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Participant Characteristics and Clinical Trial Decision-making Factors in AIDS Malignancy Consortium Treatment Trials for HIV-infected Persons with Cancer (AMC #S006)

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Abstract

Background.—Overall, people living with HIV/AIDS (PLWHA) are living longer, but compared with the general population, they are at elevated risk for numerous AIDS-defining and non-AIDS-defining cancers. The AIDS Malignancy Consortium (AMC) is dedicated to conducting clinical trials aimed at prevention and treatment of cancers among PLWHA.

Objective.—To examine patient-level characteristics and perceptions that influence decision-making regarding AMC treatment trial participation.

Methods.—PLWHA diagnosed with cancer or anal high-grade intraepithelial neoplasia who were ≥ 18 years old and offered participation on a therapeutic AMC clinical trial were eligible. Participants completed a 17-item survey assessing sociodemographic and other factors potentially influencing decision-making regarding trial participation.

Results.—The sample of 67 participants was mainly male (n = 62, 92.5%), non-Hispanic (89.5%) and white (67.2%), with a mean age of 48.3 years. About half of participants were screened for lymphoma studies. Nearly all (98.5%) of the participants learned about AMC clinical trials from a medical provider, most (73.1%) knew little about clinical trials in general, and half decided on trial participation on their own. Altruism was the most frequently cited reason for trial participation. Participant recommendations for improving AMC trial accrual included systems changes to speed access to clinical trials and reduce participant burden.

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Conclusions.—This formative study highlights the perceived benefits to others, i.e., altruism, as an important factor in trial decision-making, little knowledge about clinical trials in general, and the role of physicians in informing participants about clinical trials. Future research should address knowledge barriers and explore systems- and provider-level factors affecting accrual to AMC trials.

Keywords

HIV; AIDS; cancer; clinical trial decision-making; patient-level factors

Introduction

The widespread use of highly active antiretroviral therapy has contributed to a decline in AIDS-defining illnesses[1, 2] and a longer life expectancy for persons living with HIV/AIDS (PLWHA).[3] However, the improved life expectancy and quality of life of PLWHA are threatened by a greater incidence of numerous cancers, which are characterized as either AIDS-defining cancers (ADCs) including Kaposi sarcoma, non-Hodgkin lymphoma, and invasive cervical cancer), or non-ADCs (NADCs), such as anal, liver, lung, and head and neck cancers.[4–6] Compared with the general population, PLWHA are about 500 times more likely to be diagnosed with Kaposi sarcoma, 12 times as likely to be diagnosed with non-Hodgkin lymphoma, and, among women, 3 times as likely to be diagnosed with cervical cancer.[7] For NADCs, PLWHA are 19 times more likely to be diagnosed with anal cancer, 3 times as likely to be diagnosed with liver cancer, 2 times as likely to be diagnosed with lung cancer, and about 2 times as likely to be diagnosed with oral cavity/pharynx cancer compared with the general population.[7, 8] Finally, not only is HIV infection associated with an increased risk of cancer, but PLWHA are more likely to die of their cancer than people with these cancers who are not HIV-infected.[9, 10] Addressing the elevated cancer risks for this population is important in reducing cancer disparities as well as the incidence and mortality of cancer overall.

Prevention, early detection, and treatment efforts that are targeted and tailored to HIV-infected individuals remain important priorities in the field of HIV medicine.[11] In the U.S., the National Cancer Institute (NCI) has funded The AIDS Malignancy Consortium (AMC) since 1995, to develop and conduct innovative trials for HIV-infected patients diagnosed with ADCs or NADCs, as well as prevention trials for those at elevated risk for HIV/AIDS and certain cancers.[12]

Accrual into cancer and HIV/AIDS clinical trials has traditionally been suboptimal and challenging, and it is estimated that < 5% of US cancer patients are enrolled in clinical trials.[13] Research groups and government-sponsored organizations increasingly have focused on engaging communities to participate in cancer clinical trials. Factors influencing clinical trial participation are numerous, but they have been categorized broadly within the published literature as existing at the levels of participant/community, site/organizational system, and physician provider.[14] In 2013, Denicoff and colleagues[15] reported on an NCI–American Society of Clinical Oncology (ASCO) Cancer Trial Accrual Symposium held in 2010 that examined the state of accrual science and identified new interventions to improve clinical

trial enrollment. Barriers cited at the participant/community level were comprehension of and attitude toward randomization and placebo or no treatment assignments, and potential adverse treatment effects and impact on quality of life, as well as unease with research, and protocol burden and complexity.[16] Participant recruitment is strongly associated with trust in the physician, more so when a physician recommends a trial.[17] Challenges at the site and organizational level include a lack of institutional support, insufficient staffing, and committed time to the trial accrual process, absence of an available clinical trial, lengthy protocol review and activation timelines, and inadequate operational procedures.[18] Finally, at the physician/provider level are concerns about participant tolerance of treatment and age, comorbidities, and poor prognosis.[18–20] Attitudes toward research and worries about demands on staff as well as logistical and regulatory challenges to engaging in clinical research can impede provider research participation. Finally, clinician discomfort in discussing trials with their patients and viewing clinical trials as an option of last resort work against the clinical trials enterprise.

The AMC, like other cooperative cancer groups, has not been immune to these challenges in clinical trials enrollment. A better understanding of patient-level characteristics and perceptions that influence enrollment in AMC therapeutic trials could yield interventions to enhance rates of trial participation and retention. This study is an initial effort toward a longer-range plan to better understand variables likely to impact patient willingness to participate in AMC clinical trials, including community and physician referral factors, characteristics of the clinical trials such as inclusion and exclusion criteria and need for tissue and blood donations or other invasive procedures, and behavioral factors of study volunteers.

Methods

Sample

This AMC #S006 protocol entitled, *Improving Participation in AMC Clinical Trials* (IMPACTS), was approved by the NCI's Cancer Therapy Evaluation Program and the institutional review boards at each participating AMC study site. Participating in study recruitment were 13 unique AMC study sites primarily at academic medical centers located in 10 different states and representing five major regions of the U.S. Participants were enrolled on the study from October 3, 2013 until June 16, 2015. PLWHA were eligible for this study if diagnosed with cancer or anal high-grade intraepithelial lesions, were 18 years or older, and were offered participation via informed consent on a therapeutic AMC clinical trial. All eligible participants had to have the ability to understand, and the willingness to sign, a written informed consent document.

Procedure

Each site was responsible for selecting the methods or approaches to recruit participants into an AMC therapeutic trial. For the AMC #S006 study, the study coordinator or designated staff met with the potential participant, invited each to participate in AMC #S006, and sought informed consent. To minimize bias toward recruiting to AMC #S006, individuals were invited to participate in AMC #S006 during the same in-person meeting at which they

were approached about participation in the AMC therapeutic trial. In cases where the potential participant did not decide regarding therapeutic trial participation during the visit, the survey could be administered up to one month after consent to AMC #S006. The study staff administered the AMC #S006 survey in person.

Measure

The study survey was developed ad hoc based on a review of the published literature on factors influencing cancer clinical trial participation as well as input from AMC physicians' clinical experiences and observations in study accrual. Because this survey was focused on understanding patient-level characteristics and recognized the diversity of the HIV-infected population, questions regarding sexual orientation, gender identity, and sexual behavior were included. The survey comprised 17 items completed by the study participant and 3 items completed by the survey administrator. Ten items asked participants to provide birth date for the purpose of calculating age, race and ethnicity, whether born in the U.S.A. and territories or another country, educational attainment, income, gender identity and sexual orientation. One item asked about sexual activity within the past 12 months with the sex of the partner(s) specified. Four additional items asked participants about prior participation in any clinical trials and also AMC trials, how they learned about the therapeutic AMC clinical trial for which they were deemed eligible by checking one or more of 15 choices, e.g., medical provider, word of mouth, AMC website, or "other—please specify;" perceived knowledge about clinical trials in general (scale ranging from "very little or nothing," to "a lot"), and; a question about how they decided to participate in the therapeutic trial ("spoke with family and/or friends," "my medical provider advised me to participate," "I made the decision on my own, or "decline to answer"). One item asked those who decided not to participate in a therapeutic trial for which they were eligible to select among a list of 19 options the most important one in helping them to decide, e.g., "I do not believe this clinical trial will be effective for me," "Participating in this trial seems too risky, and "I am afraid of possible side effects," as well as an open-ended question about other reasons for declining participation. Finally, two items were administered only to those who provided informed consent for the therapeutic trial. One of these asked for the three main reasons for trial participation, e.g., "My participation will help me to get better," or "My participation may help others to get better," and "I will receive better care by participating in this clinical trial." The second of these two items was open-ended: "Is there anything else you would like to tell us that may help improve participation in AMC clinical trials for people like yourself?"

Statistical Analyses

Summary statistics (mean, standard deviation [SD], and percentages) were generated for quantitative and categorical data to describe the sample and factors influencing decision-making regarding AMC trial participation.

For analysis of open-ended responses to the item querying ideas that may help improve participation in AMC clinical trials, three co-authors reviewed the individual responses and categorized them independently according to a preliminary thematic scheme. Iterative, consensus-building discussions resolved any differences in categorization of all responses.

Results

Eighty-three patients were initially enrolled in the S006 study. Of the 83 patients, 29 (35%) had previously participated in a clinical trial, and of these, 21 (72%) had participated in an AMC trial. Of the 83 patients, 16 participants were deemed ineligible for AMC #S006 after enrollment because they did not meet the criterion of being eligible for an AMC therapeutic trial. Thus, data from 67 AMC #S006-eligible participants were analyzed for this study. Regarding eligibility and enrollment in AMC therapeutic trials, 58 of the 67 (82.1%) participants screened met the eligibility criteria, and 51 (88%) were enrolled. The seven eligible participants who did not enroll (12%) stated that they were not interested in the trial or preferred other options. The reasons for trial ineligibility were abnormal lab values (n = 2) and other protocol-specific exclusion criteria (n = 7).

The final sample (Table 1) was predominately male (92.5%), non-Hispanic (89.5%) and white (67.2%). The average age was 48.3 years. Most of the participants (73.1%) continued their education past high school, and over 40% graduated from college. About 37% reported an annual household income of less than $30,000. All the women (n = 5) reported that they were heterosexual, and most of the men identified as gay (55.2%). Most (61.2%) of the sample reported sexual activity within the past 12 months. The study participants were screened for 11 protocols. The majority of patients were screened for AMC #075 (NCT01193842; 35.8%), a lymphoma treatment trial, or AMC #087 (NCT01822522; 22.4%), a trial treating NADCs. About half of all study participants (55.2%) were screened for lymphoma treatment studies.

Table 2 shows factors influencing clinical trial decision-making. Nearly all (98.5%) of the participants learned about AMC clinical trials from a physician. Most participants (73.1%) knew little to nothing about clinical trials in general prior to screening. About half (50.8%) made the decision on their own regarding whether or not to participate in the trial, 34.3% stated that their medical provider advised them to participate, and 11.9% cited speaking with family and/or friends. The most frequently cited reason for participation in an AMC clinical trial was altruistic, i.e., that participation might help others get better (68.6%), or would help medical providers learn more about the disease (47.1%). One participant who indicated that his reasons for participation were to help others to get better and to learn more about the disease also stated that he wanted to help in the advancement of treatments. Personal benefits from trial participation were reported, e.g., will help me get better (45.1%), receiving better care (21.6%), or one’s health being followed more closely (19.6%).

There were 20 individual responses to the open-ended survey query of how to improve participation in AMC trials. Some participant responses included more than one theme; hence, the number of themes reported was greater than the sum of individual responses. The broad themes, number of reports of the themes, and illustrative quotes are shown in Table 3. The most frequently reported theme entailed recommendations for systems changes to improve the speed of trial availability and access to clinical trials, reduce participant burden, and incentivize participation. Altruism, or helping others and improving treatments was the next most frequently reported theme, followed by the theme of the good quality of AMC care and the importance of the AMC in being at the forefront of clinical trials research.

Discussion

This study is the first within the AIDS Malignancy Consortium to report on participant characteristics and clinical trial decision-making factors of PLWHA presenting for participation cancer therapeutic trials. As reported by others,[16] we observed that most of the participants learned about AMC clinical trials from a medical provider and that most reported a low level of knowledge of clinical trials. This lack of clinical trial knowledge suggests that many PLWHA who are eligible to participate in AMC therapeutic trials have a lack of understanding, or misunderstanding, of trials' scientific methods. For example, prior studies have found that attitudes toward randomization and unease with research studies in general can deter participation.[20] Although 98% reported that they learned about the clinical trial from a medical provider, only about one third reported that their physician advised them to participate in a specific AMC trial, and about half made the decision on their own regarding participation. These findings indicate the importance of physician or medical provider provision of information about clinical trials, and future research might explore how, or under which circumstances, providers make specific recommendations to participate in a trial and how important this advice is to participant decision-making.[19]

Altruistic reasons can motivate certain cancer patients to participate in cancer clinical trials, since ethics compel informed consent documents to state that direct clinical benefit from participation cannot be assured.[21, 22] Helping other patients and helping physicians learn more about their disease were the most frequently cited reasons for participation in an AMC clinical trial. However, a substantial proportion did report perceiving personal benefits from trial participation, such as receiving better care and close monitoring.[23]

Among the recommendations of the 2010 Cancer Trial Accrual Symposium: Science and Solutions[15] was community-level input on trial design and a role for peer mentors who have participated in clinical trials. These approaches can enhance motivation for individual participation through better-designed trials and community outreach, with messages emphasizing altruism as well as autonomy in educating oneself about all options for cancer care. The AMC has active involvement of community representatives in all phases of study development and implementation, and their expertise can be further leveraged based on these findings. For example, a recent study[24] sought community advisory board input to develop their 'Lunch and Learn' intervention aimed to raise awareness and knowledge of AMC clinical trials.

Systems at multiple levels within sites can significantly influence study accrual success.[14] When we asked participants for their ideas on how to improve participation in AMC trials, the most frequently reported theme was recommendations for systems changes to improve the speed of availability and access to clinical trials, reduce participant burden, and incentivize participation. These suggestions present opportunities to the AMC and its participating sites to consider ways to improve the appeal and experience of clinical trial participation and streamline the accrual process. Incorporation of principles of business management, such as commitment to a unifying vision and common incentives,[19] along with community engagement in trial development and accrual processes may increase the efficiency of clinical trial management.

Although the strength of this study is in identifying patient-level decision-making factors influencing the participation of PLWHA in cancer clinical trials there are several limitations. Items assessing decision-making factors were devised *ad hoc* and were not validated. The sample was smaller than the planned n = 100, due largely to slow AMC site uptake and approval of the AMC #S006 protocol. Although the age, gender and race of this study's sample closely mirrored those for AMC participant demographics from 2005–2013 (data not shown), there was a four-fold smaller percent of Hispanic-identified participants in this study. Lymphoma patients were disproportionately represented compared with other cancers within the AMC, due in part to limiting participation to persons eligible for treatment trials only. Further, compared with PLWHA receiving medical care in the U.S., this study's sample had substantially higher representation of males, Caucasians, and those with higher education,[25] reflecting the disproportionate number of lymphoma patients at a comprehensive cancer center whose population characteristics mirrored this sample's. As such, the study's findings may not reflect the full range of decision-making factors participants bring to considering entry into AMC clinical trials. It is notable that about 18% of participants screened for an AMC therapeutic trial did not meet the trials' eligibility criteria. Careful attention to the rationale for study inclusion and exclusion criteria can ensure that trial eligibility screening is appropriately inclusive.[18, 25, 26]

Despite these limitations, this study represents an important first step toward understanding participant-level characteristics and factors influencing the decision-making for AMC cancer therapeutic trial participation among PLWHA. Future work can build upon this study's findings to examine AMC and participating sites' study designs, such as complexity, and community or advocate input, and systems to improve accrual efficiency and reduce participant burden.

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Table 1.

Sociodemographic characteristics of the AMC #S006-eligible participants

Characteristic	Value
Age (M, sd)	48.3 (10.6)
Sex (N, %)	
Male	62 (92.5)
Female	5 (7.5)
Ethnicity (N, %)	
Hispanic	5 (7.5)
Non-Hispanic	60 (89.5)
Unknown	2 (3.0)
Race (N, %)	
White	45 (67.2)
African-American	13 (19.4)
Native Hawaiian	1 (1.5)
Asian	1 (1.5)
American Indian	1 (1.5)
Other	2 (3.0)
Unknown	4 (6.0)
Education (N, %)	
Less than high school graduate	3 (4.5)
High school graduate/GED	14 (20.9)
Some college or technical school beyond high school	19 (28.4)
College or technical school graduate	21 (31.3)
Post college coursework or graduate degree	9 (13.4)
Missing	1 (1.5)
Annual Household Income (N, %)	
$14,999 or less	16 (23.9)
$15,000 to $29,999	9 (13.4)
$30,000 to $59.999	12 (17.9)
Greater than or equal to $60,000	21 (31.3)
Declined to answer	8 (11.9)
Sexual Orientation (N, %)	
Heterosexual or straight	22 (32.8%)
Gay or lesbian	37 (55.2%)
Bisexual	4 (6.0%)
Declined to answer	3 (4.5%)
Missing	1 (1.5%)
Sexual Behavior (N, %)	
Only males	28 (41.8%)

Characteristic	Value
Only females	11 (16.4%)
Both males and females	2 (3.0%)
Not having sex	23 (34.3%)
Declined to answer	2 (3.0%)
Missing	1 (1.5%)
Disease Treated by Protocol (AMC Working Group; N, %)	
Lymphoma	37 (55.2%)
Non-AIDS Defining Cancer	17 (25.4%)
HPV	9 (13.4%)
Kaposi Sarcoma	4 (6.0%)

Table 2.

Participant factors influencing trial participation

Please tell us how you heard about this clinical trial	**N (%)**
Medical provider	66 (98.5)
Participant navigator	1 (1.5)
AMC trials updates via email	1 (1.5)
Before today, how much did you know about clinical trials	
Very little or nothing	27 (40.3)
A little bit	22 (32.8)
Quite a bit	10 (14.9)
A lot	6 (9.0)
Missing	2 (3.0)
How participants made the decision about participating in the AMC clinical trial	
I spoke with family and/or friends	8 (11.9)
My medical provider advised me to participate	23 (34.3)
I made the decision on my own	34 (50.8)
Declined to answer	1 (1.5)
Missing	1 (1.5)
Reason why participants enrolled in AMC trials	
Participation may help others get better	35 (68.6)
Participation will help medical providers learn more about the disease	24 (47.1)
Participation will help me get better	23 (45.1)
I will receive better care by participating in this clinical trial	11 (21.6)
My health will be followed more closely in this clinical trial	10 (19.6)
I trust the clinical trial physician and/or their staff	7 (13.7)
Being in this clinical trial could give me a better chance of being cured	6 (11.8)
I would get some financial reward for my participation	1 (2.0)
I have tried other cancer treatments	2 (4.0)
My partner, family or friends want me to be in the trial	1 (2.0)
This is the only treatment option available for me	1 (2.0)

Table 3.

Qualitative responses to query on ways to improve participation in AMC clinical trials

Theme	Number endorsing	Sample quotes
Systems changes	7	*It would be great if there were more trials and if drugs could be fast track for FDA approval. How can the whole process be expedited so more people can benefit?* *I think more people would participate [in clinical trials] if the dates were coordinated with other appointments.*
Altruism	5	*Just do it because it's a good thing and it will help other people and you can get healed.*
Quality and role for the AMC	4	*I think it's important to help become the frontiers of treatment.* *Your doctors care about their patients. Reaching out to Dr. [X] and getting excellent care from her made a huge difference in how I see the KS I'm dealing with. She urged me to see Dr. [Y].*
Role of physicians/staff in promoting participation	2	*A lot comes from physician/staff explaining studies, they should encourage people to join if they have the disease.*
Increase awareness of AMC clinical trials	2	*Posting advertisements brings awareness - Doctor and research screeners are best to talk to.*
Impact of survey participation	2	*Now I'll pay more attention to clinical trials in the future and maybe one day I will be some help to you.*