General attitudes toward research: a pilot survey of HIV-positive surgical patients

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Background: The general attitude of HIV-positive surgical patients toward research has not been described, and it is uncertain whether interventions aimed at improving general attitudes toward research are required in this group. The aim of this pilot survey was to address the aforementioned paucity in the literature.
Methods: This was a prospective survey of 39 HIV-positive surgical patients. The 7-item Research Attitudes Questionnaire (RAQ) and a demographic characteristics questionnaire were administered to each study participant. Likert responses for the RAQ were converted into numeric values, and cumulative research attitude scores were computed for each study participant. A descriptive analysis of study participant responses to the RAQ was performed. Statistical associations between demographic characteristics and cumulative research attitude scores were also assessed.
Results: Depending on the RAQ item, between 74.3% and 95.9% of study participants responded positively toward research. Negative responses ranged between 0.0% and 10.3%, while neutral responses to RAQ items ranged between 2.6% and 23.1%. Female study participants had lower median research attitudes scores when compared with their male counterparts ($p = 0.014$).
Conclusion: In general, study participants expressed a positive attitude toward research. The proportion of neutral responses for some RAQ items suggests there are certain aspects of research which require clarification to prospective research participants. Efforts should be made to improve female HIV-positive surgical patients' overall attitude toward research.
Keywords: HIV, Surgery, Research attitudes.

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Introduction

There are over 30 million people worldwide living with HIV/AIDS, the majority of whom live in sub-Saharan Africa.[1] Many of these individuals might suffer complications from HIV infection, which can only be effectively managed through surgical intervention.[2] There is evidence which suggests that South African HIV-positive patients are reluctant to participate in non-surgical clinical research studies.[3] This reluctance to participate might also extend to surgical clinical research studies. Participation of HIV-positive surgical patients in research is necessary if this group is to reap the benefits of clinical trials and future advances in surgical science. General attitudes toward research play an important role in a patient's decision to participate in research.[4] However, the general attitude of HIV-positive surgical patients toward research has not been described, and it is uncertain whether interventions aimed at improving the general attitude toward research are required in this group. Therefore, the aim of this study was to provide a preliminary report of HIV-positive surgical patients' overall attitude toward research.

Methods

Study design and setting:

This was a prospective pilot survey conducted at the Inkosi Albert Luthuli Central Hospital (IALCH) in Durban, South Africa.

Study sample:

The study sample consisted of 39 consecutive adult (≥ 18 years old) HIV-positive colorectal surgery patients who attended IALCH between 01 October 2016 and 31 March 2017. HIV status was determined from laboratory reports or admission notes in the patients' medical records. An additional inclusion criterion for this study was that all study participants were required to provide written informed consent and comply with the study procedures (ie. completion of the survey questionnaire). Furthermore, individual study participants were only allowed a single opportunity to complete the survey questionnaire (ie. multiple attempts at completing the survey questionnaire by the same patient were excluded).

Data collection and data management:

Study participant age, gender, demographic group, education, and prior involvement in clinical research studies was collected using a self-administered, paper-based demographic questionnaire. In addition, study participants were required to complete the Research Attitudes Questionnaire (RAQ).[4] This instrument was developed to measure attitudes toward medical research and initially consisted of 11 items, with a 5-point Likert response ("strongly disagree" to "strongly agree") for each item. This was later shortened to a 7-item scale by Rubright et al., which showed improved internal consistency and dimensionality over the original scale.[4] The 7-item RAQ was used in this research. The questionnaires used in this study were available in English and isiZulu. A bi-lingual interpreter, who was trained on the study protocol, was also present at the time a study participant completed the questionnaire to address any questions which might have been raised by the study participant. The data recorded on the aforementioned questionnaires was transferred to a password-protected electronic database in preparation for the statistical analysis.

Statistical analysis:

Descriptive statistics were used to summarise responses for the demographic questionnaire and the RAQ. Likert responses for each of the items comprising the RAQ were allocated incremental point scores ranging between 1 and 5 points, with "strongly disagree" = 1 point and "strongly agree" = 5 points. Cumulative research attitude scores were then computed for each study participant. Bivariate statistical associations between various demographic variables and cumulative research attitude score were assessed using the Mann-Whitney test. Results for this aspect of the statistical analysis are presented as median research attitude scores, interquartile ranges (IQR), and corresponding p-values. A result with a p-value < 0.050 was considered statistically significant. All statistical analyses were performed using the Statistical Package for the Social Sciences version 24.0 (IBM Corp, USA).

Ethical approval:

This study was approved by the Biomedical Research Ethics Committee of the University of KwaZulu-Natal, South Africa (Protocol BE499/16).

Results

Description of the study sample:

The median age of the study sample was 36.0 (IQR: 33.0–47.0) years old, with 25/39 (64.1%) study participants being ≤ 40 years old. A total of 27/39 (69.2%) study participants were female. Thirty-three study participants (84.6%) had completed high school. Only 9/39 (23.1%) of study participants reported prior involvement in research. Twenty-one study participants (53.8%) had prior knowledge of medical research which was gained through interactions with friends, relatives or healthcare workers.

Distribution of Research Attitudes Questionnaire responses:

The distribution of responses to the items comprising RAQ in this study is shown in Table 1. A preponderance of positive responses (ie. "Agree" or "Strongly agree") was noted for all questionnaire items, ranging between 74.3% for item 5 and 95.9% for item 1. Negative responses (ie. "Disagree" or "Strongly disagree") ranged between 0.0% for item 1 and 4, and 10.3% for item 6. Neutral responses ranged between 2.6% (item 7) and 23.1% (item 5).

Characteristics associated with research attitudes score:

The median research attitudes score for the study sample was 28.0 (IQR: 26.0-30.0) points. Table 2 shows the results of the statistical analysis performed to identify characteristics associated with research attitudes score in the study sample. Of the various characteristics investigated in this study, only gender was found to be statistically associated with research attitudes score. Specifically, the median research attitudes score was higher in males when compared with females (30.0,

Table 1. Distribution of responses for the Research Attitudes Questionnaire, expressed as a frequency (%) for each question

Questionnaire item	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Cumulative responses
1. I have a positive view about medical research in general	0 (0.0)	0 (0.0)	2 (5.1)	31 (79.5)	6 (15.4)	39 (100.0)
2. Medical researchers can be trusted to protect the interests of people who take part in their studies	0 (0.0)	1 (2.6)	5 (12.8)	27 (69.2)	6 (15.4)	39 (100.0)
3. We all have some responsibility to help others by volunteering for medical research	0 (0.0)	2 (5.1)	3 (7.7)	28 (71.8)	6 (15.4)	39 (100.0)
4. Society needs to devote more resources to medical research	0 (0.0)	0 (0.0)	2 (5.1)	27 (69.2)	10 (25.6)	39 (100.0)
5. Participating in medical research is generally safe	0 (0.0)	1 (2.6)	9 (23.1)	23 (61.5)	5 (12.8)	39 (100.0)
6. If I volunteer for medical research, I know my personal information will be kept private and confidential	1 (2.6)	3 (7.7)	2 (5.1)	27 (69.2)	6 (15.4)	39 (100.0)
7. Medical research will find cures for many major diseases during my lifetime	1 (2.6)	2 (5.1)	1 (2.6)	27 (69.2)	8 (20.5)	39 (100.0)

Table 2. Characteristics associated with/not associated with research attitudes score			
Characteristic	**Level**	**Median research attitudes score (IQR)**	**p-value**
Age			0.141
	> 40 years old	29.0 (26.8–30.5)	
	≤ 40 years old	27.0 (26.0–28.5)	
Gender			0.014
	Male	30.0 (27.3–31.8)	
	Female	27.0 (26.0–28.0)	
At least high school education			0.608
	Yes	28.0 (26.0–30.0)	
	No	27.5 (26.8–31.5)	
Prior participant in research study			0.299
	Yes	28.0 (27.5–29.0)	
	No	27.0 (26.0–30.0)	
Prior exposure to research through friends or media			0.165
	Yes	28.0 (26.5–30.0)	
	No	27.0 (25.8–28.3)	

IQR: 27.3–31.8 versus 27.0, IQR: 26.0-28.0; p = 0.014).

Discussion

Informed consent is a requirement for research which involves human participants, and one of the most important determinants of whether an individual consents to participation in a research study is their personal attitude towards research.[5] We provide a preliminary report of HIV-positive surgical patients' general attitudes toward research, as measured by the RAQ. While it might be argued that the RAQ has not been validated in South African settings or in HIV-positive populations, our decision to use this questionnaire was based on its simplicity and the general rule of thumb in survey research which discourages the development of new questionnaires where there are already relevant questionnaires in existence.[6]

The bulk of the responses to items comprising the RAQ suggest a generally positive attitude toward research in our study sample. While negative responses to items comprising the RAQ were minimal, the proportion of neutral responses for some items suggests that there are areas of research which require clarification when research study staff approach prospective research participants. This includes assuring prospective research participants that bona fide researchers are tasked with ensuring that the interests of research participants are protected and are held accountable by institutional review boards. In addition, the risks associated with the specific research being conducted should also be clearly explained to prospective research participants. For instance, the risks of injury associated with a non-interventional observational study would be lower than that which should be anticipated for an interventional phase I clinical trial, wherein side effects and the overall safety of a drug are being established. This should eliminate most of the uncertainty related to whether "participating in medical research is generally safe".

Female HIV-positive surgical patients were found to have lower median research attitudes scores when compared with their male counterparts. This is an important finding as the HIV epidemic in sub-Saharan Africa disproportionately afflicts more women than men.[1] It is therefore likely that a considerable proportion of the HIV-positive surgical population is female, which the results of our descriptive statistical analysis appears to confirm. Patient attitudes are often shaped by their level of awareness of health- or medical-related subjects.[7] Therefore, the lower research attitudes scores of the female group in our study are a potential reflection of lower levels of research awareness in this group. This explanation does not appear unrealistic, as low awareness of medical research amongst African women has been previously reported.[8] Efforts should be made to improve female HIV-positive surgical patients' overall attitude toward research. This could include targeted interventions which seek to improve awareness levels of medical research in this group.

Conclusion

We provide a preliminary report of HIV-positive surgical patients' overall attitude towards research. Study participants expressed an overall positive attitude toward research. We identified areas of study safety and study participant protection which require appropriate clarification to prospective research participants. Efforts should be made to improve female HIV-positive surgical patients' overall attitude toward research. As this was a pilot survey, additional research is required to confirm our findings and explore interventions for improving female HIV-positive surgical patients' overall attitude toward

research. This might include interventions which seek to improve awareness of medical research in this group.

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