

# BMJ Open Role of religious beliefs in adherence to antiretroviral therapy in the Cape Town metropole: a study protocol

Ivo Nchendia Azia <sup>1</sup>, Shernaaz Carelse,<sup>2</sup> Anam Nyembezi,<sup>1</sup> Ferdinand C Mukumbang <sup>3</sup>

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<sup>1</sup>School of Public Health, University of the Western Cape, Cape Town, South Africa

<sup>2</sup>Department of Social Works, University of the Western Cape Faculty of Community and Health Sciences, Cape Town, South Africa

<sup>3</sup>Department of Global Health, University of Washington, Seattle, Washington, USA

## Correspondence to

Ivo Nchendia Azia;  
aziaanster@gmail.com

## ABSTRACT

**Introduction** There are presently over four million people living with HIV (PLHIV) in the South African national antiretroviral therapy (ART) programme. However, some ART programmes are battling poor ART adherence emanating from patient-related factors, including their religious beliefs. In this paper, we outline a study protocol to understand the adherence behaviours of Pentecostal Christians living with HIV to ART and to develop guidelines that can be used to strengthen ART adherence.

**Methods and analysis** We propose an exploratory multimethod research design. In phase 1, a scoping review will be conducted. The data captured in this phase will be put into charting forms, analysed qualitatively, and then collated and summarised to hypothesise the relationship between religious beliefs and ART adherence. In phase 2, an explanatory qualitative approach will be used. Semistructured interviews will be conducted with purposefully selected religious leaders, Pentecostal Christians living with HIV who are not adhering to ART and healthcare workers delivering ART at selected healthcare facilities in the Milnerton subhealth district. The qualitative data obtained in this phase will be transcribed verbatim and analysed thematically using the ATLAS.ti v.8 software program towards strengthening the hypothesised relationship between religious beliefs and ART adherence. In phase 3, intervention mapping and nominal group techniques will be applied with purposefully selected stakeholders to develop guidelines to strengthen ART adherence among PLHIV.

**Ethics and dissemination** Phase 1 of the study will not require ethics approval. Ethics approval for phases 2 and 3 has been received from the University of the Western Cape Biomedical Research and Ethics Committee and the Western Cape Department of Health. Informed consent forms will be obtained from all participants at the different phases of the study. The study findings will be disseminated through publications in scientific journals, presentations at conferences and workshops aimed at improving ART adherence.

## INTRODUCTION

South Africa has a disproportionate burden of HIV. Of the estimated 38 million people living with HIV (PLHIV) globally, 7.97 are in South Africa.<sup>1</sup> In 2016, the South African government started implementing the

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study will use a multimethod qualitative exploratory/explanatory design to hypothesise the role of religious beliefs in adherence to antiretroviral therapy (ART) among Pentecostal Christians living with HIV in the Cape Town metropole.
- ⇒ The study will systematically explore the existing relationships between Christian religious beliefs and adherence to ART among Pentecostal Christians living with HIV in sub-Saharan Africa by a scoping review and strengthen this evidence through empirical qualitative studies.
- ⇒ The study proposes intervention mapping and nominal group techniques to guide the development of guidelines that can be used to strengthen ART adherence among Pentecostal Christians living with HIV.
- ⇒ The modest number of participants proposed by the study may limit the generalisation of the findings to the wider population of Pentecostal Christians living with HIV.
- ⇒ The purposeful selection of study participants may increase the possibility of missing out on some information-rich participants concerning religious beliefs impacting ART adherence among Pentecostal Christians living with HIV.

UNAIDS's recommendation to test and treat PLHIV irrespective of their CD4 count or WHO clinical staging.<sup>2</sup> Consequently, there are over four million PLHIV in the South African national programme, rating it the largest globally.<sup>2</sup>

PLHIV who achieve undetectable viral loads can live long and healthy lives and have a minimal risk of sexually transmitting HIV to their partners.<sup>3–5</sup> Although optimal antiretroviral therapy (ART) adherence yields great benefits, it is admittedly a demanding process requiring those on ART to remain committed to taking at least 95% of ART as prescribed.<sup>6–8</sup>

Suboptimal ART adherence leads to treatment failure, increased risk of HIV transmission, disease progression from HIV to AIDS and mortality.<sup>9–11</sup> Even though PLHIV

are usually aware of the consequences of not adhering to ART, optimal levels of adherence are seldom attained among patients due to multilevel factors, including religious beliefs.<sup>12–14</sup> These religious beliefs prompt some PLHIV to often use alternative therapy from religious prophets and pastors to ‘cure’ HIV.<sup>15–17</sup>

Generally, religion plays an important part in the lives of many people in the world. Over 88.7% of the world’s population today profess to a religion.<sup>18</sup> Africa has the highest number of Christians globally, with more than 47% of the population evangelised and 49% Christianised.<sup>19</sup> For example, in South Africa, at least 86% of South Africans are Christians and 52% of them attend religious services at least once a week.<sup>20</sup> Among the Christian denominations in sub-Saharan Africa (SSA), Pentecostal churches are the fastest and largest growing movement.<sup>21</sup> Pentecostal movements are often led by young pastors whose preaching places emphasis on prophecies, miracles and the spiritual healing of challenging diseases such as HIV.<sup>22–24</sup> PLHIV are also becoming more attracted to Pentecostal churches partly due to the testimonies shared to them by other Christians or through claims often made by pastors through social media that they have spiritual powers to heal them of HIV.<sup>12 16 23</sup> For instance, in Botswana, Pentecostal churches are mushrooming and one of their doctrines is that God heals HIV.<sup>23</sup> Such religious beliefs are among the reasons why some PLHIV do not adequately adhere to ART.<sup>25 26</sup>

The impact of religious beliefs on the prevention and management of HIV in SSA has been documented.<sup>27</sup> Various faith-linked organisations such as the Islamic Relief, Tearfund, Caritas Internationalis, World Conference of Religions for Peace, and the International Network of Religious Leaders Living with HIV are cooperating with major stakeholders like the WHO and UNAIDS to curb HIV transmission and strengthen HIV care and ART adherence.<sup>27</sup> However, there have also been instances where some faith-based organisations have contributed to inadequate ART adherence among PLHIV. Beliefs that pastors can ‘cure’ HIV by the ‘laying of hands’ on patients have been demonstrated to negatively impact patients’ adherence to ART in SSA.<sup>12 16 28</sup>

To better understand patients’ beliefs that may influence HIV care before ART initiation in Ethiopia, it was found that beliefs about ART, sexual transmission of HIV and use of holy water for HIV treatment were often inaccurate.<sup>28</sup> In Ethiopia, Teshome *et al.*<sup>29</sup> also estimated the level of ART adherence among PLHIV and the factors associated with adherence in 20 randomly selected ART clinics and found that being a young Protestant was negatively associated with adherence. From the healthcare workers’ perspectives, religious practices such as fasting, using spiritual cures such as holy water and prayers are among the contributors to inadequate ART adherence among PLHIV.<sup>25 30</sup> In a qualitative study conducted in Zambia to conceptualise factors obstructing patients from taking ART, healthcare workers agreed that religious leaders (RLs) such as pastors conducted healing

services in their communities and persuaded patients to discontinue ART.<sup>16</sup> The disengagement of patients from HIV care has also been attributed to the use of religious cures<sup>31</sup> and such influences undermine the medical community’s evidence-based effort to initiate and retain PLHIV on ART.<sup>25 29</sup>

In South African communities, some influential RLs have been documented for perpetuating miraculous healing by using undesirable practices. Some documented practices include eating of grass and snakes, drinking of petrol, and spraying of insecticides on church members.<sup>32</sup> Some RLs have also been identified as primary sources of HIV misinformation, causing some PLHIV to continue to show unwavering faith in their spiritual cures in antagonism to ART.<sup>17</sup>

To strengthen ART adherence among PLHIV with Pentecostal beliefs, more cooperation with their RLs has been recommended.<sup>25 30 33</sup> Nonetheless, in SSA, the literature describing collaborations or religious-embedded interventions to improve ART adherence among Pentecostal Christians living with HIV is limited.<sup>34 35</sup> Data regarding such collaborations or religious-embedded adherence interventions are predominantly anecdotal and often obtained from studies with limited respondents or no established empirical methods.<sup>13</sup> The varied nature of support required from various stakeholders to conduct spiritual assessments and provide spiritual care in healthcare settings has also been reported as a setback to conducting religious-embedded ART adherence interventions.<sup>35</sup> Even so, there is still a dearth of data concerning religious beliefs that influence ART adherence among Pentecostal Christians living with HIV in South Africa.

### Aim of the study

This protocol proposes a study aimed to understand the adherence behaviours of Pentecostal Christians living with HIV to ART and to develop guidelines that can be used to strengthen ART adherence.

### Objectives of the study

The objectives of the study will be addressed at different phases.

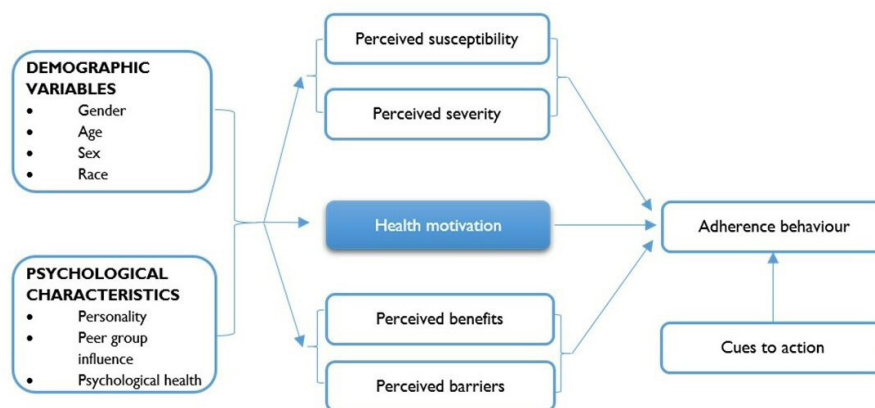
#### Phase 1: scoping review

Using a scoping review methodology, in phase 1, we aim to explore and hypothesise the relationships between religious beliefs and ART adherence among Pentecostal Christians living with HIV in SSA.

#### Phase 2: qualitative studies

Three qualitative studies will be conducted. These qualitative studies will address the following aims:

- ▶ To explore and describe the perspectives of healthcare workers on religious beliefs that affect ART adherence among Pentecostal Christians living with HIV in Milnerton.



**Figure 1** The health belief model flow chart provides a possible explanation of why people living with HIV take action to adhere to antiretroviral therapy or not. Obtained from Mukumbang *et al.*<sup>40</sup>

- ▶ To explore and describe religious beliefs that affect ART adherence among Pentecostal Christians living with HIV in Milnerton.
- ▶ To explore and describe the role that Pentecostal RLs play in ART adherence among Pentecostal Christians living with HIV in Milnerton.

#### Phase 3: development of guidelines

- ▶ To develop ART adherence guidelines that can be used to strengthen ART adherence among Pentecostal Christians living with HIV in Western Cape, South Africa.

#### Theoretical framework

This study will be guided by the health belief model (HBM).<sup>36</sup> HBM is a cognitive interpersonal model that views humans as rational beings with the ability to behave in a way that will help them to mitigate perceived threats to diseases and thus achieve what they perceive as benefits to their actions.<sup>37</sup> To explain or predict why people will take action to prevent or screen or control a health problem, the following constructs are used by HBM: perceived susceptibility, perceived severity, perceived benefits, perceived barriers and cues to take action.<sup>38</sup> The proposed HBM that will be used to guide this study is illustrated in a flow chart in [figure 1](#).

The following constructs of HBM speak to this study:

##### Perceived susceptibility

This refers to patients' self-evaluation of the risk of developing problems due to non-adherence to ART or reliance on religious beliefs to achieve and maintain a lower than detectable viral load. The role of religious beliefs, such as 'I am covered by the blood of Jesus and thus cannot be killed by HIV', will be examined concerning participants' perceived susceptibility. It is understood that such beliefs can placate patients' minds not to see any risk of developing serious health problems even if they do not take ART as prescribed.

##### Perceived severity

This refers to self-assessment of the harshness of the consequences to a patient of not adhering to ART. These consequences of poor ART adherence include developing opportunistic infections, becoming very sick, and eventually developing and succumbing to AIDS and death. The position of religious beliefs, such as 'HIV can kill the body and not the soul', implies that if patients die due to non-adherence to ART their souls can still live happily after. Such beliefs can diminish the self-assessment of the severity of the dangers of inadequate ART adherence by some PLHIV. Such beliefs will be studied in connection with perceived severity.

##### Perceived benefit

This deals with an individual's perceptions about the benefits of adhering to ART, such as achieving a lower than detectable viral load and enjoying good health. Religious beliefs such as only God alone can heal HIV are often mutually exclusive to the belief that ART can heal HIV. Consequently, PLHIV holding on to such beliefs will rely on the healing power of God and default on taking ART. Such beliefs will be examined concerning the perceived benefits.

##### Perceived barriers

These relate to an individual's evaluation of the barriers to taking ART, such as food restrictions, side effects and pill burden. If PLHIV believe in the benefit of receiving instant healing from spiritual cures such as prayers, holy water and the anointing oil, they will prefer such spiritual cures to ART. Such religious beliefs will be explored concerning perceived barriers.

Although HBM provides a plausible theoretical framework to explore non-adherence behaviours among people on ART with Pentecostal beliefs, it has been criticised for postulating that everyone has the same access and information about a disease.<sup>39</sup> Also, it fails to show what mechanisms are triggered and under what context of action they function to explain the expected health outcomes.<sup>40</sup>

## METHODS AND ANALYSIS

### Study design

We propose an exploratory multimethod research design. Phase 1 will entail a scoping review, followed by a qualitative exploratory and descriptive approach to explore the role of religious beliefs in ART adherence among Pentecostal Christians living with HIV in the Milnerton subhealth district.

#### Phase 1

We will use Arksey and O'Malley's<sup>41</sup> framework and the Joanna Briggs Institute guidelines for conducting scoping reviews<sup>42</sup> to explore the existing relationships between religious beliefs and ART adherence among Pentecostal Christians living with HIV in SSA. A scoping review protocol for this study has already been published.<sup>43</sup> The Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols checklist is also attached as online supplemental appendix 1. We intend to collect data for the final scoping review report between 25 August and 30 September 2022. The research question that will guide the final scoping review is 'In what ways do religious beliefs impact ART adherence among Pentecostal Christians living with HIV in SSA?' Data for the scoping review will be systematically searched from the following databases: Web of Science, PubMed/Medline, Academic Search Complete, EBSCOhost interface and Scopus. Free-text word search on bibliographies and data search from WHO Repository, National Health Departments, Academia.edu and Google Scholar will be done.<sup>43</sup> Grey literature will also be searched for theses and dissertations, as well as open access including reports from conference proceedings. Predetermined study selection criteria will be used to select eligible studies published in English between January 2010 and February 2022.<sup>43</sup> Data will be extracted from articles that meet the inclusion criteria and captured into a data charting form. Finally, the data will be collated, summarised and described according to the research questions and the purpose of the study. A narrative approach will be used to present the findings of the scoping review.<sup>43</sup>

#### Phase 2

In this phase, we will use an exploratory/explanatory qualitative design to investigate how religious beliefs influence ART adherence among Pentecostal Christians living with HIV in the Cape Town metropole. The data collection for this phase is planned to take place between 25 September 2022 and 30 November 2022.

### Study setting

This study will be conducted in Du Noon Clinic and in Joe Slovo and Du Noon informal settlements in the Milnerton subhealth district. Du Noon Clinic is the largest primary healthcare facility constructed over the past decade in the Cape Town metropole health district.<sup>44</sup> It was constructed to mitigate the chronic poor health service access experienced by the economically deprived communities within

its catchment population.<sup>44</sup> The clinic serves a varied community in terms of race, nationality, culture and income echelons. Patients from Du Noon and Joe Slovo constitute the lower-income clients, while those residing in Milnerton, Parkland and Table View are the middle-income and higher-income clients of the clinic.

According to the operational manager for the HIV programme in Du Noon Clinic, poor retention in care and ART adherence is a challenge as over 600 PLHIV are not adhering to ART. This number includes those who have defaulted ART from 3 months to a year. These ART defaulters are known to often return with many cases of opportunistic infections and high viral loads. Although TB/HIV Care, a non-governmental organisation in Cape Town, has trained adherence counsellors to visit and provide treatment support to ART defaulters, anecdotal reports show that there are over 120 Pentecostal churches in Milnerton and some of them also provide spiritual 'cures' to PLHIV in their congregations and the extended communities.

### Study participants

#### Healthcare workers

All healthcare workers at Du Noon Clinic will constitute the study population of healthcare workers. A healthcare worker will be considered for participation if he or she is actively involved in the delivery of ART in the catchment population of the clinic. Eligible healthcare workers who agree to participate in the study will be purposefully selected and interviewed based on their availability and experiences concerning the phenomena being researched. We anticipate that data from 18 healthcare workers will be sufficient to reach thematic saturation.

#### People living with HIV

All PLHIV in Milnerton will constitute the study population of PLHIV. Adult PLHIV not adhering to ART and enrolled in the ART programme in Du Noon Clinic for over 3 months will be eligible. Non-adhering participants will be selected from the risk of treatment failure registers by the adherence counsellors and then approached for their possible recruitment. Those who consent to participate and are physically and mentally able to undergo indepth interviews will be considered. However, only participants who self-identify as Pentecostal Christians will be purposefully selected. Potential participants must also be able to communicate in English or isiXhosa, which are the languages widely spoken in Millerton. As recommended by previous studies,<sup>45 46</sup> data from 30 PLHIV will be sufficient to reach thematic saturation.

#### Religious leaders

All RLs from Milnerton will make up the study population of RLs. RLs who self-identify as pastors, evangelists, apostles or prophets from Pentecostal congregations will qualify. Potential RLs who consent to take part in the study will be purposefully selected. The selected RL must also be capable of communicating in English or isiXhosa.

We predict that data from 30 RLs will be enough to reach thematic saturation.

### Data collection

Open-ended, semistructured, indepth individual interviews will be conducted with healthcare workers, PLHIV not adhering to ART and RLs. The interviews will be conducted in English or isiXhosa based on the participant's preference and in a place convenient to them so that they can talk freely about the phenomenon being researched. The researcher team will consist of an experienced qualitative research assistant fluent in the requisite languages. Participants' voices will be of optimum importance and the interviewers will be guided by participants' responses in deciding when to probe the emerging themes. Each interview session will last between 45 and 60 min. Interview guides will be prepared and used consistently across the study participants. Data saturation will inform the end of data collection.

### Data collection tool

Interview guides will be prepared and used to collect data from the participants. The interview guide is provided in online supplemental appendix 2. Section A focuses on the demographic characteristics of the participants, such as sex, age, denominational affiliation and level of education. Section B consists of questions focused on the general knowledge of PLHIV and RLs about HIV and its treatment. Questions from sections C to F are informed by the HBM constructs.

### Pilot interviews

Pilot interviews will be conducted with six participants as follows: two healthcare workers, two PLHIV not adhering to ART and two RLs purposively selected. The goal of the pilot interview will be to test the interview guides for clarity and to ensure that they elicit the requisite information in the study.

### Patient and public involvement

We will use publicly available data and data from study participants to conduct the study. However, the public or PLHIV will not take part in the design, conduct or plans to disseminate the results of the study.

### Data analysis

Qualitative data obtained from the participants will be analysed following the six steps of data analysis proposed by Braun and Clarke.<sup>47</sup> In the initial step, the research team will listen to the audio recordings repeatedly to check the audibility and completeness of the recordings and for familiarisation. This will be followed by transcribing the recorded data verbatim. The transcribed data will be read several times to understand their meaning and essence. Thereafter, a thematic analysis will be used to analyse the data. The computer program ATLAS.ti V.8 will be used to organise data into codes, families and themes. The research team will code the data using open coding<sup>48</sup> and the open codes will then be examined, revised and placed

into categories, themes and subthemes. These themes will be used to substantiate the initial hypothesis elicited from the scoping review.

### Trustworthiness

The trustworthiness of the study will be ensured by enforcing, credibility, conformability, dependability and transferability as guided by Lincoln and Guba.<sup>49</sup> The research team will hold several meetings during which the approach to data collection and interpretation will be cautiously selected. Dependability in the results will be ensured by sharing the transcripts with the four members of the research team towards developing a codebook to inform the data analysis. Discursive sessions will be continuously held by the research team to reconcile any differences in the coding decisions and planning for the next steps.

### Phase 3

The intervention mapping (IM) steps proposed by Eldredge *et al*<sup>50</sup> in designing multilevel health promotion interventions and strategies for implementation will be modified and used to develop guidelines to strengthen ART adherence in this phase of the study. Step 1 of this phase will entail an assessment of the needs of non-adhering Pentecostal Christians concerning guidelines that can be used to strengthen their adherence to ART. This will be done by examining the evidence obtained from the scoping review in phase 1, the qualitative studies in phase 2 and consultations with selected information-rich stakeholders.

In the next step, we will use the information collected in the previous steps to identify important religious determinants of non-adherence to ART among Pentecostal Christians living with HIV and those judged as most relevant to inform the process of developing the guidelines. The identified determinants will then be cross-examined with religious determinants of optimum ART adherence among Pentecostals living with HIV in Milnerton.

In step 3, we will select appropriate theoretical methods underpinning ways in which guidelines can be developed, taking into consideration the hypothesis elicited on how religious beliefs impact on ART non-adherence among Pentecostal Christians living with HIV that were identified in step 2.

In step 4, the guidelines will then be developed using the information gathered in the previous steps and bearing in mind the existing guidelines being used to strengthen ART adherence among PLHIV. However, the adoption, implementation and evaluation of the guidelines (steps 5 and 6 of the IM) will not be considered in this study.

### Refining the developed guidelines for ART adherence

The guidelines developed earlier in this phase will be refined through discursive workshops using the steps of the nominal group technique (NGT) by Potter *et al*.<sup>51</sup>

## Participants and procedure

Healthcare professionals, RLS, PLHIV and other relevant stakeholders will participate in the NGT workshops. A proposed sample of 18 information-rich participants will be identified and requested to participate in the workshops. Two groups of nine members per group will be purposefully selected. According to Varga-Atkins *et al.*,<sup>52</sup> two groups of nine members each are sufficient for an NGT workshop. At the workshop, a worksheet will be distributed to the participants to generate new ideas for the preliminary guidelines to be developed using the IM technique. This will be followed by a round-robin recording of ideas, which will be collated by a research assistant.

Next, a group discussion facilitated by the researchers and supported by a research assistant (an isiXhosa interpreter) will focus on other ideas that were generated by the participants. This will be followed by ranking and voting while prioritising the recorded ideas concerning the original items written on the draft guidelines developed previously. If 50% plus one participant agree on an item in the draft, the item will be accepted. The time taken to refine the draft will determine the number of workshops needed. Finally, discussing and editing the final guidelines will be done with the participants before they are finally written. PowerPoint presentations and hard copies of the study findings and guidelines will be shared with relevant stakeholders within 6 months after the completion of the study.

## ETHICS AND DISSEMINATION

Ethics approval will not be required for the scoping review, which will be synthesising information from already published articles. Ethics approval for the other phases has been received from the Biomedical Research and Ethics Committee at the University of the Western Cape and the Western Cape Department of Health. We plan to obtain informed consent from all participants. Regarding the dissemination of the study results, research articles emanating from the study will be prepared and submitted for publication in scientific journals and presented at conferences and workshops aimed at improving ART adherence.

**Contributors** IA and FCM conceptualised the study. IA wrote the first draft of the protocol. FCM, AN and CS provided input for subsequent drafts. All authors read and approved the final submission.

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## ORCID iDs

Ivo Nchendia Azia <http://orcid.org/0000-0003-4254-4922>

Ferdinand C Mukumbang <http://orcid.org/0000-0003-1441-2172>

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