



ORIGINAL ARTICLE

Organ donation and HIV: Awareness and willingness to be a living donor among people with HIV in Uganda

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Abstract

Background: HIV+ to-HIV+ organ transplantation has demonstrated promise and is now authorized for research purposes in certain countries. However, organ transplantation is dependent on the availability of organ donors. We assessed the awareness and willingness to donate organs among people with HIV (PWH) in Uganda.

Methods: We conducted a multicenter cross-sectional study between October 2023 and January 2024 in four large HIV clinics in Northern Uganda. The study population consisted of PWH. A structured questionnaire was used to collect data regarding awareness, willingness, and beliefs regarding organ donation. Organ donation was defined as the willingness to be a living donor of a solid organ. We conducted multi-variable logistic regression to assess for an association between willingness to donate organs and selected exposures. Data were analyzed in Stata version 15.0. Results are expressed as adjusted odds ratio (AOR) with 95% confidence intervals (CI).

Results: A total of 232 participants were recruited. The mean age \pm standard deviation of the participants was 42.2 \pm 11.8 years. All participants were on antiretroviral therapy. Sixty-two (26.7%) had a CD4 count less than or equal to 200 cells/mm³. The majority (80.6%, $n = 187$) had ever heard of organ donation. Slightly more than a third (34.9%, $n = 81$) were willing to donate organs. Factors associated with willingness to be a living organ donor included being female (AOR: 1.56; 95% CI: 1.15–2.11), having a tertiary education level (AOR: 1.79; 95% CI: 1.03–3.11), average monthly income >500 000 UGX (135.1USD) (AOR: 5.5; 95% CI: 1.97–15.40), ever heard about organ donation (AOR: 5.4; 95% CI: 1.67–17.8), and attending an organ donation campaign (AOR: 2.0; 95% CI: 1.07–3.74).

Conclusions: Awareness about organ donation was high but the willingness to be a living organ donor was low among PWH in Uganda. There is a need to sensitize the community about the need and benefits of organ donation with the involvement of media and the healthcare workers.

KEYWORDS

HIV, organ donation



1 | INTRODUCTION

Organ donation and transplantation, ranging from cells, tissues, and organs, have contributed to the advancement of medicine worldwide, and have progressively become a more acceptable and popular approach to improve healthcare, quality of life, and increase the life expectancy of organ recipients.¹ According to the Centers for Disease Control and Prevention, there are approximately 100 000 people on the active waiting list for organs in the United States whereas, there are only 6000 organs provided by living donors per year.² Approximately 14 000 deceased organ donors providing about 3.5 organs per donor were registered in 2021.² In South Africa, even much lower organ donation rates have been reported,^{3,4} there are approximately 4700 people are waiting for a life-saving organ or cornea transplant, but only 0.2% of the population are registered organ donors.⁵ This indicates a large gap between the demand and supply of organs worldwide.

There is a notable rise in the prevalence of noncommunicable diseases worldwide with an increased need for kidney and liver transplantation among patients with end-stage disease. In addition, due to the increased advances in care for people with HIV (PWH), this population has grown older and has an increased risk of contracting and suffering complications from noncommunicable diseases that may ultimately lead to a need for organ transplantation.⁶ Furthermore, medical advances in HIV care have challenged perceptions which eventually caused a re-evaluation of the possibilities and policies surrounding organ transplantation among PWH. The HIV Organ Policy Equity (HOPE) Act, recently enacted, has legalized the process of organ donation and transplantation among PWH.⁷ This development offers a potential solution to address the shortage of organs and provides equitable opportunities for PWH, potentially leading to a substantial improvement in their quality of life.^{8,9} In fact, recent publications revealed a high willingness among PWH to be organ donors, ranging between 55% and 79%.^{10–13} However, the practice of organ donation and transplantation is still largely unacceptable to many individuals.

Despite the progress, challenges such as stigma, both within the medical community and society at large, remain a significant barrier to organ donation and transplant among PWH.^{10,14} In addition, the fear of discrimination, misconceptions about HIV transmission, stringent criteria for organ acceptance, and a limited number of donors living with HIV further complicate organ donation among this population.^{10,13,15} Several people have cited factors such as fear of misuse or trafficking of their organs, cultural and religious beliefs, and lack of knowledge as some of the factors for refusal of organ donation.^{16–20} Several pilot studies and successful cases have demonstrated outstanding feasibility of organ donation and transplantation among PWH.²¹ In Africa, HIV+ to-HIV+ transplantation has been done in South Africa with profound success.²²

Uganda, in accordance with the Uganda Human Organ Donation and Transplant Act, has formally legalized organ transplantation and donation.²³ The act describes the procurement of organs, tissues, and cells of living, cadaveric, and brain-dead persons, and the need or screening for all transmittable diseases from all potential donors, without a specific mention of HIV infection.²³ However, operational

capacity for conducting organ donation and transplantation remains constrained. Consequently, more efforts have been directed toward augmenting the infrastructure and proficiency of organ transplantation in Uganda. In fact, Uganda achieved a milestone by successfully conducting its inaugural living-related donor kidney transplantation in 2023,²⁴ thereby fostering heightened expectations for the prospect of conducting additional transplantations in the future.

Uganda has a high HIV prevalence estimated at 5.5%.²⁵ The roll-out of antiretroviral therapy (ART) has successfully extended the lives of PWH in Uganda, with many of them now reaching old age.^{26,27} However, old age may put PWH at an increased risk of getting noncommunicable diseases which rises the need of organ transplantation with end-stage disease in this population. When making decisions regarding transplantation and organ donation from PWH, several factors including cultural and religious differences may influence acceptance.^{20,28} Therefore, there is a need for targeted studies to identify knowledge gaps, demystify myths and misconceptions, reduce stigma, and increase awareness among health professionals and PWH regarding solid organ transplantation. Therefore, in this study, we sought to determine the awareness and willingness to donate organs among PWH in Northern Uganda.

2 | METHODS

2.1 | Study design and settings

We conducted a multicenter cross-sectional study between October 2023 and January 2024 across four large HIV clinics in Northern Uganda. The study sites consisted of St. Mary's Hospital, Lacor, a private not-for-profit hospital in Gulu; Anaka General Hospital, a public general hospital in Nwoya; Kitgum General Hospital, a public hospital in Gulu; and Gulu Regional Referral Hospital, a tertiary public hospital in Gulu City. We followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Guidelines.²⁹

2.2 | Study population

Eligible participants were registered PWH attending outpatient HIV clinics at the selected study sites or PWH and hospitalized in one of the four study sites. We included registered PWH attending outpatient HIV clinics at the selected study sites or PWH and hospitalized in one of the four study sites who were > 18 years. Hospitalized participants who were critically ill were excluded. Participants were consecutively enrolled into the study.

2.3 | Data collection

We adapted the data collection tool from previous studies of knowledge and attitudes regarding organ donation.^{16,30,31} The questionnaire had questions regarding awareness, willingness, and attitudes toward



organ donation (Supplementary Material 1). The study tool was administered by trained research assistants who are nurses or doctors working in the respective HIV clinics. The questionnaires were administered face-to-face by the research assistants who explained the purpose of the study and ensured confidentiality of responses. Anonymity was guaranteed and the data collection process was carried out in a private and comfortable setting to encourage open and honest responses.

2.4 | Variables

Our outcome variable was willingness to be a living donor of solid organs. This was assessed by asking a single question on living-related solid organ donation “*Would you consider donating your solid organs while alive?*” with responses categorized as Yes (coded as 1) and No (coded as 0).

The independent variables included demographic characteristics such as age, gender, religion, marital status, education level, occupation, and average monthly income; clinical characteristics such as baseline CD4 count, newly diagnosed HIV infection (within the last 4 weeks from date of the survey), and history of opportunistic infections; heard about organ donation, ever attending an organ donation campaign, history of organ/tissue donation, history of family benefit from organ/tissue donation, and behavioral and control beliefs regarding organ donation. Behavioral and control beliefs regarding organ donation were assessed using Likert scale questions with response categories; strongly agree, agree, neutral, disagree, and strongly disagree. Responses strongly agree and agree were combined into one “agree” and strongly disagree and disagree were combined into one “disagree.” Behavioral and control beliefs, as conceptualized within the theory of planned behavior model, encompass an individual’s perceptions of the likely outcomes or consequences of engaging in a behavior and the presence or absence of factors that may facilitate or impede its performance, respectively.

2.5 | Statistical analysis

Data were analyzed in Stata version 15.0. Categorical data were summarized as proportions, while numerical data were summarized as mean (standard deviation [SD]). We conducted a multivariable logistic regression analysis to examine the associations between willingness to donate organs and selected exposures. Variables with a *p*-value less than .2 at bivariable analysis and those with biological plausibility were added to the multivariable model. Multivariable model results are expressed as adjusted odds ratio (AOR) with 95% confidence intervals (CI). The significance level was set at *p* < .05.

2.6 | Ethical considerations

The study protocol was approved by the Gulu University Research and Ethics Committee (GUREC# GUREC-2023-635) and the Uganda

TABLE 1 Sociodemographic characteristics of the participants.

Characteristic (n = 232)	Frequency (%)
Age (years)	42.2 ± 11.8
<20	3 (1.3)
20–34	56 (24.1)
≥35	173 (74.6)
Settings	
Outpatient Department (OPD)	210 (90.5)
Inpatient Department (IPD)	22 (9.5)
Gender	
Male	100 (43.1)
Female	132 (56.9)
Marital status	
Single	26 (11.2)
Married	152 (65.5)
Divorced	18 (7.8)
Widowed	36 (15.5)
Highest education level attained	
None	38 (16.4)
Primary	92 (39.7)
Secondary	59 (25.4)
Tertiary	43 (18.5)
Occupation	
Teacher	15 (6.5)
Health worker	8 (3.4)
Business	42 (18.1)
Politician	10 (4.3)
Farmer	96 (41.4)
Housewife	11 (4.7)
Tailor	7 ³
Other ^a	43 (18.5)
Average monthly income (in UGX)	160 000 (80 000–300 000)
0–100 000 (0–27 USD)	92 (39.7)
100 001–500 000 (27–135 USD)	110 (47.4)
>500 000 (>135 USD)	30 (12.9)
Newly diagnosed HIV patient (at current visit)	
1. Yes	19 (8.2)
2. No	213 (91.8)

^aDriver, hairdresser, police officer, carpenter, mechanic, and engineer.

National Council for Science and Technology (HS3378ES). Written informed consent was obtained from all participants. Ethical regulations outlined in the *Declaration of Helsinki* were observed throughout the study. Anonymity was guaranteed during data collection to ensure confidentiality and encourage honest responses. No hospital or participant-identifiable characteristics beyond basic demographics were collected.

TABLE 2 Awareness about organ donation among people with HIV in Northern Uganda.

Variable	Frequency (%)
Ever heard of organ donation	
Yes	187 (80.6)
No	45 (19.4)
Source of information	
Healthcare worker	94 (50.3)
Media	119 (63.6)
Family/Friends	98 (52.4)
Other	4 (2.1)
Attended an organ donation campaign	
Yes	31 (13.4)
No	201 (86.6)
Do you feel there is need for organ donation?	
Yes	202 (87.1)
No	30 (12.9)
Has anyone in your family/friends ever donated blood or blood products?	
Yes	60 (25.9)
No	172 (74.1)
Have you ever donated blood or blood products?	
Yes	90 (38.8)
No	142 (61.2)
If yes, which solid organ or tissue?	
Blood	90 (100)
Kidney	0 (0.0)
Liver	0 (0.0)
Bone marrow	0 (0.0)

3 | RESULTS

3.1 | Characteristics of study participants

A total of 232 participants were recruited. The majority (74.6%, $n = 173$) were at least 35 years and the mean age of all the participants was 42.2 ± 11.8 years (Table 1). More than half (56.9%, $n = 132$) were female, and 152 (65.5%) were married. More than a third (39.7%, $n = 92$) had attained a primary level of education. Only (8.2%, $n = 19$) were newly diagnosed with HIV. The mean time living with HIV was 8.1 ± 5.4 years (Table 1).

3.2 | Awareness about organ donation among PWH in Northern Uganda

The majority (80.6%, $n = 187$) had heard of organ donation and most (63.6%, 119) reported that their source of information was media.

TABLE 3 Willingness to donate organs among people with HIV in Northern Uganda.

Reasons for accepting solid organ donation (n = 84)	
I know about the benefits of organ donation to the needy and I want to help them	77 (95.1)
I want to contribute to medical science	11 (13.6)
I want to be useful	7 (8.6)
Other reasons ^a	1 (1.2)
Reasons for refusing solid organ donation (n = 151)	
I am afraid that the process of procuring organs will disfigure my body	48 (31.8)
It is against my religious beliefs	6 (4)
I am afraid my organs will be misused or trafficked	19 (12.6)
Other reasons ^b	93 (61.6)
Would you prefer a close relative or friend only receive your solid organ(s)? (n = 232)	
1. Yes, to my close ones only	63 (27.2)
2. Only to the ones who can't afford it	1 (0.4)
4. No, it doesn't matter who receives my organs	168 (72.4)
If you decide to donate your solid organs, do you think your family will support your decision? (n = 232)	
1. Yes	133 (57.3)
2. No	99 (42.7)
Would you agree if one of your family members wishes to donate his/her solid organs? (n = 232)	
1. Yes	189 (81.5)
2. No	43 (18.5)
Have you or your family ever benefited from blood donation? (n = 232)^c	
1. Yes	85 (36.6)
2. No	147 (63.4)

^aOne time I was helped with blood.

^bAm HIV positive; am old; am weak; am not healthy; am not fit; my condition doesn't allow me; am sick; because God gave me what is enough for me; am not aware of any benefit.

^cNone of the participants reported to have or their family members benefited from solid organ donation.

Less than a quarter (13.4%, $n = 31$) had attended an organ donation campaign. More than a third (38.8%, $n = 90$) had donated blood and 25.9% ($n = 60$) reported that their family/friends had donated blood (Table 2).

3.3 | Willingness to donate solid organs among PWH in Northern Uganda

A total of 81 of 232 (34.9%) participants were willing to donate solid organs. Knowing about the benefits of organ donation to the needy was the most common reason cited for participants' willingness to donate organs and being afraid that the process of recovering organs

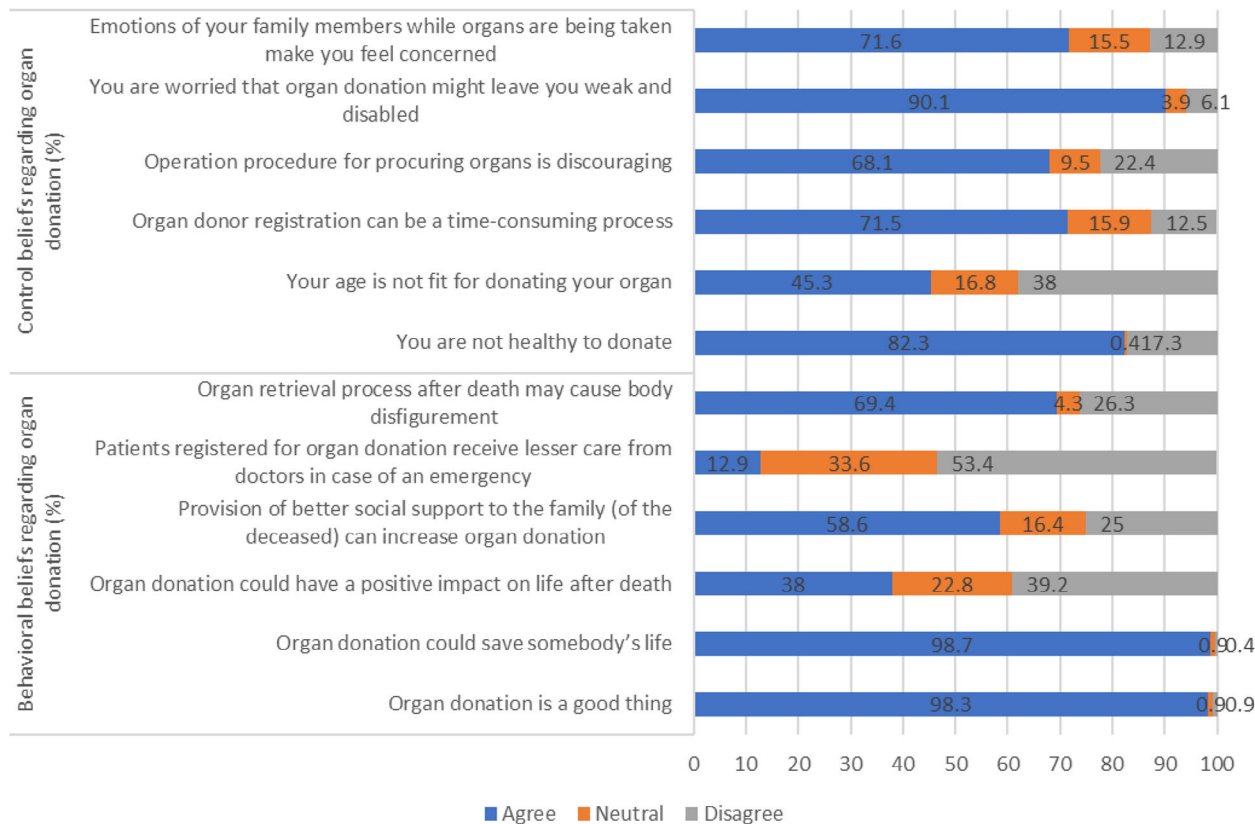


FIGURE 1 Perception and beliefs regarding organ donation among people with HIV in Northern Uganda.

disfigures one's body was the common reason cited for participants' unwillingness to donate organs (Table 3).

3.4 | Perception and beliefs regarding organ donation among PWH in Northern Uganda

Almost all study participants (98.3%, $n = 228$) agreed that organ donation is a good thing and 98.7% ($n = 229$) agreed that organ donation could save somebody's life (Figure 1). Only 38.0% ($n = 88$) agreed that organ donation could have a positive impact on life after death and only 12.9% ($n = 30$) of the study participants agreed with the statement that patients registered for organ donation receive lesser care from doctors in case of an emergency. The majority 69.4% ($n = 161$) agreed that the organ retrieval process after death may cause body disfigurement. Finally, 58.6% agreed that the provision of better social support to families (of the deceased) can increase organ donation.

The majority (82.3%, $n = 191$) agreed that they are not sufficiently healthy to donate organs (Figure 1). More than a third (45.3%, $n = 105$) agreed that their age was not appropriate for donating organs. Most (71.5%, $n = 166$) agreed that organ donor registration can be a time-consuming process and 68.1% ($n = 158$) agreed that the operation procedure for procuring/obtaining organs is discouraging. The majority (90.1%, $n = 209$) agreed with the statement that organ donation might leave you weak and disabled and 71.6% ($n = 166$) agreed that they are

concerned with the emotions of their family members related to organ donation (Figure 1).

3.5 | Factors associated with willingness to donate organs among PWH in Northern Uganda

Factors associated with willingness to donate organs include being female (AOR: 1.56; 95% CI: 1.15–2.11), having a tertiary education level (AOR: 1.79; 95% CI: 1.03–3.11), average monthly income >500 000 UGX (135.1USD) (AOR: 5.5; 95% CI: 1.97–15.40), heard about organ donation (AOR: 5.4; 95% CI: 1.67–17.8), and attending an organ donation campaign (AOR: 2.0; 95% CI: 1.07–3.74) (Table 4).

4 | DISCUSSION

In this survey, we aimed to assess the awareness and willingness to be a living donor of a solid organ among PWH in Northern Uganda. We observed a relatively high awareness regarding solid organ donation. However, only 38.8% had previously donated blood or blood products. Most participants acknowledged the need for solid organ donation, but only about one-third expressed willingness to bring living donors of solid organs.

TABLE 4 Factors associated with willingness to donate organs among people with HIV in Northern Uganda.

Variable	Crude odds ratio	95% CI	p-value	Adjusted odds ratio	95% CI	p-value
Age in years						
<20	1			1		
20–34	1.29	(0.25–6.59)	.756	0.58	(0.13–2.65)	.484
≥35	1.01	(0.19–5.42)	.992	0.48	(0.11–2.03)	.320
Marital status						
Single	1			1		
Married	1.08	(0.95–1.24)	.247	0.89	(0.65–1.22)	.484
Settings						
Outpatient Department (OPD)	1			1		
Inpatient Department (IPD)	2.00	(0.50–8.08)	.330	1.64	(0.57–4.69)	.356
Gender						
Male	1			1		
Female	0.92	(0.45–1.87)	.817	1.56	(1.15–2.11)	.005
Highest education level attained						
None	1			1		
Primary	1.64	(1.32–2.04)	<.001	1.42	(0.99–2.04)	.056
Secondary	1.92	(0.92–4.01)	.081	0.88	(0.79–0.98)	.022
Tertiary	5.21	(1.21–22.46)	.027	1.79	(1.03–3.11)	.039
Average monthly income (in UGX)						
0–100 000 (0–27 USD)	1			1		
100 001–500 000 (27–135.1 USD)	1.52	(0.57–4.03)	.399	1.45	(0.54–3.85)	.459
>500 000 (>135 USD)	7.00	(1.10–44.66)	.040	5.50	(1.97–15.40)	.001
Newly diagnosed HIV patient						
Yes	1			1		
No	0.28	(0.07–1.09)	.066	0.40	(0.06–2.63)	.341
Ever heard about organ donation						
Yes	7.20	(3.2–16.1)	<.001	5.40	(1.67–17.8)	.005
No	1			1		
Ever attended an organ donation campaign						
Yes	2.60	(1.05–6.45)	.039	2.00	(1.07–3.74)	.028
No	1			1		
Family ever benefited from organ donation						
Yes	1			1		
No	0.76	(0.36–1.64)	.490	0.81	(0.38–1.74)	.592

Bold values indicates statistically significant.

Our results show a low willingness to donate organs among PWH compared to studies conducted in the United Kingdom and Taiwan where the estimated willingness to donate among PWH was estimated at 62% and 71.9%, respectively.¹¹ In the United States, the reported willingness to donate organs among PWH was estimated at 79.8% for deceased donation and 62.3% for living donation, with 80.7% being aware of organ shortages.^{10,17} Similarly, medical school interns and residents in India showed a high willingness to donate organs (88.8%), although knowledge about organ donation and the Human

Organ Transplantation Act was limited (25.2%).¹⁶ However, a study by Bookholane and colleagues in South Africa among families of potential donors revealed lower organ donation acceptance levels, where only 27.7% consented to organ donation.³ In a prior study in Uganda, the general population demonstrated even higher willingness at 93.2%, despite having low awareness (10%) about government policies on solid organ donation and transplantation.¹⁷ Findings from these studies, therefore, demonstrate a significant difference between the general population and PWH regarding their willingness to donate organs.



Factors associated with the willingness to donate organs in our study included being female, having a tertiary education level, having an average monthly income exceeding 500 000 UGX (135.1USD), having prior knowledge about organ donation, and participating in organ donation campaigns. Consistent with our findings, Lee and colleagues observed that PWH with higher education levels and prior knowledge of organ donation exhibited a greater willingness to donate.¹² Other studies also highlighted motivations for organ donation among PWH, including a desire to help others, solidarity with potential recipients, and a willingness to overcome HIV-related stigma.¹³

Furthermore, in our study, approximately 12.6% and 31.8% of participants expressed concerns about the potential misuse or trafficking of their organs and disfigurement upon donation, and 4% attributed their reluctance toward donation to perceived conflicts with their religious beliefs. Similar sentiments were observed in the United Kingdom, where PWH trusting the medical system or believing in the optimal functioning of their donated organs were more willing to be deceased donors.¹⁰ Conversely, individuals with concerns about surgery, post-donation health deterioration, or alterations in HIV treatment following donation were less willing to be living donors.¹⁰ In addition, fear of a prolonged recovery period, organ failure, and transmission of another strain of the virus to the recipient were identified as factors contributing to the decline of organ donation among PWH.¹³ Taha and colleagues revealed that Black Africans were more unsure about solid organ donation.¹¹ Regarding control beliefs toward organ donation, majority, 71% felt donation registration is time-consuming, 68% think the operation procedure is discouraging, and 90% think they will be weak and disabled.

As such, to address the identified concerns of PWH and foster a more positive attitude toward organ donation, there is a need for increased awareness and educational programs tailored specifically for this population. Moreover, advocacy efforts led by healthcare professionals, community leaders, and government should be intensified to enhance public understanding and acceptance of organ donation among PWH. Building on the existing body of knowledge, resources in addition to collaborative efforts should be allocated to enhance the capacity of organ donation infrastructure in Uganda.

Our study had some limitations. The sample size of our study was small; therefore, the findings may not be generalizable to the broader population of PWH in Uganda or elsewhere in sub-Saharan Africa. In addition, the cross-sectional design limits our ability to establish causal relationships, and the self-reporting nature introduces the possibility of social desirability bias, and the questionnaire was not pilot-tested. However, this was a multicenter study, including both out and inpatient PWH, and hence is representative of the study population in both urban and rural settings.

5 | CONCLUSIONS

Awareness about organ donation was high but the willingness to be a living donor of an organ was low among PWH. There is a need to sensitize the community about the need and benefits of organ dona-

tion with the involvement of media and the healthcare fraternity. A comprehensive strategy encompassing awareness programs, advocacy efforts, and capacity-building initiatives is crucial to fostering a positive environment for organ donation among PWH in Uganda.

AUTHOR CONTRIBUTIONS

Felix Bongomin: Conceptualization; investigation; funding acquisition; writing—original draft; writing—review and editing; visualization; validation; methodology; software; formal analysis; project administration; resources; supervision; data curation. **Ritah Nantale:** Investigation; writing—original draft; methodology; validation; visualization; writing—review and editing; software; formal analysis; project administration; data curation. **Winnie Kibone:** Conceptualization; investigation; writing—original draft; methodology; validation; visualization; writing—review and editing; project administration; data curation. **Byron Awekonimungu:** Investigation; writing—original draft; writing—review and editing; methodology; data curation; project administration. **Nixon Oyoo:** Investigation; writing—original draft; writing—review and editing; data curation. **James Okello:** Investigation; writing—review and editing; writing—original draft; project administration. **Conrad Muzoora:** Resources; supervision; data curation; software; formal analysis; project administration; writing—review and editing; visualization; validation; methodology; conceptualization; investigation; funding acquisition; writing—original draft. **Davidson H. Hamer:** Conceptualization; investigation; funding acquisition; writing—original draft; methodology; validation; visualization; writing—review and editing; formal analysis; software; project administration; resources; supervision; data curation.

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CONFLICT OF INTEREST STATEMENT

The authors declared no potential conflict of interest with respect to the research, authorship, and/or publication of this article.

DATA AVAILABILITY STATEMENT

All relevant data are within the article and its supporting information files. Data are available upon reasonable request from the first author.


CONSENT FOR PUBLICATION

Consent for publication was obtained from all study participants during the process of obtaining informed consent to participate in the study.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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