two-prong approach, using doctors and nurses, as well as traditional media to communicate information and educate patients about clinical trials.

These findings can help health communicators develop tailored strategic communication messages to increase awareness, address misperceptions, and accrue enrollment in cancer clinical trials. For instance, videos featuring local nurses and doctors addressing patients' main misperceptions about clinical trials should be produced and played on monitors in clinics' waiting rooms. Cancer patients should also receive a brochure about cancer clinical trials that clearly explains how clinical trials are conducted, emphasize the high quality of care clinical trial patients receive, and demystify the notion that clinical trial patients are experimental guinea pigs. Nurses and/or doctors should review the content of the brochure with cancer patients and re-emphasize those points. Nurses and doctors should also have a small booklet that includes key terms to explain cancer clinical trials free of medical jargon and that lists the main misperceptions they should address when discussing clinical trials with patients. Significant attention should be given to address health literacy concerns and making sure the information contained in all printed and mediated materials is at an adequate readability and comprehension level and is culturally tailored for the patients.

Contrary to the barriers for patient participation in cancer clinical trials identified in previous studies, findings from this study suggest that the two main challenges to overcome for accrual to cancer clinical trials are to increase awareness and change misperceptions of clinical trials. These challenges may be more difficult to overcome in rural areas than in inner-city ones, as rural patients displayed *less* awareness and *more* misperceptions about clinical trials compared to inner-city patients.

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