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The views and experiences of HIV research participants in sub-Saharan Africa: a worked example of a qualitative systematic review

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Background

HIV clinical trials are increasingly being conducted in sub-Saharan Africa [1–3]. There is a tension between the pressure to increase levels of research participation whilst at the same time ensuring informed consent and the protection of participants' rights [4,5]. Researchers need to be aware of the particular ethical issues that underpin HIV research conducted in low-income settings. This necessitates hearing from those who have agreed to participate in research and who have experienced the research process.

This qualitative systematic review aims to synthesise existing qualitative literature to answer the question: What are the views and experiences of HIV research participants in sub-Saharan Africa? The review aims to highlight key issues that need to be addressed to ensure high-quality ethical HIV research practice in sub-Saharan Africa.

Methods

This meta-synthesis employs the meta-aggregation approach developed by the Joanna Briggs Institute (JBI) [6]. This approach involves assembling the findings from primary studies and categorising them based on similarity in meaning to reach overarching conclusions [7]. Studies that focus on qualitative data, including but not limited to designs such as phenomenology, ethnography, grounded theory and action research, are considered. The review includes studies whose

participants are current or former adult HIV research participants from sub-Saharan African countries.

Nine databases (CINAHL, MEDLINE, ASSIA, PsycINFO, Web of Science, Embase, The Cochrane Library, Joanna Briggs Institute Library and African Index Medicus) were searched in June 2013, followed by hand searching of reference lists. Studies published between 1995 to present were considered. The grey literature included reports from the World Health Organization and UNAIDS, while hand searching was carried out from Google web and the Google Scholar database. Table 1 shows the search strategy used.

Results

The systematic search yielded 8334 articles, while another four papers were identified from hand searching. Out of these, only 12 studies met the inclusion criteria and were critically assessed using the JBI's Qualitative Assessment and Review Instrument (QARI). Following quality appraisal, one study [8] was excluded on the basis of poor quality. This left 11 studies to be included in the review. Figure 1 presents the details of the search results.

Main characteristics of included studies

All 11 included studies were published within the past decade, between 2004 and 2012; and of these,

Table 1: Search strategy

Key concept	Synonyms/related terms/alternative forms for key words
<i>Views and experiences</i>	view*, experience*, understand*, comprehen*, concern*, opinion*, attitude*, perspective*, belie*, knowledge, perception*
<i>Research participants</i>	research participant*, research subject*, study participant*, study subject*, healthy volunteer*, trial participant*, trial subject*, lay people, community member*, public, opinion leader*, stake holder*, client*, patient*, family member*
<i>HIV research</i>	HIV, HIV? AIDS, AIDS, malaria, TB, tuberculosis, vaccine trial*, health? related research, health research, health service* research, biomedical research, research, clinical research, medical research, clinical trial*, social science research, health survey*, experimental stud*
<i>Sub-Saharan Africa</i>	sub? Saharan Africa, Africa, African countries, low income countr*, resource limited countr*, resource limited setting*, developing countr*, non? Western countr*, developing world, under? developed countr*, poor countr*, low resource setting*, third world nation*
<i>Informed consent</i>	Informed consent, consent*, ethic*, bioethics*, participation
? and *, wild-card characters used in the searches	

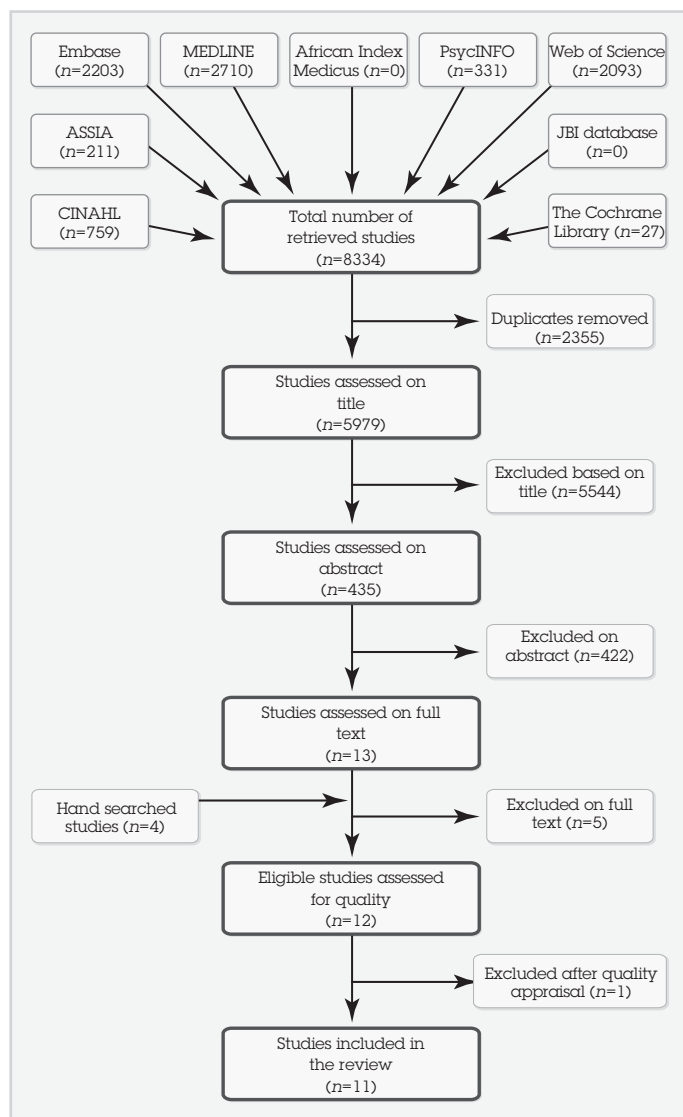


Figure 1: The process of identifying studies for inclusion in the review.

eight studies [9–16] were recently published (2011 or 2012). The included studies represented only five sub-Saharan African countries; four from South Africa [11,12,17,18], one from Kenya [10], three from Tanzania [9,15,16], one from both South Africa and Zimbabwe [13], and one from both Zimbabwe and Malawi [14]. In addition, one study [19], was carried out in three countries, one Caribbean and two African, but did not provide details of the specific countries.

Findings

The 11 studies reported findings from a total of 461 participants. A total of 58 findings were extracted from the included studies and were included in the synthesis. The findings were grouped into eight categories based on similarity of meaning, and were further synthesised in a meta-synthesis which yielded four synthesised and directive findings to be used as the basis for evidence-based practice and evidence-based recommendations. These were:

(i) Participation in HIV research is related to perceived personal benefits and benefits for wider society.

- (ii) Research participation is influenced by fear of social or physical harm.
- (iii) Poor understanding of research processes and concepts is common.
- (iv) Social relationships and domestic contexts have a significant impact on HIV research participation and adherence.

Table 2 presents the categories and synthesised findings from the review. The latter will be discussed in turn below.

Participation in HIV research is related to perceived personal benefits and benefits for wider society

This review indicates that individuals were motivated to participate in HIV research due to a range of perceived benefits. These include personal gains such as lifestyle change [15]; accessing prompt and adequate medical care and treatment [15,16,18,19]; receiving information about their health status [14,17]; and protection from infections and rape [13,14]. These benefits were motivations for research participation as cited by one participant:

'I have not been sick since I knew that I am HIV-positive but I know that if you are HIV-positive you must always check your CD4 count, you must not wait until your CD4 count goes down. I think that is the thing that made me decide to come and join the study even though they told me that they are doing research but I wanted to see if they were going to help me' [12].

Interestingly, the review showed that financial benefits were rarely cited as primary motivations for research participation. For those who mentioned money as a motivation, it was as an added benefit rather than a primary motivation as illustrated by one participant:

'I would say money also helped me in addition to the other things that I was getting here' [12].

The review also indicates that participants were motivated to take part in research for altruistic reasons [11–13,15]. Participants who mentioned altruism as a motivating factor believed that their participation could make a positive contribution to society, as illustrated in the statement:

'I have decided to sacrifice myself; I have already sacrificed to rescue this world. If it is a vaccine, then it will help other people ... Jesus died on the cross to save others. So, I sacrifice myself too ...' [15].

This review has shown that perceived benefits are vital for motivating participation in HIV research. Previous studies have had similar findings [20–23]. Researchers should endeavour to disclose fully all

Table 2: Categories and synthesised findings from the review

	Categories	Synthesised findings
1	Perceived personal benefits	Participation in HIV research is related to perceived personal benefits and benefits for wider society
2	Motivating factors for research participation	
3	Fears related to HIV stigma	Research participation is influenced by fear of social or physical harm
4	Fears related to potential harm associated with the HIV vaccine	
5	Misconceptions about HIV research	Poor understanding of research processes and concepts is common
6	Mixed understanding of the research	
7	Influence from social relationships	Social relationships and domestic contexts have a significant impact on HIV research participation and adherence
8	Economic and domestic factors	

the likely benefits, including individual benefits and those for wider society.

Research participation is influenced by fear of social or physical harm

Participation in HIV research can be associated with considerable fear and uncertainty, mainly due to HIV stigma and worry about potential harm from research interventions. For example, the fear of finding out one's HIV sero-status was a common barrier to research participation [10,11,15], as illustrated by this quote:

'I think people can come [to participate in an HIV vaccine trial] but they fear knowing their HIV status and stigma from people when they know your status ... There is no problem in joining the protocol; the fear is knowing their HIV status. What will be done to me once they know my HIV status?'

This fear of stigmatisation cuts across both HIV-positive and HIV-negative research participants [10].

Other findings illustrate fears related to uncertainties about HIV research interventions, such as the possibility of acquiring HIV through the vaccine, possible harmful effects related to the vaccine [9,16], and the efficacy of the research interventions [13]. Related to this finding, it was obvious that some participants did not trust the researchers as they mentioned being unsure of what their intentions were [9]. Participants also expressed fears related to specific trial interventions such as blood draws, which were perceived to be harmful to health [16].

Previous literature has also shown that HIV research evokes significant fears [24–26]. Since the majority of HIV research studies will require a confirmation of one's HIV sero-status, it is crucial that fears related to HIV testing are addressed early in the research. HIV stigmatisation can have other negative effects such

as discrimination, which can result in stress or problems within the family or community. HIV research participants require continuous assessment to identify potential negative effects, and counselling and support facilities should be available if required. Research nurses can be helpful in this role since they possess counselling skills and interact more with research participants compared to the rest of the research team.

Poor understanding of research processes and concepts is common

This review indicates that misconceptions about HIV and related research processes are still common among HIV research participants. For example, some participants thought that participation in HIV research meant that someone was HIV positive [11]. This resulted in some of them becoming reluctant to participate as reflected in this illustration:

'If I were positive I would join all these programmes but because I am HIV negative I just don't care. I feel this way after testing; before testing I just had faith that I was negative' [11].

Furthermore, the review reveals mixed understandings of the research process and of some key concepts in HIV research. Some concepts of the research would be understood while others would not. For example, some studies revealed that participants had understood well the study purpose and did not feel forced to participate in the research, while at the same time it was difficult for some participants to fully understand concepts such as randomisation [16,19]. This can be confirmed from the two illustrations below which were from one study:

'This research was about the product ... like the gel that you put into the vagina if it can prevent STDs.'

'She said they decided to give her AZT because she had had a miscarriage' [19].

In relation to this finding, the review shows that repeated explanations are necessary to improve understanding of key concepts among some participants [18].

Another misconception was related to misunderstanding the overall goal of HIV research referred to by some authors as 'therapeutic misconception' [8]. This is when some participants attribute the study intervention as being intended for their treatment (rather than for research).

When such misconceptions occur, there may be a lack of voluntary participation and informed consent [27]. Some studies suggest that misconceptions arise out of problems with language and the use of translators has been recommended as a strategy to enhance understanding of the research among lay populations who may not speak English [28]. However, this may present some challenges such as the misinterpretation of research concepts, especially when lay translators with no knowledge of scientific terms are used. In addition, some scientific terms do not exist in local languages and therefore cannot be translated directly. Therefore, employing qualified and knowledgeable research staff to undertake informed consent, or providing in-depth training for lay persons involved in eliciting informed consent, is essential.

Social relationships and domestic contexts have a significant impact on HIV research participation and adherence

This review reveals that social, economic and domestic factors are critical in determining HIV research participation and adherence to study requirements among participants in sub-Saharan Africa. Findings indicate that participants encountered a number of discouragements from family, friends or even non-research medical personnel which had a negative influence on their decisions to participate [9,15].

In some cases, individuals were willing to participate in principle, but could not due to the strong pressure exerted on them by close relatives or intimate partners as illustrated by this quote:

'My fiancé did not accept it completely! And he warned if I enrol in the trial our relationship would end; even though he had already paid a dowry, he would cancel our marriage plans ... I felt bad because I had already committed myself with that relationship and I saw there is no need to force him' [9].

The findings show that failure to adhere to trial interventions was often attributed to the influence of intimate partners, especially where study interventions affected their sexual life such as using condoms, diaphragms or microbicide gel [12,13]. This was illustrated by one participant:

'Yes I did have a problem with my partner – he did not want to use condoms. When I asked him to use condoms, he said it means I do not trust him, you see' [12].

These barriers appear to be more common among female participants. This review also identifies a range of other barriers that affected HIV research participation, for example, financial and domestic commitments [11], and the requirement to travel long distances [12].

Despite the challenges and barriers affecting HIV research participation in sub-Saharan Africa, findings from this review show that there are some factors that motivated research participation. For example, participants noted that the kind and caring treatment they received from the study team was a strong motivation to stay enrolled:

'I think it [staff attitude] helped me because when I thought about coming to the clinic I knew that I am going to be laughing and talking to people who care about me and I loved to come to the clinic' [12].

Encouragement from close family members also motivated participants to participate [12].

Although some of the social influences were facilitators to research participation, the majority acted as barriers and seemed to be highly associated with a lack of understanding of HIV research by the general population. Sensitisation about HIV research programs therefore should be given a priority in sub-Saharan Africa, and such activities should target the entire community. Economic and domestic factors seemed to affect women more than men, and could be attributed to gender inequalities identified in African settings [29]. These factors can be addressed by strategies such as reimbursements (for time spent on the research study) and transport refunds [27].

Conclusion

The results of this review show a willingness by participants to participate in HIV research. However, their understanding of the process can be limited and the experience may cause anxiety or have negative consequences. Furthermore, sustained participation may become problematic due to social pressure or social commitments. The review findings suggest that there is an ongoing need to develop better ways to explain research processes and to support the participants when/if they encounter problems. Research nurses have a key role to play here. Interestingly, there were no studies that explored reasons for drop-out after enrolment or that explored the post-trial experience. This is an important gap in our current understanding of the experience of HIV research participation.

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