Research Article

Health-related quality of life in HIV patients

Naila Bajwa[1], Meha Siddiqui[2], Muhammad Awais[3], Marina Akhtar[4], Alishba Rasool[5], Saira Afzal[6], Athar Ahmed Saeed[7]

(7) Queen Elizabeth Hospital, Gateshead, United Kingdom

(1-6) Mayo Hospital, Lahore /King Edward Medical University Lahore, Pakistan

Abstract:

Introduction: Health-related quality of life (HRQoL) continues to be significantly impacted by the numerous health and social issues that PLHIV continues to face. The UNAIDS Worldwide Guides System emphasizes the need of raising individuals' levels of contentment, however, it fails to specify which instruments should constitute what percentages of HRQoL.

Methods: The purpose of this research was to conduct a systematic review of HRQoL tools for PLHIV. Articles published between January 2010 and June 2023 were used to compile this systematic review**.**

Results: The most commonly used instruments were (WHOQOL-HIV BREF)22%, (EQ-5D-5L)17%, (SF-36)13%, (SF-12)13% (MOS-HIV)13%, (HAT-QOL)13%and (WHOQOL-BREF)9%. The majority of instruments (6/7; 86%) addressed domains including mobility, daily activities, discomfort, negative emotions, good emotions, energy, and social factors. More than half (4/7; 57%) addressed broad health concerns, such as mental health, medical care, social support, financial stability, sexual health, and quality of healthcare. Domains covered by (2/7; 29%) instrument were self-esteem, mortality, spirituality, environmental and personal safety.

Conclusion: Wide range of instruments have been utilized to survey HRQoL in PLHIV, and the decision of instrument might be founded on the qualities and reasoning for utilizing that specific instrument. Future researcher should look into the use of these instruments.

Corresponding Author: Naila Bajwa

Supervisor: Prof. Dr. Saira Afzal **|** Department of Community Medicine, KEMU, Lahore.

Keywords: HIV-specific instrument, HIV, People living with HIV, Generic instrument, patient-reported outcome measure.

INTRODUCTION:

About 38 million people worldwide are infected with the human immunodeficiency virus (HIV). The Global AIDS Strategy 2021–2026 of the Joint United Nations Programme on HIV/AIDS (UNAIDS) seeks to end the pandemic as a public health hazard by 2030. [1] A subjective multidimensional assessment of one's functioning and well-being in daily life is known as quality of life (QOL). When referring to QOL as it relates to illnesses or treatments, the phrase "health-related quality of life" (HRQOL) is frequently used and important indicator in healthcare decision-making and the outcomes of intervention. [2]

To the existing "90-90-90" aim, Lazarus and colleagues suggested adding a fourth "90" in 2016. 90% of people living with HIV (PLHIV) have viral load suppression and good HRQoL is the fourth 90% target. The 90-90-90-90 goals of the World Health Organisation state that enhancing the HRQoL of PLHIV is much important in the treatment of HIV/AIDS. [3]

Although virological suppression remains a key objective, it shouldn't be the main focus of HIV therapy because many HIV-positive individuals (PLHIV) have suppressed viral loads but lower health and quality of life (HRQoL) than the general population. There are evaluations of HRQoL that are both general and HIV-specific. Generic PRO instruments may not effectively address personal satisfaction issues relating to PLHIV, such as HIV-associated shame or explicit antiretroviral medication side effects, despite their ability to access correlations across infections. Although they may have limits in terms of their ability to be used in conjunction with other diseases, HIV-specific related instruments are likely to be flexible to changes in the disease state. [4]

Many instruments exist, but there are no suggested instruments for use with PLHIV in clinical and research settings. There is an absence of consistency among the HRQoL's particular aspects. The scientific writing expressly looks at the different outcome measures but the quality of life in PLHIV is scant. Most of HRQoL information has been gotten from exploratory clinical medication preliminaries, researching HRQoL as an optional measure or from studies looking at the effect of PLHIV [5].

The purpose of this study was to survey and assess the most well-known HRQoL apparatuses for PLHIV utilized in research settings. We explicitly give an outline of the instruments presently being used and examine the connection between the choice of generic or HIV-specific instruments and logical factors including country, type of study, and domains covered by each HRQoL instrument.

MATERIALS AND METHODS:

We systematically evaluated the writing to recognize and explore that how the personal satisfaction of patients living with HIV after antiretroviral treatment. We follow the proposals of the PRISMA (The Preferred Reporting Items for Systematic Review and Meta-Examinations) for broad exploration. The accompanying headings sum up the procedures utilized in this review.

We searched on 14 July 2023 and utilized two databases (Medline and Google Researcher). Articles that were selected were published from January 2010

to June 2023. The keywords that were utilized for the search procedure, including HIV, patient-reported outcomes, and quality of life QoL and the Boolean operators "OR", and" AND" were used. The study selection procedure did not include all clinical trials (RCTS), meta-analyses, perspectives, case reports, case series, and grey literature.

Studies employed a tool to assess HRQoL in HIV-treated patients and the age of patients 16 or above. All selected articles are cross-sectional studies.

Papers that exclusively addressed a specific feature of HRQoL or those reported on HRQoL measurements in children or qualitatively evaluated HRQoL of PLHIV were eliminated.

Reviews, conference abstracts, protocol articles, editorials without primary data, and papers written in any language other than English were disqualified.

After removing duplicates, the five authors (MS, MA, AR, MA,) independently checked the titles and abstracts according to the eligibility criteria. The articles selected were subjected to the next phase, and the Full text was read. The selected four authors the articles independently. In case of confusion, the other authors (NB,MS) read the papers to finalize their eligibility.

Reviewer independently extracted data on the features of the included studies (e.g. country, type of study, year of publication. Instrument used for quality of life). The extracted data were assembled by explaining the research characteristics identified in such studies. For data extraction and data synthesis, using Microsoft Excel Software and shown in Table 1.

550 papers were found in the two databases (PubMed/Medline and Google Scholar). We found 235 unique papers after removing 315 duplicates and reading through their abstracts and titles. We found only 140 studies out of 235 that fit our criteria. After evaluating the titles and abstracts, 95 publications were eliminated for various reasons (described in Fig. 1).

This process was repeated until only 70 articles remained. After reading the entire contents of the remaining 70 items, we discarded 43 for being irrelevant or lacking an English translation of the entire piece. The database searches led to the analysis of 21 papers.

RESULTS:

From 21 papers author identified the following health-related quality of life instruments used for (PLHIV) were EQ-5D-5L(17%), WHOQOL-HIV bref (22%), SF-12(13%), SF-36(13%), MOS-HIV(13%) HAT-QOL(13%), and WHOQOL-BREF (9%) showed in Fig 2. The selected studies were conducted in different regions of the world. Six were conducted in China [5][7][14][15][17][26], 3 in Brazil [10][24][27], 3 in Nigeria [8][23][26], 2 in the U.K [2][3], 2 in Vietnam [1][6] and the rest of all studies conducted in different region one in Finland[4], India[9], Uganda[11], Poland[12], Belgium[13], Thailand[16], Tunisia[30], Iran[20], USA[21], Kenya[22], Tanzania[25]

We used the Newcastle-Ottawa scale for the quality assessment of studies. 6 studies were high-quality scores, 12 were moderate scores and 3 studies have low-quality scores.

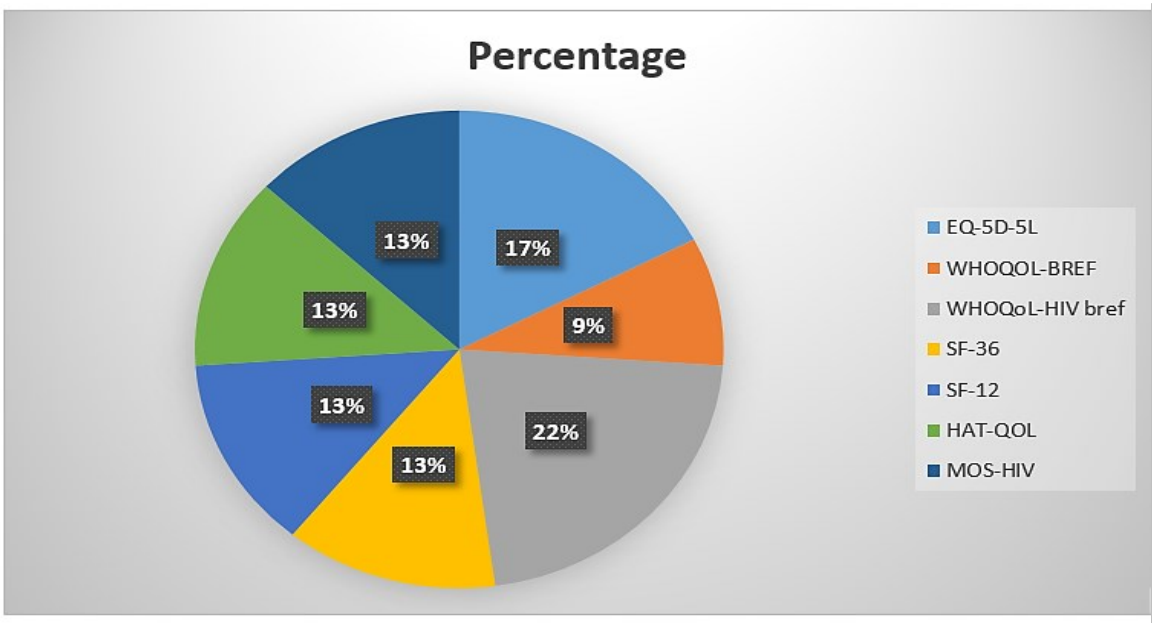

Fig 2. Percentage of HRQol instruments in HIV patients

Table 1. Characteristics of studies

S. No	Author Year	Title	Type of Study	Place of study	HRQoL Instruments	Rf
1	Martin. K et al 2019	Physical activity and quality of life in people living with HIV	Cross-sectional	U.K	EQ_5D-5L	6
2	Herdman. M et al 2011	Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L)	Cross-sectional	U.K	EQ_5D-5L	7
3	Purola. P et al 2023	Comparison of three health-related quality of life instruments in relation to visual acuity: EQ-5D, 15D, and EUROHIS-QOL8	Cross-sectional	Finland	EQ_5D-5L	8
4	Tran. B et a 2011	Determinants of health-related quality of life in adults living with HIV in Vietnam	Cross-sectional	Vietnam	EQ- 5D	9
5	Liping.M et al 2015	Quality of Life of People Living with HIV/ AIDS: A Cross-Sectional Study in Zhejiang Province, China	Cross-sectional	China	WHOQOL-BREF	10
6	Wakawa.I et al 2014	The Impact of Comorbid Clinical Depression on The Health-Related Quality of Life of Adults on Highly Active Antiretroviral Therapy in Maiduguri, Northeastern Nigeria	Cross-sectional	Nigeria	WHOQOL-HIV bref	11
7	Hiremath.S et al 2018	A STUDY ON ASSOCIATION OF DEPRESSION WITH SOCIAL SUPPORT AND QUALITY OF LIFE AMONG WOMEN LIVING WITH HIV/AIDS IN SOUTH INDIA	Cross-sectional	India	WHOQOL-BREF	12
8	Mwesiga. E et al 2015	Depression with pain co morbidity effect on quality of life among HIV positive patients in Uganda: a cross sectional study	Cross-sectional	Uganda	WHOQOL-HIV bref	13
9	Rzeszutek.M et al 2018	Consistency of health-related quality of life among people living with HIV: Latent state-trait analysis	Cross-sectional	Poland	WHOQOL-HIV bref	14

10	Ferreira.A et al 2018	Quality of life predictors for people living with HIV/AIDS in an impoverished region of Brazil	Cross sectional	Brazil	WHOQOL-HIV bref	15
11	Reychler.G et al 2013	Validation of the French Version of the World Health Organization Quality of Life HIV Instrument	Cross-sectional	Belgium	WHOQOL-HIV bref, SF- 36	16
12	Xie. F et al 2019	Social Capital Associated with Quality of Life among People Living with HIV/AIDS in Nanchang, China	Cross-sectional	China	MOS- HIV	17
13	Chariyalertsak.S et al 2011	Reliability and validity of Thai versions of the MOS-HIV and SF-12 quality of life questionnaires in people living with HIV/AIDS	Cross-sectional	Thailand	M OS-HIV SF-12	18
14	Huang. Y et al 2019	Role of psychosocial status in predicting health-related quality of life at 1-year followup among newly diagnosed people living with HIV	Cross-sectional	China	MOS- HIV	19
15	Zarei. N et al 2016	Perceived Stigma and Quality of Life Among Women Living with HIV/AIDS	Cross-sectional	Iran	SF-12	20
16	Sun.W et al 2013	Quality of Life of People Living with HIV/AIDS under the New Epidemic Characteristics in China and the Associated Factors	Cross-sectional	China	SF-36	21
17	Delate.T Et al 2014	The Discriminative Ability of the 12-Item Short Form Health Survey (SF-12) in a Sample of Persons Infected with HIV	Cross-sectional	USA	SF-12	22
18	Shaahu.v et al 2022	Health-Related Quality of Life of Patients on Antiretroviral Therapy at the Federal Medical Center, Makurdi, Nigeria	Cross-sectional	Nigeria	Sf-36	23
19	Mohammadi.M et al 2022	Quality of Life and Its Association With HIV-Related Stigma Among People Living With HIV in Kerman, Iran: A Cross-Sectional Study	Cross-sectional	Iran	HAT-QOL	24
20	Parcesepe.A et al 2020	Gender, HIV-Related Stigma, and Health-Related Quality of Life Among Adults Enrolling in HIV Care in Tanzania	Cross-sectional	Tanzania	HAT-QOL	25
21	Dutra. B et al 2019	Changes health-related quality of life in HIV-infected patients following initiation of antiretroviral therapy: a longitudinal study	Cross-sectional	Brazil	HAT-QOL	26

There are two types of instruments used to assess the quality of life in HIV patients generic and HIV-specific. All characteristics of these instruments are described in detail and given below.

Martin. K et al proposed that it was a generic 5-item quality of life (QoL) tool, the EQ-5D measures mobility, self-care, daily activities, pain or discomfort, and anxiety or depressive symptoms. This instrument comes in two variations: the older EQ-5D-3L, which rates the five domains on a 3-point scale, and the more recent EQ-5D-5L, which rates the domains on a 5-point scale.[5] Because of their time-saving features and convenience, the EQ-5D-3L and EQ-5D-5L have relatively good acceptability and completion rates (>90%) for people living with HIV (PLHIV) in both hospital, clinic, and outpatient settings proposed by Herdman M et al[6]. The economic evaluation of medical therapies may benefit from using cost-utility analysis, which can convert EQ-5D scores to health utility values suggested by Purola et al [7]

The Short Form-36 (SF-36) is a general QoL tool that includes eight domains, including physical function

(PF), social function (SF), role limitations due to physical health (or "role physical" or "RP"), role limitations due to emotional problems (or "RE"), mental health (MH), vitality (VT), bodily pain (BP), and general health (GH), all of which are factors in the physical component summary (PCS) and mental component summary (MCS) scores. It will take you 5 to 10 minutes to finish this instrument proposed by Sun w et al. [21] Comparing research samples to general population data has been made possible by its application in a variety of situations and populations with representative normative population data produced for many nations. In cross-sectional research and psychometric testing in middle- and high-income countries, this measure has demonstrated good test-retest reliability in PLHIV. RCT, cohort studies, cross-sectional studies, and other types of settings and research have all shown that the SF-36 has good completion rates suggested by Shaaha. V et al[23].

The SF-12 is a condensed version of the SF-36 (already explained). Physical function (PF), social function (SF), role limitations due to physical health (or "role physical"), role limitations due to emotional problems (or "role emotional"), mental health (MH), vitality (VT), bodily pain (BP), and general health (GH) are the eight domains covered by the 12-item SF-12, which is used to calculate physical health summary (PHS) and mental health summary (MHS) scores. The SF-12 can give a glimpse of a patient's HRQoL and can be finished in under two minutes given by Zarei et al. [20]. The SF-36 instrument is shortened into the SF-12 (24). The SF-12 is less thorough than the SF-36 in gathering data on health status and outcomes, but in research looking at the general physical and mental health of HIV patients, the SF-12 may be adequate at gathering the necessary data. SF-12 responds to disease severity as determined by viral RNA levels and CD4+ cell count proposed by Delate et al[22].

The WHOQOL BREF is a 26-item generic QoL instrument encompassing four domains: physical health, psychological health, social relationships, and environment, and two general items measuring overall quality of life and general health. Items are rated on a 5-point Likert scale and summated to give an overall QoL rating, with higher ratings indicating better Quality of life suggested by Liping. M et al [10] . According to reports, the WHOQOL BREF is simple for patients to complete and has high completion rates of>80% in a variety of settings (such as a hospital or clinic) and studies (such as an RCT, a cohort study, or a cross-sectional study) proposed by hire math. S et al [12].

A 35-item HIV-specific QoL tool called the Medical Outcomes Study HIV (MOS-HIV) measures 11 different aspects of quality of life, including general health perceptions, physical function, role function, social function, cognitive function, pain, mental health, energy, health distress, and health transition. The physical health summary (PHS) and mental health summary (MHS) scores are based on the scores attained in each domain. The average time to finish this instrument is five minutes. MOS-HIV has been translated into a wide variety of languages and has undergone cultural adaptation these findings were proposed by Xie. F et al [17]. With, reasonably good completion rates in a variety of settings, including

hospitals, clinics, and community-based organizations, MOS-HIV is an acceptable measure of patient outcomes in clinical trials, cohort, and cross-sectional research these findings given by Huang. Y et al [19]. The HIV-specific and generic items in MOS-HIV enable comparisons of the HRQoL of PLHIV and healthy populations. The MOS-HIV's health transition subscale measures how other MOS-HIV domain scores would be impacted by perceived changes in health proposed by Chariyalertsak.S et al [18].

A 31-item HIV-specific QoL test called the WHOQOL-HIV BREF examines six different aspects of quality of life: the physical, psychological, level of independence, social relationships, environment, and spiritual. The World Health Organisation created the 120-item WHOQOL-HIV instrument, which was condensed into this shorter form to measure QoL in PLHIV. A total QoL score is calculated from the 31 items using a 5-point Likert scale, with higher scores indicating higher QoL these findings are given by Wakawa.I et al [11]. The WHOQOL-HIV bref designed instruments are the only ones that include a spiritual domain given by Ferreira et al [15]. Since spirituality has been found to have a major positive impact on people with serious or terminal illnesses like HIV. According to the study, the WHOQOL-HIV BREF properly addresses HIV-specific health issues suggested by Reychler. G et al [16].

The HAT-QOL is a 42-item HIV-specific QoL test that covers nine categories, including overall function, life satisfaction, health and financial concerns, pharmaceutical concerns, concerns about HIV mastery, concerns about disclosure, provider trust, and sexual function. Items are assessed on a Likert scale according to how frequently HIV patients experienced occurrences related to the nine domains during the course of the previous four weeks: always, frequently, occasionnally, rarely, or never. Higher subscale scores, which are evaluated on a 0-100 scale, indicate a higher quality of life. This instrument also comes in a condensed 34-item version these are all findings given by Mohammadi. M et al [24]. It typically takes 10 to 15 minutes to complete the HAT-QoL. The HAT-QoL instrument was created using the personal suggestions of PLHIV; as a result, it is believed to have items that reflect matters relevant to PLHIV suggested by Praesepe. A et al [25]. HAT-QoL has been praised for being simple to understand and adaptable to a variety of research scenarios, including cross-sectional, cohort, and RCT investigations in both clinical and hospital settings, and these are all suggested by Dutra. B et al [27].

The most popular HRQoL instruments scopes, as well as details on how certain items were categorized, are summarised in Table 2. The instruments measured a wide range of factors, including mobility, daily activities, discomfort, and negative emotions (such as stress, anxiety, despair, and anxiety). Six of seven instruments (or 86% of the total) addressed positive feelings (such as enjoyment, tranquility, satisfaction, and happiness), energy, and social factors. More than half (4/7; 57%) addressed broad health concerns, while just 3 addressed specifics such as mental health, medical care, social support, financial stability, sexual health, and access to and quality of healthcare. (2/7; 29%) addressed body image, mortality, spirituality /

religion, and environment/safety. The HIV-specific instruments were virtually identical to the generic ones, except for questions about mortality, stigma, and HIV declaration.

Table 2. Domains captured by HRQOL Instruments.

Domains of Qol instruments	EQ-5D-5L	SF-36	SF-12	WHOQOL-BREF	WHOQOL-HIV bref	HAT-QOL	MOS-HIV
General Health	.	X	X	.	.	X	X
Mobility	X	X	X	X	X	X	X
Usual activities	X	X	X	X	X	X	X
Pain	X	X	X	X	X	X	X
Negative feeling (Anxiety/ Depression)	X	X	X	X	X	X	X
Positive feeling		X	X	X	X	X	X
Energy/Validity		X	X	X	X	X	X
Cognitive				X	X		X
Bodily appearance/Self-esteem				X	X		
Medical treatment				X	X	X	
Support by others / self				X	X	X	
HIV disclosure							
Relationships		X		X	X	X	X
Sex life				X	X	X	
Physical environment				X	X		
Financial security				X	X	X	
Quality of health services				X	X	X	
Spirituality/Religion				X	X		
Blame for HIV					X		
Death worry					X	X	

DISCUSSION:

Increased emphasis on the benefit of assessing HRQoL might be reflected in the ascent of distributions among PLHIV utilizing HRQoL instruments, or it might just be the common pattern of additional distributions after some time. We noticed a decrease in the use of MOS-HIV and an ascent in the utilization of WHOQOL-HIV BREF and EQ-5D-3L/EQ-5D-5L.

The WHOQOL-HIV BREF has been translated into over 20 languages because of its widespread use in assessing the quality of life of people living with HIV across cultural contexts. One of the few HRQoL measures that take spirituality into account is the WHO instruments. Since spirituality has been shown to have a substantial positive impact on the health of people with severe terminal illnesses like HIV, it may become more evident as medical practitioners that spiritual approach is necessary in HIV care.[27] Taking only about a minute to finish, the EQ-5D-3L/EQ-5D-5D. This could be helpful for investigators pursuing multiple clinical outcomes in either observational studies or clinical trials. Furthermore, this generic tool is useful for epidemiological studies as it allows the comparison in the managements of population living with HIV.[28]

MOS-HIV is more sensitive towards the adverse effects, worsening symptoms, opportunistic infections, due to HIV, when it comes to clinically meaningful outcomes. Changes in the MOS-HIV may have less to do with defects in the MOS-HIV instrument and more to do with differences in opinion among doctors and researchers. We found it quite interesting that the rate of growth in the use of both general-purpose and HIV-

specific tools was nearly the same. However, we found a few things to consider when picking out instruments. For instance, studies comparing PLHIV and non-PLHIV were more likely to employ general question-nnaires because comparison studies accurately capture the difference in the personal satisfaction between those with and without illness. [3o]

There are representative normative population data for several countries, and the use of SF-36 is more evident in comparative studies. Colautti et al. [28] argue that because of its high construct validity and good association with illness severity, it is the best general tool for evaluating HRQoL in PLHIV. Using the SF-36, policymakers can compute health utility scores, analyse the expense and quality of life changed in years which is acquired due to some other infections.

Since HIV-specific instruments (such as the WHOQOL-HIV BREF or the MOS-HIV) measure outcomes directly connected to the intervention, they are more likely to be used in clinical and research investigations including just PLHIV. After controlling for potential confounding factors such as study design, we discovered that more money and more space were related to the use of specific instruments for HIV as opposed to more general ones. In contrast to high-income nations, middle- and low-income nations were mostly used specific tools for HIV. The use of a specific instrument for HIV was more common in research undertaken in Europe and USA than in Africa [30]. How crucial it is to measure various aspects of HRQOL will determine whether a generic or HIV-specific instrument is used. To assess the impact of disclosure of HIV in (HAT-QOL) stigma and blame in (WHOQOL-HIV BREF), only these two mentioned HRQoL instrument exists.[27]

Research shows a connection among shame and lower mental wellbeing in beset people, and this disgrace is a tireless side effect of living with HIV. Human-related personal satisfaction (HRQoL) was demonstrated to be lower among those living with HIV who were exposed to both social and deliberate marks of disgrace, as per research directed in Spain. Instruments that can evaluate the impacts of destitution, deficient social and wellbeing framework, and personal satisfaction of PLHIV might be particularly useful in low-income countries.[29]

There are a few significant limitations to our paper. We used data from two popular online databases. Non-English articles and papers published other than in the databases we chose were, however, left out. We did not report the total number of respondents. The results of our study may not apply to other situations or contexts because almost all studies are cross-sectional. Despite these constraints, we were, however, able to describe health-related quality-of-life instruments in HIV patients.

CONCLUSION:

In addition to helping policymakers better meet the needs of people living with HIV/AIDS, the infor-mation provided by these surveys will allow for a more concerted effort to address bigger social determinants of health, such as poverty alleviation, sustainable food system development, and infrastructure improvement. We found no instruments to be consistently more popular than others, however, this may be attributable to selection bias in the underlying research. We were

unable to locate any information comparing these two potential determinants of instrument selection the cost and availability of resources.

ACKNOWLEDGMENTS:

We would like to express our sincere gratitude and appreciation to Dr. Athar Ahmed Saeed, Dr. Saira Tariq for their unwavering support and assistance in this research work. Their valuable guidance and input have been instrumental in ensuring the success of our publication. We are truly grateful for their contributions.

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