



OPEN A retrospective case-control study of reasons for referral, main distresses, and goals of care among HIV/AIDS and cancer patients in palliative care

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As many as 80% of patients receiving palliative care at Hospice Africa Uganda have cancer and/or HIV/AIDS. Given that cancer and HIV/AIDS have different trajectories since antiretroviral therapy (ART) became widely available, these two patients groups may differ in their care needs. This study's main objective was to identify, summarise and compare the reasons for referral, main distresses, and goals of care among cancer and HIV/AIDS patients in palliative care. A cross-sectional study employing a retrospective design was conducted on 100 consecutively sampled charts consisting of 50 cancer and 50 HIV/AIDS patients. Data were extracted using a researcher-developed structured checklist. Data were entered and analysed in STATA, version 17 using descriptive statistics and Chi-Square (χ^2) test. A *P*-value less than 0.05 was considered statistically significant. The primary reason for referral to palliative care was pain and symptom control at 22 (44%) and 36 (72%) among cancer patients and HIV/AIDS patients respectively ($\chi^2 = 8.046$, *P* = 0.005). The most prevalent main distress in both groups was unrelieved pain at 23 (46%) in the cancer group versus 24 (48%) in the HIV/AIDS group ($\chi^2 = 0.0401$, *P* = 0.841). The most common goal of care was pain and symptom control at 33 (66%) and 29 (58%) among cancer patients and HIV/AIDS patients respectively ($\chi^2 = 0.6791$, *P* = 0.41). The study findings showed that pain is the most prevalent symptom and the main cause of distress in HIV/AIDS and cancer patients in palliative care. Clinicians need to prioritize pain and symptoms assessment and management in order to optimise quality of life for patients and their families.

Keywords Cancer pain, Chronic disease, Cross-sectional studies, Palliative care, Patients, HIV/AIDS

Cancer is a major cause of suffering, disability, death and impoverishment to millions of livelihoods throughout the world¹. In 2020, 19.3 million new cases of cancer were diagnosed worldwide^{2,3}. The greatest burden of cancer is seen in low- and middle-income countries (LMICs) where 70% of deaths are registered⁴. Globally, it is predicted that by 2030, there will be 21 million new cancer cases per year and two-thirds (75%) of the global cancer burden, will be in LMICs⁵. Enough body of research shows cancer and its treatments have profound consequences on the quality of life (QOL) of patients and their families^{6–10}. Prioritizing high-quality palliative care including appropriate comprehensive symptom assessment and management is essential in alleviating distressing symptoms and suffering and promotes comfort^{4,11,12}. Care should take into account the holistic needs of the patients and their families i.e. physical, social, psychological, spiritual and emotional needs to optimise comfort^{12–14}.

In Uganda, cancer burden is huge and ever increasing. In 2022, 35,968 new cases, 24,629 deaths and 77,028 5-year prevalent cases were registered¹⁵. This is higher than 32,617 new cases and 21,829 cancer deaths registered in 2018^{16,17}. Sadly, at least 80% of cancer cases are diagnosed in advanced stages (3 and 4) with poorer survival outcomes¹⁷. Research has shown that most patients with advanced cancer suffer moderate to severe pain, and require strong opioid medications for pain control¹⁸. HIV/AIDS has similarly been associated with pain, symptoms and a poor quality of life¹⁹. At presentation for palliative care at Hospice Africa Uganda (HAU), most patients complain of pain, usually with other distressing symptoms. However, the reasons for referral to

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HAU appear to be varied. HAU frequently finds that whilst patients are referred for specific reasons, the main distresses some patients report on enquiry on the index encounter with the PC team are sometimes different and unrelated to the reasons for referral.

As part of holistic assessment to identify individual needs, patients are also asked about their goals of care. It is also possible that there are differences in the reasons for referral and goals of care between HIV/AIDS and cancer patients, but these have not yet been studied and documented through an empirical enquiry. People Living with HIV/AIDS (PLWHA) may also have unique needs. For example, PLWHA have been shown to have higher mortality rates compared with HIV-negative persons²⁰, due to multiple factors including higher prevalence of HIV-related immunosuppression and impaired control of oncogenic viral infections²¹. In a population-based study of 52,306 HIV-positive and 19,115,520 HIV-negative cancer cases, Islam et al.²² found PLWHA diagnosed with stage I-III cancer were more likely to receive palliative care compared with their HIV-negative counterparts. Given that HIV/AIDS and cancer have different trajectories since Antiretroviral therapy (ART) became widely available²³, it is plausible that these two groups of patients may have crucial differences in their reasons for referral, main distresses and goals of care. Generally, the findings of the review conducted for this study show that there exists sparse published research on the topic.

Thus, the main aim of this study was to identify and document main reasons for referral to palliative care, main distresses, and goals of care among HIV/AIDS and cancer patients receiving palliative care at HAU. This comparison is important and could give better insights rather than generalizing or even assuming that these two distinct patient groups experience similar distresses or have similar needs and goals of care. The study findings could influence how HAU and other cancer and HIV/AIDS care providers elsewhere approach care for people living with cancer and HIV/AIDS.

Materials and methods

Setting and design

This retrospective case-control study was conducted at HAU. Founded in 1993, HAU is a non-profit organisation whose mission is ‘to bring peace to the suffering in Africa through providing and facilitating affordable and accessible palliative care in Uganda and other African countries’. The facility provides holistic patient- and family-centered palliative care to those living with life-limiting and/or life-threatening illnesses, including but not limited to cancer and HIV/AIDS. HAU²⁴ has cared for at least 37,000 patients across its three service centres in capital Kampala, south west and Midwest Uganda, most of whom have cancer and/or HIV/AIDS. Care is provided at hospice, in hospital, and in the community (homes, outreach and roadside clinics) by multidisciplinary teams comprising nurses, doctors, social workers and volunteers.

Sampling and sample size calculation

HAU’s database was searched with the help of the monitoring and evaluation officer to generate a list of charts or case notes with either a cancer or HIV/AIDS diagnosis. Consecutive sampling was applied to select charts of 50 cancer patients (cases group) and 50 HIV/AIDS patients (control group). According to Krejcie and Morgan’s²⁵ table for determining sample size for categorical data, a sample size of 100 was deemed adequate to have equal sample size in each of the two groups. The HIV/AIDS group (few in number) was used as a reference group to determine the sample size, and to have equal sample size in the cancer patients group as well.

Eligibility criteria

A patient’s chart was eligible for inclusion in the study if: (1) the patient was currently receiving care at HAU Kampala branch, (2) enrolled in 2016 onwards, (3) with a primary diagnosis of either cancer only, or HIV/AIDS only but not both, (4) cancer and other comorbidities, and (5) HIV/AIDS and other comorbidities. A case note was excluded if: (1) patient had diagnosis of both cancer and HIV/AIDS, (2) patient enrolled into care before 2016, (3) patient died, (4) patient below 16 years of age, (5) the researcher established that the patient had impaired mental capacity to communicate own needs at the time the medical notes were documented.

Data collection instruments and procedure

Data were extracted from the selected eligible charts by the principal investigator (IS) using an investigator-developed structured checklist from June 2, 2023 to June 12, 2023. The data abstraction instrument was pretested on the first five sampled charts and amendments were made accordingly to make it more suitable to the aims of the study. Key variables collected included patients’ biodata, reasons for referral, main distress and goals of care.

Data analysis

Data were entered and analysed in STATA, version 17. Data analysis utilised a combination of descriptive statistics and a comparative analysis of the study variables between cancer and HIV/AIDS patients. A Chi-Square (χ^2) test was performed to examine reasons for referral, main distress and goals of care between the two patient groups. A *P*-value less than 0.05 was considered statistically significant.

Ethics statement

The study was ethically reviewed and approved by the HAU research ethics committee, reference HAU-2023-46 on May 2, 2023 and University College Dublin (UCD) research ethics committee, reference number UTMREC-SM-E-23-276-Soares-Natuhwera on 5th May 2023. Administrative permission to access the database and patients’ case notes was granted by Hospice Africa Uganda on 23rd April 2023. As data were collected from patients’ case notes, patient consent was not required. To ensure patient anonymity, identity-revealing information was not collected. Only the study team had accessibility to the data. Any requests to access data are granted upon

reasonable request and only if there is no potential breach of HAU's mechanisms of patient data protection and privacy.

Patient and public involvement statement

This study team did not engage patients at any stage of the study. The public was involved at dissemination of findings, mainly to the team at Hospice Africa Uganda and at poster competition award at University College Dublin.

Results

Sociodemographic characteristics of the participants

Of the 100 patient case files sampled, the majority (65%) were female. The mean age was 53.4 ± 18.0 years and the age range was 16–88 years Table 1.

As seen in Fig. 1 above, regarding diagnosis, the patients' case files reported diagnoses of cancer (27%), HIV/AIDS (18%), cancer and other comorbidities (23%), HIV/AIDS and other comorbidities (32%). This demonstrates that the majority of each of cancer and HIV/AIDS patient groups presented with comorbidities in addition to their primary HIV/AIDS or cancer diagnosis. The most common comorbidity among the participants was found to be neurological illnesses (14%).

In Table 2 above, Pearson's Chi-Square (χ^2) test demonstrated that reason for referral between the two patient groups was statistically significant ($\chi^2 = 8.046$, $P = 0.005$). There existed no differences between the two groups in regard to goal of care ($\chi^2 = 0.6791$, $P = 0.41$) and main distress ($\chi^2 = 0.0401$, $P = 0.841$).

In Fig. 2 above, when investigating main reason for referral among cancer and HIV/AIDS patients, data demonstrated that the most commonly reported reason for referral were pain and symptom control and psychosocial support. 44% (22 out of 50) cancer patients versus 72% (36 out of 50) HIV/AIDS patients reported pain and symptom control. Psychosocial support was found in 28(56%) of cancer patients versus 11(22%) of HIV/AIDS patients.

In Fig. 3 above, when investigating patients' main distress, unrelieved pain was most prevalent at 23(46%) in the cancer group versus 24(48%) in the HIV/AIDS group. Financial problems and progress of disease concerns were more common in the cancer patient group (24%, 20%) than in the HIV/AIDS patient group (16%, 16%). According to our findings, there were no patients that reported cultural or spiritual concerns. It is not clear whether this is the reality in practice or rather a practice gap in clinicians' documentation of patients' spiritual issues.

In Fig. 4 above, when investigating goals of care, the most commonly reported was pain and symptom control in both groups, reported by 66% cancer patients and 58% HIV/AIDS patients. 17% versus 21% cancer patients and HIV/AIDS respectively had a range of other goals of care including curative care, financial and psychosocial support and spiritual care. More cancer patients than HIV/AIDS patients reported the need for financial support (20%) and emotional/psychosocial support/care (14%). HIV/AIDS patients reported a slightly higher need for 'curative care' as their goal of care compared to their counterpart cancer patients. Surprisingly, there were no patients that reported spiritual care as their goal of care. It is likely the need for this crucial element of care by patients is rarely assessed and so is missed or is assessed but not documented by clinicians.

Discussion

This study's main objective was to identify and compare reasons for referral, main distress and goals of care among cancer and HIV/AIDS patients at HAU. Regarding the main reason for referral, pain control and psychosocial support were most prevalent among cancer and HIV/AIDS patients in this study. A prospective observational study conducted on hospital palliative care patients in Japan, of whom 95% had cancer, found that the main reason for referral was pain (63%) while 22% had depression/anxiety/emotional burden/grief²⁶. However, surprisingly, findings in this study demonstrate fewer cancer patients 44% versus 72% HIV/AIDS patient participants reported pain/symptom control as the main reason for their referral to palliative care. Whereas there is documented evidence indicating that the increased availability and use of anti-retroviral therapy (ART) has a significant positive role in modifying HIV trajectory including reducing symptom burden among HIV/AIDS patients (Anema et al.²⁷, Shao et al.²⁸), study findings indicate pain remains a common complaint reported by HIV/AIDS patients as is in cancer patients. Findings underscore the need to integrate palliative care for pain and symptom control into HIV/AIDS care.

Similarly, another study conducted with 140 PLWHA observed the most common reasons for referral were symptom control (33%), and patient support (14%)²⁹. However, this study outlined the frequency and nature of reasons for referral in HIV/AIDS patients only but not cancer. A study on End-of-Life (EOL) palliative care practices and referrals conducted at the Uganda Cancer Institute found that 66 of the 595 (11.1%) cancer patients studied were referred to palliative care services³⁰. The four common reasons for referral reported by doctors were, (1) patients not responding to chemotherapy, (2) patients at EOL, (3) insufficient time to address EOL problems, (4) the need for more holistic care. The study further pointed out that to achieve efficient and effective referral of patients to palliative care, there is need for more specific parameters to help health professionals including oncologists decide on who, where, and when to refer³⁰. However, the study did not investigate and report about the prevalence of reasons for referral. Our study has addressed this gap and assessed these three variables.

The most prevalent main distress in each of the cancer and HIV/AIDS study groups was unrelieved pain at 46% in the cancer versus 48% in the HIV/AIDS group. Literature shows that pain and other symptoms are most frequent and serious symptoms experienced by patients in palliative care settings. For example, 80% of patients with AIDS or cancer, and 67% of patients with cardiovascular disease or chronic obstructive pulmonary

Variable	Frequency (n = 100)	Percentage (%)
Age		
16–35: Youth	19	19
36–88: Adults	81	81
Gender		
Female	65	65
Male	35	35
Diagnosis		
Cancer	50	50
HIV/AIDS	50	50
Comorbid Illnesses		
Diabetes	15	15
None	46	46
Hypertension	21	21
Neuropathy	15	15
Religion		
Catholic	36	36
Protestant	19	19
Pentecostal	23	23
Muslem	11	11
Other	11	11
Stage of illness		
Early disease stage	31	31
Late/advanced disease stage	30	30
Unclear	39	39
Main Caregiver		
Immediate family member	72	72
Other relative	12	12
Non-relative	16	16
Source of referral		
Doctor	39	39
Nurse	4	4
Community Volunteer Worker/Village Health Team	20	20
Self	22	22
Other	15	15
Reasons for referral		
Pain and symptom control	96	96
Psychosocial support	41	41
End of Life Care	2	2
Financial support	1	1
Patient's distresses		
Unrelieved pain	57	57
Financial problems	20	20
Progress of Disease	20	20
Other physical symptoms	13	13
Psychological concerns	11	11
Cultural issues	0	0
Spiritual Concerns	0	0
Not Listed	3	3
Symptoms		
Respiratory Symptoms		
Cough	5	5
Dyspnea	3	3
Gastrointestinal Symptoms		
Constipation	39	39
Nausea/Vomiting	12	12
Diarrhea	3	3
Continued		

Variable	Frequency (n = 100)	Percentage (%)
Anorexia	1	1
Neuropsychological/ Neuropsychiatric Symptoms		
Pain	80	80
Headache	12	12
Dizziness	9	9
Insomnia	2	2
Depression	1	1
Dermatological Symptoms		
Pruritus/itchy skin	10	10
Skin Rash	5	5
Hematological Symptoms		
Bleeding	5	5
Anemia	2	2
General Symptoms		
Edema	9	9
Fatigue	0	0
Urinary Symptoms	8	8
Significant Weight Loss	0	0
Dysphagia	0	0
Mobility Issues	13	13
Other		
Pain severity		
No pain	16	16
Mild pain	1	1
More pain	3	3
Moderate pain	25	25
Severe pain	24	24
Overwhelming pain	31	31
Main goals of care		
Pain/symptom control	62	62
Curative care	3	3
Financial support	4	4
Emotional/psychosocial support/care	4	4
Spiritual care	9	9
Unclear/Not listed	10	10

Table 1. Sociodemographic characteristics of participants (n = 100).

Frequencies of The Diagnoses Among Patients

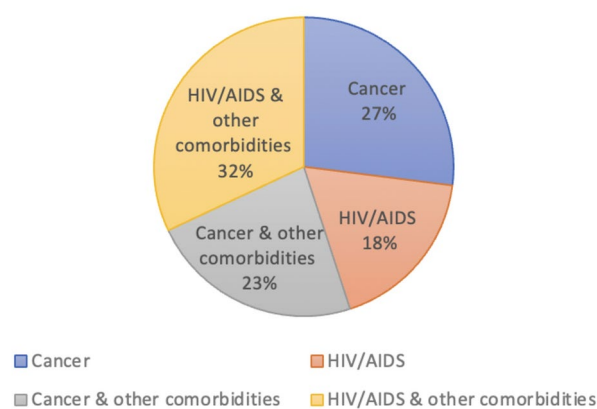


Fig. 1. Frequency of diagnoses among study participants.

Variable	Main goal of care		Chi-square (χ^2)	P-value
Diagnosis	Pain/Symptom control	Others	0.6791	0.41
Cancer	33(66%)	17(34%)		
HIV/AIDS	29(58%)	21(42%)		
Variable	Reasons for referral to palliative care			
Diagnosis	Pain & Symptom control	Others	8.046	0.005*
Cancer	22(44%)	28(56%)		
HIV/AIDS	36(72%)	14(28%)		
Variable	Patient's main distress			
Diagnosis	Unrelieved pain	Others	0.0401	0.841
Cancer	23(46%)	27(54%)		
HIV/AIDS	24(48%)	26(52%)		

Table 2. Pearson's Chi-Square (χ^2) analysis of reasons for referral, main distress, and goals of care between cancer and HIV/AIDS patient groups. *Represents statistically Significant P-value. P-value less than 0.05 was considered statistically significant

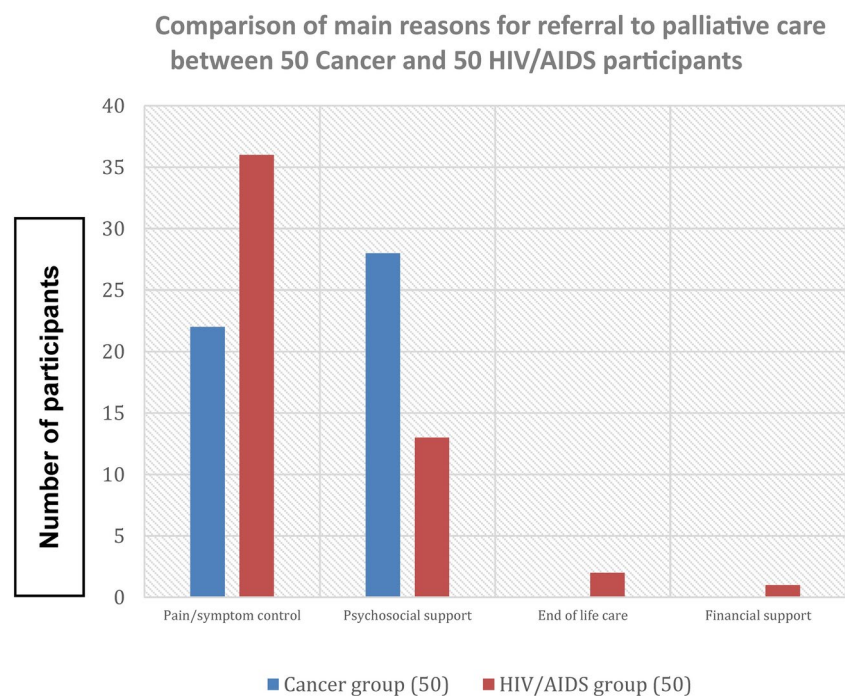


Fig. 2. Main reason for referral to palliative care.

disease will experience moderate to severe pain at the end of their lives³¹. PLWHA are disproportionately more likely to experience a high burden of poor mental health outcomes, including depression perpetuated by HIV-related stigma, discrimination, and worries stemming from the reality of chronicity of HIV illness and other social inequities^{32–35}. In one retrospective cross-sectional study conducted at the Princess Margaret Hospital in Toronto, one of the largest Cancer facilities in Canada, it was discovered that the main distresses of Cancer patients (determined using the Edmonton symptom assessment system (ESAS) receiving palliative care were, fatigue (77%), pain (75%), and lack of appetite (66%)³⁶. However, this study was only able to identify the main distresses of cancer patients but not HIV/AIDS patients. Hence, the main distresses of HIV/AIDS patients remain largely unknown, or are based on assumptions.

Study findings demonstrate that socioeconomic concerns and progress of disease were more prevalent in the cancer patient group, while other physical symptoms and psychological concerns were more prevalent in the HIV/AIDS patients group. These differences in distributions may be due to the different trajectories of the two illnesses as HIV/AIDS patients who receive ART may have a normal life expectancy and reduced symptom burden (Shao et al.²⁸). Similarly, pain is the commonest complaint reported in studies with cancer patients globally^{9,37–39}. As many as 55% of patients undergoing anti-cancer treatment and 66% of patients who have advanced, metastatic, or terminal disease experience pain³⁹.

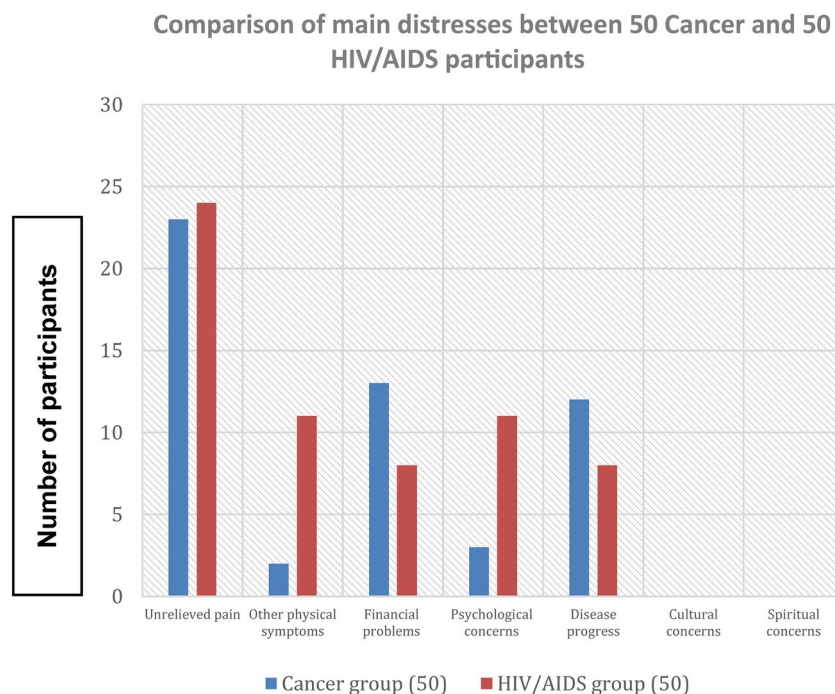


Fig. 3. Main distresses among cancer and HIV/AIDS patient groups.

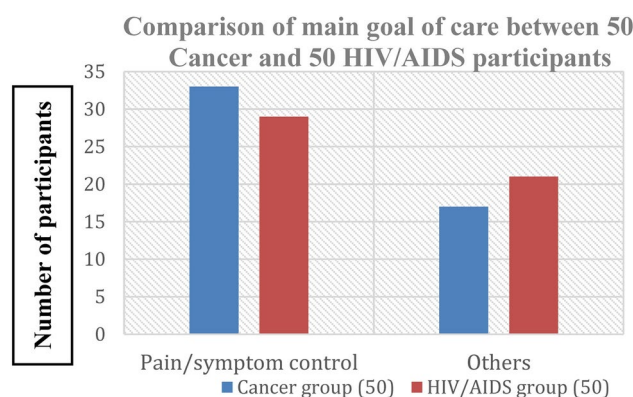


Fig. 4. Goals of care in the two patient groups.

The findings in this study are similar to those of previous studies. For example, in a study conducted in four palliative care centers, one in Uganda and three in South Africa, the five main distresses mentioned by the 112 patients enrolled in the study included pain (87.5%), lack of energy (77.7%), feeling upset (75.9%), feeling drowsy (72.3%) and anxiety/worry (69.6%)⁴⁰. Only 19.6% of the participants had HIV/AIDS. It is worth noting that the main focus of the study was to determine the main distresses of advanced cancer patients. This study did not attempt to compare and/or discuss main distresses in the two groups (Cancer versus HIV/AIDS). Since the early days of the AIDS epidemic, PLWHA have been found to have a high prevalence of pain and other symptoms^{41–44}. In PLWHA, neuropathic pain is prevalent in at least 40% of patients with advanced disease⁴⁵.

The aetiology of neuropathic pain is primarily due to the syndrome of distal symmetric polyneuropathy (DSP) - an axonal neuropathy caused by HIV infection itself, opportunistic infections or malignancies, antiretroviral therapy mainly nucleoside reverse transcriptase inhibitors (NRTIs), and/or other coexisting comorbidities such as diabetes⁴⁶. Numerous previous research studies have reported that neuropathic pain has a classical characteristic presentation of numbness, tingling, “pins and needles” sensation and allodynia, particularly involving the distal lower extremities and feet^{47–50}. Effective palliative care including proper assessment and appropriate use of both drug and non-drug measures can reduce or prevent pain and other symptoms and promote comfort in PLWHA⁵¹.

The most prevalent goal of care was pain and symptom control among cancer (66%) and HIV/AIDS (58%) patients. Generally, cancer patients reported greater need for financial support and emotional/psychosocial care, whereas, surprisingly, HIV/AIDS patients reported greater need for curative care. It can be hypothesised that with the advent and wide availability of ART, many HIV/AIDS patients lead a normal life with less

severe and frequent symptoms, hence they may experience less severe emotional/psychosocial problems than cancer patients. However, even when HIV/AIDS patients are receiving ART, they are still susceptible to opportunistic infections and symptoms associated with the disease or its treatments⁴⁶. In a large study of 4,804 cancer patients done at the Canadian Tertiary Care Cancer Center, 96% of the study participants signed do-not-resuscitate orders, 86% followed supportive care plans and 76% had a diagnosis of dying⁵². Although this study is titled ‘goals of care’ it fails to address such other crucial goals of care in the domains of pain management, spirituality, and psychological or social.

Conclusion

The study found that pain is a major complain, cause of distress, and main reason for referral and consultation with palliative care for both cancer and HIV/AIDS patients. Socioeconomic and disease progress distresses were more prevalent at 26% and 18% respectively in the cancer patient group than in HIV/AIDS patient group at 16% each.

Findings demonstrate that as part of holistic palliative care, clinicians need to give pain and symptom assessment and management a priority so as to be able to identify patients’ distresses and develop comprehensive individualised care plans tailored to the address the needs to optimize quality of life of patients. Pain and symptom management should be integrated into HIV care to optimise better care outcomes for PLWHA. Of particular importance to note, in addition, is the need for healthcare professionals to prioritise psychosocial care, particularly strengthening assessment and documentation to be able to identify and address the multiple emotional and psychosocial concerns such as fear, worries and uncertainty associated with cancer and HIV/AIDS, as these could potentially compromise QOL of patients and their families.

Future research should employ longitudinal design to better examine factors and relationships over time that could influence HIV/AIDS and cancer patients’ symptom experience and needs. In addition, qualitative studies are needed to gain better insights into the topic. For example, it can be hypothesised that pain and other symptoms experience and needs of these two groups of patients could differ in many other dimensions that may not be sufficiently elicited, examined and explained using quantitative methodology.

Strengths and limitations of this study

Strengths

- This is one of the first studies to attempt to understand as to whether there are differences in relation to the three categories of reasons for referral, main distress and goals of care between Cancer and HIV/AIDS patient groups.
- Hence, the study contributes crucial evidence to add to limited evidence available e.g. the study showed that unrelieved pain is prevalent and is the common cause of distress in both cancer and HIV/AIDS.

Limitations

- Participants in this study were recruited from a single centre. Thus, findings might have limited generalizability. Given the small sample size, the study findings need to be interpreted with caution. Recruiting participants from other sites and increasing the sample size would increase the power of the study and give more generalizable findings.
- The cross-sectional design precludes observations over time, e.g. how goals of care and distresses change over time. Future research, preferably employing longitudinal design is needed to examine factors and relationships over time that could influence patients’ symptom experience and needs. Furthermore, the study relied on clinicians’ documented data of patient-clinician interactions which could have limited the richness of the data. For example, the study is unable to account for lack of documented data on cultural and spiritual concerns in the sample; whether this is due to documentation bias or reflects a true reality.

Data availability

Data is provided within the manuscript. Access to raw datasets generated and analysed in this study can be requested through the corresponding author ngermans16@gmail.com or gnatuhwera@hospice-africa.org upon provision of satisfactory reason.

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Author contributions

IS proposal development, data collection, data analysis, report writing, writing of original manuscript. GN conceptualisation of the study, supervision, data analysis, writing, reviewing and editing of manuscript for intellectual content for publication. Both authors contributed substantially to the work-; took part in drafting, critically revising and reviewing the article; gave final approval of the final manuscript submitted for publication; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Declarations

Competing interests

The authors declare that they have no competing interests.

Additional information

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