

Assessment of Awareness and Acceptability of Hospital Autopsy Among People Living with HIV and Their Caregivers in Northern Uganda

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Background: Autopsy is a valuable diagnostic tool utilized to identify causes of death and to confirm ante-mortem diagnoses of opportunistic infections among people living with HIV (PLHIV). We assessed acceptance of full or minimally invasive hospital (non-medicolegal) autopsies.

Methods: We conducted a multicentre, observational, cross-sectional study between October 2023 and January 2024 in four large HIV clinics in Northern Uganda among adult PLHIV and their caregivers, using a structured questionnaire. We conducted multi-variable logistic regression to assess for association between acceptance of autopsy and selected exposures among PLHIV and caregivers with results expressed as adjusted odds ratios (aOR) and 95% confidence intervals (CI).

Results: A total of 310 participants, including 232 PLHIV and 78 caregivers were enrolled. Most participants (77.4%, n=240) had heard of autopsy. Overall, 132 (42.6%) participants reported that they would accept autopsy; 38/78 (48.7%) of the caregivers versus 94/232 (40.5%) of PLHIV. Most (81.3%, n=252) cited desire for accurate cause of death as their reason for accepting autopsy. However, 133 (42.9%) reported fear of body disfigurement, 77 (24.8%) lack of perceived benefit, 35 (11.3%) religiously unacceptable, and 52 (16.8%) culturally/traditionally forbidden as reasons for autopsy refusal. Autopsy acceptance among PLHIV was associated with being an inpatient (aOR: 4.6; 95% CI: 2.04–10.4), autopsy awareness (aOR: 5.1; 95% CI: 1.2–22.0), and inversely with having a primary education level (aOR: 0.44; 95% CI: 1.61–3.18). Among caregivers, no education was associated with acceptance of autopsy (aOR: 0.09; 95% CI: 0.02–0.55).

Conclusion: In Uganda, less than half of PLHIV or their caregivers would accept having an autopsy when they die. There is need for public sensitization about the relevance of autopsies in this population, with emphasis that the clinical diagnosis may not necessarily be the cause of death.

Keywords: cause of death, minimally invasive autopsy, Uganda, HIV

Introduction

Human immunodeficiency virus (HIV) infection remains a significant global health concern with unacceptably high prevalence rates in sub-Saharan Africa. In Uganda, HIV-related mortality remains elevated, particularly among hospitalized patients, despite efforts to ensure widespread availability and accessibility of antiretroviral therapy (ART).^{1–5} Of the estimated 39.0 million people living with HIV (PLHIV) worldwide in 2022, approximately 630,000 people died from HIV-related causes.⁶ In Uganda, HIV prevalence among adults varies across regions, with mid-Northern Uganda having

one of the highest rates at approximately 7.6%.⁷ In 2022, an estimated 17,000 HIV-associated deaths were reported in Uganda.⁸ While tuberculosis (TB), *Pneumocystis pneumonia*, and cryptococcosis continue to be prominent contributors to HIV-related mortality in Uganda, a considerable proportion of PLHIV succumb without a definitive diagnosis.⁹ Therefore, ascertaining the causes of death among PLHIV is crucial in the steps towards improving the quality of health care, diagnostics, and overall lifespan of this population.

Autopsy remains a valuable diagnostic tool globally and has been extensively utilized not only for identifying causes of death, but also for confirming ante-mortem diagnoses of opportunistic infections among PLHIV.^{10,11} Diagnostic approaches for certain infections including fungal infections are limited in sub-Saharan Africa despite their significant contribution to mortality among individuals with advanced HIV disease.^{12–14} Pathological autopsies offer a unique opportunity to uncover the underlying causes of death and better understand the pathophysiology of fatal outcomes in PLHIV.¹⁴ PLHIV and their caregivers play a crucial role in improving diagnostic accuracy, understanding disease progression, and guiding patient care as they are the key consenters to the procedure. However, despite the known benefits of autopsy in providing insights into pathological processes and determining contributing factors to a patient's death, patients and their caregivers still widely view the procedure as unacceptable. In fact, the acceptance rate of autopsies in Uganda is estimated at about 38% among the next-of-kin to individuals who die due to advanced HIV in clinical trials settings.¹⁵ A recent observational study in urban Uganda reported an acceptance rate of 35% among predominantly HIV co-infected patients with TB.¹⁶

The level of general knowledge and awareness about autopsy procedures and perceived benefits by the public significantly impact the acceptance of autopsy among patients and their caregivers. Facilitators to autopsy acceptance include higher levels of education of the consentor, greater knowledge about specific aspects of autopsies, the desire for clarity regarding the cause of death, the approach to the bereaved family while seeking consent, the timing of the request, and timely execution of the autopsy.^{17–19} However, factors such as myths and misconceptions, cultural beliefs, and religious attitudes toward autopsies negatively influence caregivers' decisions in consenting to an autopsy.^{15,20} In addition, time constraints, family satisfaction with clinical diagnosis, fear of disfigurement of the remains, and lack of perceived benefit have been cited as reasons for declining autopsies.²¹ However, little is known about the acceptance of minimally invasive autopsy in this population. Consequently, more efforts exploring the challenges surrounding the intricacies of autopsies are necessary to improve its acceptance. Addressing misconceptions and making autopsies more accessible and convenient may improve autopsy acceptance rates.¹⁷

However, due to the ethical and socio-cultural intricacies surrounding ante-mortem consenting for hospital (non-medical legal) autopsies in PLHIV, there is a significant knowledge gap regarding the ante-mortem acceptance levels of full versus minimally invasive autopsies in this specific population and reasons for refusal. Therefore, in this study, we aimed to assess the ante-mortem level of acceptance of full or minimally invasive autopsy among PLHIV and/or their caregivers in selected hospitals in northern Uganda.

Methods

Study Design and Setting

We conducted a multicentre, observational, cross-sectional study across four large HIV clinics in Northern Uganda between October 2023 and January 2024. The study sites consisted of St. Mary's Hospital-Lacor, a private not-for-profit hospital in Gulu district; Anaka General Hospital, a public general hospital in Nwoya district; Kitgum General Hospital, a public hospital in Kitgum district; 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.²²

Study Population

The study population consisted of PLHIV admitted (inpatients) or attending outpatient ART clinics at the selected hospitals in Northern Uganda or their caregiver/next of kin. We defined a caregiver as a family member or legal representative responsible for the care and support of a person living with HIV. A caregiver was eligible to participate regardless of whether their patient had participated in the study.

Study Eligibility Criteria

The inclusion criteria for study participation required individuals to meet the following conditions: Having a documented HIV diagnosis or being a caregiver of someone with a documented HIV diagnosis and aged 18 years or older demonstrated competency and the ability to provide written informed consent, and expressed willingness to participate. Exclusion criteria encompassed severely ill patients, those in unconscious states, and individuals exhibiting emotional lability.

Sample Size

A sample size of 384 participants was calculated using the Kish-Leslie formula, with a modest acceptance level of 50%, type I error of 5%, at 95% confidence interval [CI]. We had 80% power to detect an effect size at 5%. Of the calculated sample size, we planned to recruit three-quarters (288) people living with HIV (PLHIV) and one-quarter (96) caregivers or next of kin. However, we recruited a total of 310 participants, comprising 232 PLHIV and 78 caregivers.

Data Collection

Convenience sampling method was employed to recruit participants. PLHIV and their next-of-kin who were present at the selected hospitals during the study period were approached and invited to participate.

Data were collected electronically using an interviewer-administered structured questionnaire upon receiving informed consent. The questionnaire was designed in KoBo Toolbox and included items related to demographic information, knowledge and awareness of autopsy, cultural and religious beliefs, and reasons for acceptance or refusal of autopsy. We assessed the internal reliability of the questionnaire items and obtained a Cronbach's alpha coefficient of 0.85, indicating good internal consistency. The questionnaire was administered face-to-face by trained research assistants who explained the study purpose and ensured confidentiality of responses. The data collection process was carried out in a private and comfortable setting to encourage open and honest responses.

Variables

Our outcome variable was acceptance of autopsy. This was assessed by asking a question "Would you accept to have autopsy done on you when you die?" with four responses (1. Yes, full autopsy, 2. Yes, minimal autopsy, 3. Yes, only if my body will not be disfigured and treated respectfully (hesitant), and 4. Not at all, regardless of the form). Participants who said they would accept a full or minimal autopsy were considered willing to accept autopsy, while those who were hesitant or those who declined were considered unwilling to accept autopsy.

The independent variables included demographic characteristics: age, gender, religion, marital status, education level, occupation, and monthly income; knowledge and awareness of autopsy; awareness of autopsy; knowledge of the definition of autopsy; and awareness of the benefits and drawbacks associated with autopsy.

Statistical Analyses

Data were analysed in Stata version 15.0. Descriptive statistics, including frequencies, percentages, medians (interquartile range), means, and standard deviations, were used to summarize the demographic characteristics and responses of the participants. We used multivariable logistic regression to analyze the associations between acceptance of autopsy and selected exposures, we adjusted for potential confounders such as age, level of education and profession. Variables with $p < 0.2$ at bivariable analysis and those with biological plausibility were added to the multivariable model. The final model was tested for goodness-of-fit using the Hosmer and Lemeshow goodness-of-fit test. Outputs were presented as crude odds ratio (cOR), adjusted OR (aOR), with corresponding 95% confidence interval (CI). The significance level was set at $p < 0.05$.

Ethical Considerations

The study protocol was approved by the Gulu University Research Ethics Committee (GUREC #GUREC-2023-635). Written informed consent was obtained from all participants. Ethical regulations outlined in the Declaration of Helsinki were observed throughout the study. Confidentiality was guaranteed during data collection to encourage honest

responses. No hospital or participant identifiable characteristics beyond basic demographics were collected, and access to the data was restricted to only authorized study personnel.

Results

Participant Characteristics

A total of 232 PLHIV and 78 caregivers to PLHIV were enrolled. The majority of PLHIV were female (56.9%, n=132), and 74.6% (n=173) were 35 years of age or older. Most caregivers to PLHIV were female (78.2%, n=61). The mean age of the enrolled caregivers was 42.2±11.8 years (Table 1).

Knowledge and Awareness About Autopsy Among PLHIV and Their Caregivers

Among PLHIV, the majority 76.3% (n=177) had heard of autopsy. Most 60.5% (n=107) heard about autopsy from media and 59.3% (n=105) from family/friends. About three-quarters (76.3%, n=177) knew the definition of autopsy. Regarding benefits of autopsy, the majority (79.3%, n=184) recognized that it can provide accurate causes of death, while 30.6%

Table 1 Sociodemographic Characteristics of the Study Participants

Characteristic	Frequency, n (%)	
	Caregivers	PLHIV
Facility		
Gulu Regional Referral Hospital	18 (20.1)	43 (18.5)
Lacor Hospital	23 (29.5)	16 (6.9)
Anaka General Hospital	21 (26.9)	99 (42.7)
Kitgum Hospital	16 (20.5)	74 (31.9)
Age (years)	48.6±11.7	42.2±11.8
<20	1 (1.3)	3 (1.3)
20 to 24	7 (8.9)	56 (24.1)
≥35	70 (89.7)	173 (74.6)
Gender		
Male	17 (21.8)	100 (43.1)
Female	61 (78.2)	132 (56.9)
Setting		
Outpatient Department (OPD)	46 (58.9)	210 (90.5)
Inpatient Department (IPD)	32 (41.0)	22 (9.5)
Highest Education level attained		
None	9 (11.5)	38 (16.4)
Primary	28 (35.9)	92 (39.7)
Secondary	29 (37.2)	59 (25.4)
Tertiary	12 (15.4)	43 (18.5)
Monthly income (in USD)	64 (28–135)	45 (23–85)
<28 USD	23 (29.5)	92 (39.7)
28–135 USD	36 (46.2)	110 (47.4)
>135 USD	19 (24.4)	30 (12.9)
Occupation		
Teacher	6 (7.7)	15 (6.5)
Health worker	1 (1.3)	8 (3.5)
Businessperson	17 (21.8)	42 (18.1)
Politician	4 (5.1)	10 (4.3)
Farmer	30 (38.5)	96 (41.4)
Housewife	10 (12.8)	11 (4.7)
Tailor	1 (1.3)	7 (3.0)
Other	9 (11.5)	43 (18.5)

(n=71) understood that it helps in medical research and advancements. Concerning drawbacks associated with autopsy, 34.5% (n=80) reported disfigurement of the body, 18.5% (n=43) cited lack of respect for the deceased, 13.8% (n=32) violation of cultural beliefs, and 12.1% (n=28) violation of religious beliefs

Regarding caregivers, the majority 80.8% (n=63) had also heard of autopsy (Table 2).

Acceptance of Autopsy Among PLHIV and Their Caregivers

Less than a half of PLHIV (40.5%, n=94) and caregivers (48%, n=38) reported that they would accept autopsy. Eighty-one (34.9%) patients reported that they would accept a full autopsy and 5.6% (n=13) minimal autopsy. Seventeen percent (n=41) were hesitant (would only accept if their body would not be disfigured and would be treated respectfully) and 41.8% (n=97) declined autopsy. Among PLHIV who reported that they would accept autopsy (n=94), 46.2% (n=61) reported that they would provide an advanced directive (will) to have autopsy done on them. Regarding caregivers, thirty-five (44.9%) reported that they would accept a full autopsy and 3.9% (n=3) a minimally invasive autopsy. Twenty-three percent (n=18) were hesitant (would only accept if their body would not be disfigured and would be treated respectfully) and 28.2% (n=22) declined autopsy. Overall, 15.9% (n=37) of the patients reported that their caregiver or family members opinion would influence their opinion regarding autopsy.

Most patients (81.3%, n=187) and caregivers (83.3%, n=65) cited desire for accurate cause of death as their reason for accepting autopsy (Figure 1). Regarding reasons for not accepting autopsy, most patients (46.9%, n=109) and caregivers (30.8, n=24) reported fear of body disfigurement (Figure 2).

Table 2 Knowledge and Awareness About Autopsy Among PLHIV and Their Caregivers

Variable (n=232)	Frequency n (%)	
	Caregivers	PLHIV
Ever heard of autopsy		
Yes	63 (80.8)	177 (76.3)
No	15 (19.2)	55 (23.7)
Source of information (multiple responses)		
Health worker	22 (34.9)	83 (46.9)
Media	54 (85.7)	105 (59.3)
Family/ Friends	40 (63.5)	107 (60.5)
Other	0 (0.0)	20 (11.3)
Definition of autopsy		
A medical procedure to determine the cause of death	61 (78.2)	177 (76.3)
A religious ritual performed after death	1 (1.3)	0 (0.0)
Do not know	16 (20.5)	55 (23.7)
Benefits of autopsy		
Provides accurate cause of death	63 (80.8)	184 (79.3)
Helps in medical research and advancements	24 (30.6)	71 (30.6)
Assists in improving healthcare practices	8 (10.2)	34 (14.7)
Provides closure for the family	13 (16.7)	56 (24.1)
Other	0 (0.0)	2 (0.9)
No benefits	14 (17.9)	47 (79.7)
Drawbacks or concerns associated with autopsy		
Violation of religious beliefs	10 (12.8)	28 (12.1)
Violation of cultural beliefs	9 (11.5)	32 (13.8)
Disfigurement of the body	23 (29.5)	80 (34.5)
Lack of respect for the deceased	7 (8.9)	43 (18.5)
Fear of body tampering	6 (7.7)	21 (9.1)
No drawbacks or concerns	47 (60.3)	122 (52.6)

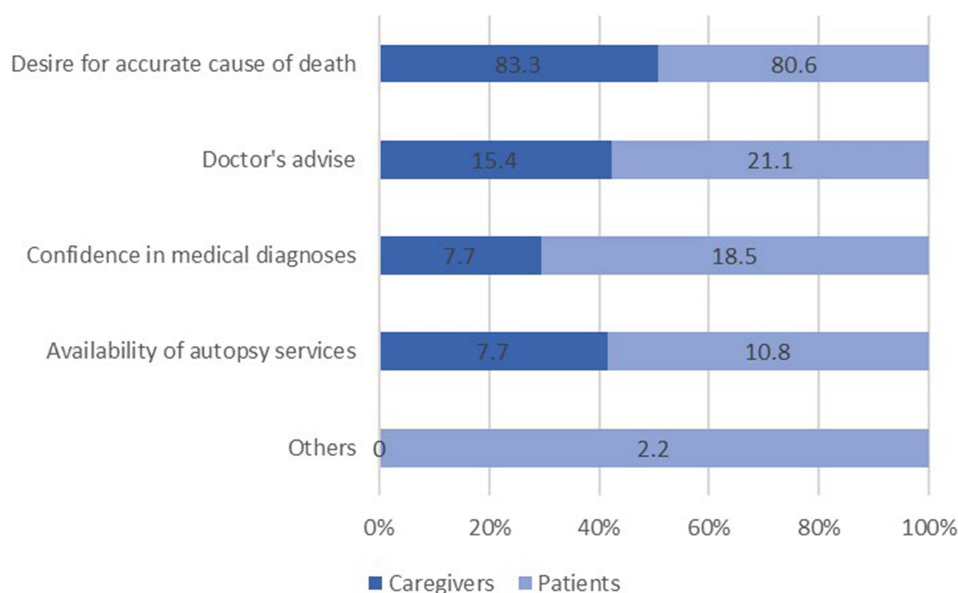


Figure 1 Reasons for accepting autopsy.

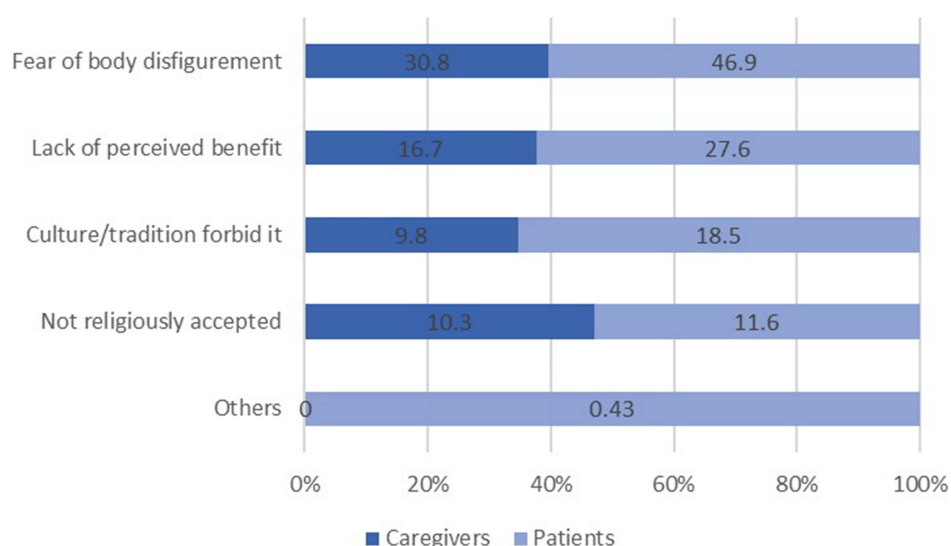


Figure 2 Reasons for not accepting autopsy.

Factors Associated with Acceptance of Autopsy Among PLHIV

Factors associated with acceptance of autopsy among PLHIV included being an inpatient (Adjusted Odds Ratio (aOR): 4.6; 95% CI: 2.04–10.4), awareness about autopsy (aOR: 5.1; 95% CI: 1.2–22.0), and education level (aOR: 0.71; 95% CI: 0.52–0.96). PLHIV with primary education level had 66% less odds of accepting autopsy as compared to those with secondary education level (aOR: 0.44; 95% CI: 1.61–3.18) (Table 3).

Factors Associated with Acceptance of Autopsy Among Caregivers of PLHIV

Caregivers with no education had 99.9% less odds of accepting autopsy as compared to those with secondary education level (aOR: 0.09; 95% CI: 0.02–0.55) (Table 4).

Table 3 Factors Associated with Acceptance of Autopsy Among PLHIV

Variable	Crude OR	95% CI	p-value	Adjusted OR	95% CI	p-value
Setting						
Outpatient Department	1			1		
Inpatient Department	5.87	(2.14–16.09)	0.001	4.6	(2.04–10.4)	<0.001
Gender						
Male	1			1		
Female	0.67	(0.28–1.61)	0.372	0.92	(0.68–1.24)	0.591
Marital status						
Single	1			1		
Married	0.88	(0.67–1.16)	0.368	0.77	(0.52–1.14)	0.186
Highest Education level attained						
None	0.36	(0.17–0.76)	0.007	0.62	(0.38–1.03)	0.066
Primary	0.31	(0.16–0.60)	<0.001	0.44	(1.61–3.18)	<0.001
Secondary	1			1		
Tertiary	0.91	(0.61–5.09)	0.911	0.66	(0.16–2.69)	0.564
Age (years)						
<20	1			1		
20 to 34	0.38	(0.04–3.59)	0.395	0.55	(0.04–6.68)	0.636
≥35	0.32	(0.03–3.57)	0.357	0.49	(0.04–5.49)	0.564
Monthly income (in USD)						
<28 USD	1			1		
28–135 USD	1.62	(0.62–4.25)	0.326	1.05	(0.38–2.92)	0.919
>135 USD	3.26	(0.33–31.78)	0.309	1.82	(0.54–6.20)	0.335
Ever heard about autopsy						
Yes	6.63	(0.8–53.5)	0.076	5.1	(1.2–22.0)	0.029
No	1			1		

Table 4 Factors Associated with Acceptance of Autopsy Among Caregivers of PLHIV

Variable	Crude OR	95% CI	p-value	Adjusted OR	95% CI	p-value
Settings						
1. Outpatient Department (OPD)	1			1		
2. Inpatient Department (IPD)	0.88	(0.36–2.14)	0.781	1.57	(0.95–2.61)	0.081
Gender						
1. Male	1			1		
2. Female	0.59	(0.28–1.28)	0.183	0.68	(0.30–1.52)	0.347
Marital status						
Single	1			1		
Married	2.83	(1.13–7.08)	0.026	1.57	(0.57–4.36)	0.387
Highest Education level attained						
1. None	0.09	(0.02–0.34)	<0.001	0.09	(0.02–0.55)	0.009
2. Primary	0.39	(0.10–1.53)	0.177	0.39	(0.10–1.45)	0.160
3. Secondary	1			1		
4. Tertiary	3.53	(0.61–20.28)	0.158	3.69	(0.73–18.68)	0.114
Monthly income (in USD)						
<28 USD	1			1		
28–135 USD	1.68	(0.70–4.02)	0.246	0.77	(0.22–2.70)	0.678
>135 USD	4.06	(0.27–61.32)	0.311	1.25	(0.05–28.94)	0.889

Discussion

In this study, we aimed to assess the ante-mortem acceptance levels of autopsies among PLHIV and their caregivers in selected hospitals in Northern Uganda. Most PLHIV and caregivers were female and were aged at least 35 years, consistent with findings from previous research and reports.^{23–25} We found a low ante-mortem acceptance rate of autopsies among PLHIV and their caregivers, with only 42.6% indicating willingness. The acceptance level of autopsy in our study is comparable to that reported in a study by Cox and colleagues¹⁵ done at Mulago Hospital in Uganda, which showed an acceptance rate of autopsy of 38% among deceased HIV patients' next-of-kin. However, our finding is lower than that reported from a study by Namuju and colleagues at Mulago Hospital²¹ that revealed a 55% acceptance rate of autopsy among caregivers of HIV-positive decedents. This observed difference in autopsy acceptance rates could be because the previous study assessed post-mortem acceptance of autopsy, while our study assessed ante-mortem acceptance.

Our study showed that patient acceptance is lower than that of caregivers. In the post-mortem decision-making process, there is lack of patient involvement; the individual who would undergo the autopsy is no longer present to object or feel discomfort about the procedure. This is in line with our findings where only 40.5% of the PLHIV reported that they would accept autopsy. Additionally, after death, there may be a greater recognition of the clinical necessity of an autopsy to determine cause of death among caregivers and health care providers.

We found that the most cited reason for accepting autopsy was a desire for accurate cause of death. Similarly, an in-depth examination of reasons for autopsy acceptance and refusal in Northern Tanzania and a study by Bunei and colleagues in Nairobi, Kenya, revealed that desire to know the cause of death was the most common reason for accepting autopsy.^{17,18} Identifying the cause of death can enable one to understand the circumstances surrounding the loss and alleviate any uncertainty about the cause.^{26,27} Furthermore, autopsies can uncover genetic or hereditary factors that may have contributed to the individual's death.²⁸

The most common reasons for declining autopsy were fear of body disfigurement, lack of perceived benefit, and culture or religion forbidden. Similar reasons have been reported in previous studies.^{15,17,18,21} However, we postulate that public sensitization about the relevance of autopsies in this population, emphasizing the point that the clinical diagnosis may not necessarily be the cause of death, will increase acceptance of autopsy. In this study, inpatient PLHIV had higher odds of accepting autopsy compared to those receiving care from the outpatient department. Inpatients may feel closer to the end of their life compared to outpatients who are receiving ongoing care, thus being more likely to consider procedures occurring post-mortem, such as autopsy.

Our study also showed that PLHIV who had ever heard of autopsy had higher odds of accepting autopsy compared to those who had never heard of autopsy. Patients who have heard of autopsies may have a better understanding of the purpose and potential benefits of the procedure, thus having higher odds of accepting autopsy. Consistent with our finding, a study by Bunei and colleagues showed that individuals were more likely to provide consent for autopsy if they had knowledge about certain aspects of autopsies.¹⁸ PLHIV with primary education level had less odds of accepting autopsy compared to those with secondary education level. We also found out that caregivers with no education had less odds of accepting autopsy as compared to those with secondary education level. Individuals with higher education levels may be more likely to consider autopsy because they recognize the value of autopsy in identifying the accurate cause of death. Similarly, a study in Nairobi, Kenya, showed that individuals with higher education levels were more likely to accept autopsy.¹⁸

Strengths and Limitations

Our study had certain limitations. The sample size was underpowered, as we achieved a sample size of 310 as opposed to the calculated sample size (384), the 80% power required sample size; hence the findings may not be generalizable to the broader population of PLHIV in Uganda. Moreover, the cross-sectional design restricts our ability to establish causal relationships, and the self-reporting nature introduces the possibility of social desirability bias. In addition, the use of convenience sampling increases the risk of selection bias because participants are chosen based on accessibility, rather than randomly. However, it is important to note that this study was conducted across multiple centers in northern Uganda and the first of its kind to assess ante-mortem acceptance of autopsy among both PLHIV and their caregivers.

Conclusions

We found a low antemortem level of acceptance of autopsy, with only a little more than 40% of PLHIV or their caregivers showing acceptance of this procedure. The most common reasons for refusal of autopsy included fear of body disfigurement, lack of perceived benefit, and culture or religion forbidden. Our findings emphasize the need to increase public awareness regarding the importance of autopsies in advancing medical knowledge, improving healthcare practices, and identifying the cause of death. Future research should explore context-specific strategies to address sociocultural and religious barriers to autopsy acceptance, including community engagement and targeted health education interventions.

Data Sharing Statement

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

Acknowledgments

We acknowledge administrative support from the collaborating study sites.

Funding

Research reported in this publication was supported by the Fogarty International Center of the National Institutes of Health under Award Number D43 TW010543. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Disclosure

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

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