ORIGINAL ARTICLE

Patient satisfaction with palliative care services among adolescents living with HIV at Arua Regional Referral Hospital, Uganda

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ABSTRACT

Background: Patient satisfaction with care among adolescents living with HIV is generally higher in high-income settings but remains limited in sub-Saharan Africa, including Uganda, where access to quality palliative care is constrained. Adolescents often face challenges in receiving responsive and supportive care despite national efforts to improve HIV services. This study assessed factors associated with satisfaction with palliative care services among adolescents living with HIV at Arua Regional Referral Hospital, Uganda. **Methods:** A cross-sectional study was conducted among 138 adolescent HIV patients. Data were collected via a researcher-administered structured questionnaire. Data were analyzed using SPSS version 22, with Pearson's chi-square (χ^2) and binary logistic regression applied to identify factors associated with patient satisfaction. **Results:** Overall satisfaction with palliative care was 85.5%. Multivariate analysis revealed that absence of health workers [AOR = 0.21; 95% CI: 0.052–0.857; p = 0.030], low social support [AOR = 0.25; 95% CI: 0.062–0.984; p = 0.047], and poor facility sanitation [AOR = 0.23; 95% CI: 0.064–0.847; p = 0.027] were significantly associated with lower satisfaction of palliative care among adolescents living with HIV ($p < 0.05$). **Conclusion:** Adequate staffing, strong psychosocial support, and hygienic facilities are key determinants of satisfaction with palliative care among adolescents living with HIV. Prioritizing these areas may improve patient experience, adherence to treatment, and overall quality of HIV palliative care services.

Keywords: Patient satisfaction; Palliative care; Adolescents living with HIV; HIV care services; Arua Regional Referral Hospital; Uganda

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INTRODUCTION

Globally, HIV/AIDS remains a critical public health concern, particularly among adolescents. According to the United Nations Children's Fund [UNICEF], approximately 1.55 million adolescents aged 10–19 years live with HIV worldwide, with over 88% of these cases concentrated in sub-Saharan Africa [1,2]. Spencer and Gomez reported that only about 14% of individuals in need of palliative care globally receive it, with satisfaction levels generally higher in high-income countries where services are better structured [3].

In the North Indian state, most in-patients expressed satisfaction with care received from nurses and doctors, the availability of medicines, and the hospital environment; however, domains of dissatisfaction included the cleanliness of rooms and bathrooms [4]. Similarly, Abdou and colleagues found that effective communication, respectful attitudes of healthcare providers, reduced waiting times, and maintained privacy were strongly associated with high patient satisfaction among adolescents receiving palliative care. Additionally, the availability of essential medicines, supportive services (such as food and water), and favorable socioeconomic conditions significantly contributed to positive care experiences [5]. In public hospitals of the Eastern Amhara region, North-eastern Ethiopia, the overall proportion of admitted patients satisfied with nursing care was substandard at 48.9% [6]. Many patients reported dissatisfaction with nursing, pharmacy, and laboratory services, while others expressed dissatisfaction with the level of health education, communication, and information provided about their illness [7].

In Sub-Saharan Africa, coverage of palliative care remains limited, with less than 10% of individuals requiring care receiving adequate services [8]. According to the Uganda National Palliative Care Policy review, approximately 62% of patients reported moderate satisfaction, citing long waiting times, insufficient adolescent-friendly services, and limited psychosocial support [9]. Adolescents, in particular, are underrepresented in satisfaction studies, highlighting a significant gap in tailored service delivery.

In Uganda, the integration of palliative care into national health services began in the early 2000s, making it one of the first African countries to develop a national palliative care policy [10]. However, a 2022 health sector performance report by the West Nile Regional Health Office indicated that only 41% of patients receiving palliative care in the region reported being satisfied with services. In Arua district, a 2023 District Health Office [DHO] report revealed that just 38% of patients, including adolescents, received comprehensive palliative care. Specific to Arua Regional Referral Hospital, a 2023 internal assessment showed that approximately 34% of adolescent HIV patients reported satisfaction with palliative care services. The primary barrier to effective palliative care in Arua is limited knowledge about palliative care among both the population and healthcare providers, with many patients receiving care at home through strong family involvement [11]. These statistics underscore the urgent need to identify and address factors influencing patient satisfaction to improve outcomes among adolescent HIV patients in this high-burden region.

MATERIALS AND METHODS

Study Design

This study employed a cross-sectional survey design using quantitative methods [12]. The design was appropriate for assessing factors associated with patient satisfaction among adolescent HIV-positive patients receiving palliative care services.

Study Setting and Participants

The study was conducted at Arua Regional Referral Hospital, located in Arua City in northwestern Uganda, along the northwestern edge of the River Nile, east of the Democratic Republic of Congo. The hospital serves as a referral center for the West Nile region, providing holistic care for survivors of sexual violence, maternal health services, and family planning.

The target population comprised all adolescent HIV-positive patients receiving care at the hospital in 2025, estimated at approximately 1,200 individuals. The study population consisted of 500 adolescents aged 10–19 years actively receiving palliative care services between January and May 2025. Inclusion criteria were: ages 10–19 years, confirmed HIV-positive status, active receipt of palliative care, and willingness to provide consent or assent. Adolescents not receiving palliative care, critically ill, or unable to participate in interviews were excluded.

Sampling and Recruitment

A total of 138 adolescents were recruited and completed the study. The minimum required sample size had been calculated as 205 participants using the single population proportion Yamane's formula with finite population correction [13],

assuming an estimated satisfaction prevalence of 34% (p = 0.34), a 95% confidence level (Z = 1.96), and a 5% margin of error (d = 0.05). Participants were selected using a systematic random sampling technique with a sampling interval of 2 (k = 2) and a randomly selected starting point, whereby every second adolescent on the palliative care register was approached for enrolment. Even though the target sample size was 205, only 138 eligible adolescents were available and consented to participate during the study period; hence, all analyses were based on the sample achieved of 138 participants.

Data Collection

Quantitative data were collected using a researcher-administered structured questionnaire. Questionnaires were administered in English or Lugbara according to participant preference, with questionnaire administration lasting approximately 30 minutes. Content validity was ensured through literature review and expert consultation, yielding a content validity index of 0.84 [14]. Reliability was assessed through a pre-test involving 17 adolescents, with subsequent modifications made based on participant feedback to improve the clarity and appropriateness of the study instrument.

Data Analysis

Quantitative data were analyzed using SPSS version 22. Descriptive statistics summarized participant characteristics, while Pearson's chi-square (χ^2) and binary logistic regression were used to determine associations between independent variables and patient satisfaction.

Ethical Considerations

The study adhered to national and international ethical guidelines, including the Uganda National Council for Science and Technology [15] and the 2013 Declaration of Helsinki [16]. Ethical clearance was obtained from the Research Ethics Committee (REC) of Bugema University. Administrative permission was sought from hospital authorities. Written informed consent was obtained from participants aged 18–19 years, while written assent and parental/guardian consent were obtained for participants under 18 years. Participation was voluntary, with confidentiality strictly maintained.

RESULTS

This study examined factors influencing satisfaction with palliative care services among adolescent HIV patients at Arua Regional Referral Hospital. Data were analyzed and presented according to key domains, including overall satisfaction levels, patient-related factors, health facility–related factors regarding the quality and delivery of care. A total of 138 adolescents participated in the study.

According to Figure 1, the majority of participants reported satisfaction with palliative care services, with only 20 adolescents (14.5%) indicating dissatisfaction at Arua Regional Referral Hospital.

From Table 1, most adolescents were aged 15–19 years (80, 58.0%), with a mean age of 15 ± 2.5 years. Approximately half of the respondents were female (71, 51.4%), and the highest proportion resided in peri-urban areas (56, 40.6%).

Table 2 shows that most adolescents reported good quality of care (113, 81.9%), experienced long waiting times (96, 69.6%), and observed good patient privacy practices (96, 69.6%). The majority also reported positive health worker attitudes (118, 85.5%), consistent availability of health workers (106, 76.8%), availability of medicines and supplies (101, 73.2%), strong social support (107, 77.5%), and satisfactory sanitary conditions (117, 84.8%).

Table 3 highlights the key factors significantly associated with satisfaction with care. Availability of healthcare workers was strongly associated with satisfaction. At bivariate analysis, the crude odds ratio [COR = 0.299; 95% CI: 0.085–0.618] indicated that adolescents reporting unavailability of healthcare workers had approximately three times lower odds of being satisfied compared to those reporting availability. After controlling for confounding, the multivariate analysis revealed that adolescents who reported that healthcare workers were unavailable had 79% lower odds of being satisfied compared to those who reported they were available **[**AOR = 0.21; 95% CI: 0.052–0.857].

Short waiting time (<1 hour) was significantly associated with the outcome in the bivariate analysis (COR = 0.372; 95% CI: 0.142–0.978); however, this association was attenuated and no longer statistically significant after adjustment for potential confounding factors in the multivariable analysis (AOR = 0.280; 95% CI: 0.076–1.054).

Social support was also significantly associated with satisfaction. At bivariate analysis, adolescents reporting low social support had four times lower odds of satisfaction [COR = 0.280; 95% CI: 0.104–0.758]. This association persisted after adjustment [AOR = 0.25; 95% CI: 0.062–0.984; p = 0.047].

Finally, sanitary conditions significantly influenced satisfaction with care. Adolescents reporting poor sanitary conditions had

seven times lower odds of satisfaction at bivariate analysis [COR = 0.138; 95% CI: 0.048–0.401], and four times lower odds after adjustment [AOR = 0.23; 95% CI: 0.064–0.847; p = 0.027].

These results indicate that healthcare worker availability, social support, and sanitary conditions are critical factors influencing satisfaction with palliative care among adolescent HIV patients at Arua Regional Referral Hospital.

DISCUSSION

Level of Satisfaction with Care

The level of satisfaction with palliative care services in this study was high, with 85.5% of adolescents reporting positive experiences. This indicates that the majority perceive the services as meeting their needs, which may promote treatment adherence, retention in care, viral suppression, and overall quality of life. Even though the 34% estimate used for sample size calculation was obtained from routine hospital records, the absence of a comparable population-based satisfaction estimate may limit the accuracy of the assumed prevalence and should be considered when interpreting the findings. The findings also reflect strong performance of the palliative care program at Arua Regional Referral Hospital. In comparison, Beneberu et al. [17] reported a moderate level of satisfaction (55.0%), while Katsuki and colleagues [18] observed very high satisfaction levels (94.1%). The 34% estimate was not derived from a previous population-based study but was obtained from routine hospital records and was used solely as an assumption for sample size calculation.

Differences in satisfaction levels across studies reflect variations in healthcare capacity, infrastructure, patient characteristics, service organization, staffing and contextual factors. These findings highlight that satisfaction is shaped not only by clinical care but also by the broader health system environment.

According to Getie et al. [19], satisfaction with palliative care represents the approval or positive feedback patients provide regarding healthcare services designed to enhance quality of life within the healthcare system.

Factors Associated with Palliative Care Satisfaction

Availability of Healthcare Workers: The absence of healthcare workers significantly reduced satisfaction among adolescent HIV-positive patients. Regular staff presence ensures timely attention, ART refills, counseling, and symptom management, whereas staff shortages may lead to delays or missed services, reducing satisfaction. These findings align with a study in a tertiary care hospital in Ranchi, India, where 91% of patients were satisfied with nursing availability, but 80% reported dissatisfaction with inadequate paramedical staff [20]. Similarly, Gembe [21] and Sekandi et al. [22] found lower satisfaction (46%) regarding doctor availability among admitted patients. Healthcare worker availability remains a key determinant of patient experience, although its effect varies with staffing levels, provider capacity, workload, and health system constraints, particularly in resource-limited settings.

Social Support: Insufficient social support significantly lowered satisfaction with care. Adolescents living with HIV often encounter stigma, disclosure concerns, and psychosocial stressors; strong social support can buffer these challenges, improve adherence, and enhance perceptions of the healthcare system. Supporting this, Harding et al. [23] reported that home-based care with family support improved satisfaction in Uganda and Kenya. Additionally, interventions such as group therapy and day care programs were associated with improved psychological well-being and quality of life [24,25]. Variations in satisfaction may reflect differences in psychosocial support systems. Comprehensive peer support, adolescent-friendly services, and community interventions address clinical and emotional needs, whereas limited support may increase stigma and isolation, negatively affecting care experiences.

Sanitary Conditions: Poor facility sanitation significantly reduced satisfaction among adolescent HIV patients. Clean, well-maintained environments are crucial for infection prevention and patients' overall perception of care quality. Unsanitary conditions may heighten anxiety and reinforce negative experiences, particularly for immunocompromised adolescents. These findings are consistent with Okae [26], who reported a significant association between sanitary conditions and care satisfaction, and with Kaur et al. [4], who highlighted poor cleanliness of rooms and bathrooms as a major source of dissatisfaction among inpatients in North India. Satisfaction related to environmental conditions may reflect disparities in sanitation resources, infrastructure, quality improvement practices, and facility maintenance, highlighting the need for holistic approaches that address both clinical and non-clinical aspects of care quality.

Limitations

The cross-sectional design limits causal inference and assessment of changes over time. Furthermore, the sample size

estimate was based on routine hospital records rather than population-based data, which may have introduced uncertainty in the assumed prevalence.

Conclusions and Implications

This study demonstrated that adolescents living with HIV at Arua Regional Referral Hospital generally perceived palliative care services positively. However, unavailability of healthcare workers, limited social support, and poor sanitary conditions were significant factors that reduced patient satisfaction. These findings underscore that adequate staffing, robust psychosocial support systems, and well-maintained, hygienic facilities are critical determinants of satisfaction with palliative care among adolescent HIV patients.

The study revealed important implications for practice and policy. Interventions that strengthen human resource capacity, promote family and community support mechanisms, and improve the physical environment of healthcare facilities are likely to enhance patient experience, adherence to antiretroviral therapy, and quality of HIV palliative care. Policymakers and program implementers should prioritize palliative care services that are responsive to the specific needs of adolescents, ultimately improving clinical outcomes and quality of life in this vulnerable population.

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TABLES AND A FIGURE

Table 1: Descriptive statistics of Patient Related Factors

Variable & Categories		Frequency (n = 138)	Percent (%)
Age of Respondent			
15.0±2.5	10 - 14 Years	58	42.0
	15 - 19 Years	80	58.0
Sex			
	Male	67	48.6
	Female	71	51.4
Place of Residence			
	Urban (Arua City)	52	37.7
	Peri-Urban	56	40.6
	Rural	30	21.7

Source: Primary Data (2025)

Table 2: Descriptive Statistics of Health Facility Related Factors

Variable & Categories	Frequency (n = 138)	Percent (%)
Quality of Care		
Poor	25	18.1
Good	113	81.9
Waiting Time		
Short (< 1 Hour)	42	30.4
Long (≥ 1 Hour)	96	69.6
Patient Privacy		
Poor Privacy	23	16.7
Good Privacy	115	83.3
Attitude of Healthcare Workers		
Poor	20	14.5
Good	118	85.5
Availability of Healthcare Workers		
Not Available	32	23.2
Available	106	76.8
Availability of Medicines & Supplies		
Not Available	37	26.8
Available	101	73.2
Social Support		
Low Support	31	22.5
High Support	107	77.5
Sanitary Conditions		
Poor	21	15.2
Good	117	84.8

Source: Primary Data (2025)

Table 3: Binary and Multiple Logistic Regressions of Factors Associated with Satisfaction with Care among Adolescent HIV Patients Receiving Palliative Care Services at Arua Regional Referral Hospital in Arua City, Uganda

Variable & Categories	Satisfaction with Palliative Care Services		COR [95%CI]	AOR [95%CI]
	Unsatisfied n (%)	Satisfied n (%)		
Age of Respondent				
10 - 14 Years	11 (19.0)	47 (81.0)	1.846 (0.711-4.798)	0.65 (0.172-2.478)
15 - 19 Years	9 (11.3)	71 (88.8)	1	1
Sex				
Male	13 (19.4)	54 (80.6)	0.454 (0.169-1.220)	0.38 (0.103-1.378)
Female	7 (9.9)	64 (90.1)	1	1
Place of Residence				
Urban (Arua City)	2 (3.8)	50 (96.2)	6.250 (1.173-33.290)	9.15 (0.903-92.75)
Peri-Urban	12 (21.4)	44 (78.6)	0.917 (0.305-2.751)	1.10 (0.286-4.264)
Rural	6 (20.0)	24 (80.0)	1	1
Quality of Care				
Poor	10 (40.0)	15 (60.0)	0.146 (0.052-0.408)	0.27 (0.067-1.053)
Good	10 (8.8)	103 (91.2)	1	1
Waiting Time				
Short (< 1 Hour)	10 (10.4)	86 (89.6)	0.372 (0.142-0.978)	0.28 (0.076-1.054)
Long (≥ 1 Hour)	10 (23.8)	32 (76.2)	1	1
Attitude of HCWs				
Poor	8 (40.0)	12 (60.0)	0.170 (0.058-0.498)	0.47 (0.105-2.058)
Good	12 (10.2)	106 (89.8)	1	1
Availability of HCWs				
Not Available	10 (31.3)	22 (68.8)	0.299 (0.085-0.618)	**0.21 (0.052-0.857) ***
Available	10 (9.4)	96 (90.6)	1	**1**
Social Support				
Low Support	9 (29.0)	22 (71.0)	0.280 (0.104-0.758)	**0.25 (0.062-0.984) ***
High Support	11 (10.3)	96 (89.7)	1	**1**
Sanitary Conditions				
Poor	9 (42.9)	12 (57.1)	0.138 (0.048-0.401)	**0.23 (0.064-0.847)***
Good	11 (9.4)	106 (90.6)	1	**1**

COR = Crude Odds Ratio; AOR = Adjusted Odds Ratio; CI = Confidence Interval. *Statistically significant at p < 0.05. AORs were adjusted for age, and sex.

Figure

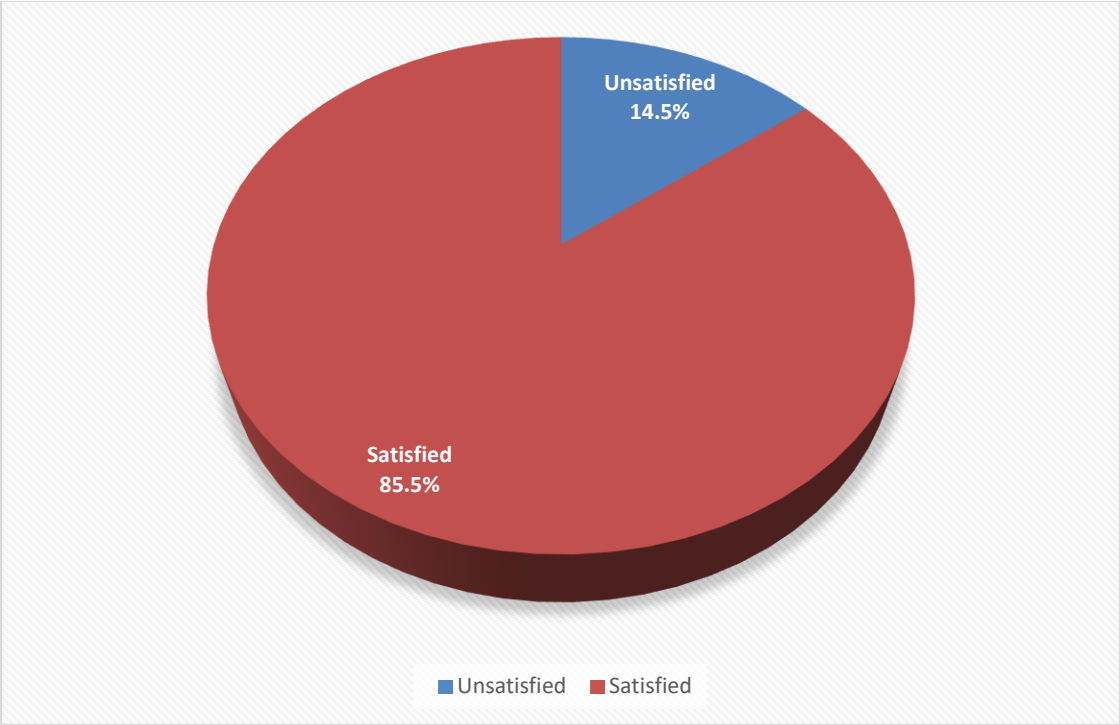

Figure 1: Level of Satisfaction with Care among Adolescent HIV Patients Receiving Palliative Care Services at Arua Regional Referral Hospital in Arua City, Uganda (Source: Primary Data (2025)