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The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries

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ABSTRACT

Background: The majority of cancer presentations in Africa are advanced and incurable, with incidence of malignancies projected to increase significantly. Despite the African cancer burden, almost nothing is known about the symptomatology of malignant progressive disease. This study aimed to determine the symptom prevalence and burden amongst advanced cancer patients in two African countries.

Methods: The Memorial Symptom Assessment Schedule Short Form (MSAS-SF) was used to measure the 7-d period prevalence and associated burden of multidimensional symptoms amongst adult patients attending palliative care in South Africa and Uganda. Further demographic and clinical variables were collected.

Results: Of the 112 patients recruited, 22 (19.6%) had an underlying HIV diagnosis. The most common cancer primaries were breast ($N = 24$), cervix ($N = 21$) and lung ($N = 14$). The mean number of symptoms was 18 (SD = 6.6). The five most prevalent symptoms were pain (87.5%), lack of energy (77.7%), feeling sad (75.9%), feeling drowsy (72.3%) and worrying (69.6%). The five symptoms ranked as most severe were as follows: pain $n = 26$ (23.2%), sexual problems $n = 24$ (21.4%), weight loss $n = 21$ (18.8%), 'I don't look like myself' $n = 21$ (18.8%) and lack of energy $n = 20$ (17.9%).

Discussion: Pain and psychological problems were four of the five most common symptoms, found in more than 3 out of 4 patients. Our sample's reported mean number of symptoms was far higher than reported in other global studies. These data can inform the delivery of appropriate clinical care. The prevalence of multidimensional symptoms underlines the importance of holistic approaches to patient assessment and management, taking account of multiple and potentially interacting symptoms and locally appropriate intervention.

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1. Background

The lack of developed cancer registries in many countries in Africa hampers the collection of robust surveillance data to determine incidence and mortality, with fewer than 1% of abstracts within the global cancer registration literature originating from Africa.[1] Data to inform evidence-based clinical practice are urgently needed to improve outcomes for Africans affected by cancer, as by 2030 the developing world is expected to bear 70% of the global cancer burden.[2] GLOBCAN estimates that there were 622,190 new Sub-Saharan African cancer cases and 483,557 deaths[3] in 2007. Poverty continues to be linked to cancer.[4] The link between cancer and poverty disproportionately affects SSA, and limited access to health services is a factor leading to cancers having already progressed to an incurable stage in 80% of patients by the time of detection and diagnosis.[5] Malignancies are a common presentation of HIV.[6] Around 36% of cancers in Africa are infection related, which is twice the global average.[7] This reflects the challenge of infectious disease (particularly of HIV), and that many cancer patients have underlying HIV infection.

In Africa, the lifetime risk of a woman dying of cancer is double that of developed country.[8] A population-based analysis of cancer survival rates found survival in African to be poorer to the comparators of Asia and Central America,[9] with survival not exceeding 22% for any cancer site in the Gambia or 13% (except for breast) in Uganda. A review of childhood cancer treatment in developing countries concluded that the high cure rates seen in Western countries are not anticipated for Africa, due to the lack of resources and locally adapted treatment protocols, late presentation and poor cancer treatment compliance.[10]

Advances have been achieved in palliative care service provision in some countries in Africa, addressing the highly prevalent and burdensome problems experienced by those with incurable progressive disease. However, a systematic appraisal of the status of palliative care in Sub-Saharan African countries found almost no evidence on the problems and outcomes of patients.[11] A comparison of the global data on the prevalence of symptoms between advanced progressive conditions found no data on cancer patients in Africa.[12] Although palliative care is now advocated as a global human right,[13] the research evidence in African to date has focused almost exclusively on advanced HIV, and specifically on the availability of opioids to improve pain relief.[14,15] The symptom profile (in terms of prevalence and burden) of Africans with advanced cancer is not known. If appropriate clinical and public health responses are to be generated to address the growing cancer incidence and mortality in African countries, it is essential to understand patients' physical and psychological needs, as it cannot be assumed that they are the same as those in developed countries with different prevailing malignancies and health systems, beliefs and behaviours.

This study aimed to determine the symptom prevalence and burden amongst advanced cancer patients in two African countries.

2. Methods

This study used an international multi-centred cross-sectional design utilising a well-validated cancer symptom scale.

2.1. *Participating sites*

This study was undertaken in four palliative care facilities, three in South Africa and one in Uganda, serving peri-urban and urban areas with a range of home-care, day-care, hospital consulting and palliative inpatient services.

2.2. *Recruitment*

Inclusion criteria were adult patients (at least 18 years old) under cancer palliative care with sufficient physical and cognitive ability to participate in interviews. All information and consent forms and tools were translated from English (forward and back) into the principle languages of Luganda, Runyankole, Sesotho, Runyoro, SeTswana, isiXhosa and two isiZulu dialects. Informed consent was obtained from all participants. The study was reviewed and approved by the Ethical Review Boards of the Universities of Cape Town, KwaZulu Natal and Witwatersrand, the Ugandan National Council for Science and Technology, Hospice Africa Uganda and the Hospice Palliative Care Association of South Africa.

2.3. *Translation and data collection*

The following patient demographic and clinical data were collected: age, gender, first language, language of interview, primary cancer diagnosis, household size, number of children responsible for, location of home (urban, peri-urban, rural), primary place of care (home, inpatient/outpatient unit, day care facility), functional status (using the ECOG[23]) and time under care in weeks. We elected to collect data on the number of children that the respondents were responsible for, rather than number of biological children. This was because adults may often care for children other than their own, e.g. grandchildren, nephews and nieces, a situation which has been exacerbated by AIDS-related deaths. The Memorial Symptom Assessment Schedule Short Form (MSAS-SF) was used to measure the 7-d period prevalence and associated burden of multidimensional symptoms. The MSAS-SF offers three subscale indices of Physical Symptom Distress Index (MSAS-Phys), Psychological Symptom Distress Index (MSAS-Psych) and Global Distress Index (MSAS-GDI).[16] Each of these three subscales has a possible score range of 0–4. This well-validated multidimensional instrument captures the presence and distress of 26 physical and four psychological symptoms amongst cancer patients.

Following a study in Uganda to determine whether additional items are necessary for measurement amongst cancer and HIV palliative populations (involving patient and staff focus group studies and item testing, data submitted) the following items were included in the pool of physical symptom items: bad smell/odour; sores/lumps on genitals; discharge from genitals; difficulty moving; difficulty walking; poor vision, poor hearing; hunger.

The MSAS-SF, demographic record and information and consent sheets were translated from English into the main local languages (isiXhosa, isiZulu (Gauteng and KwaZulu Natal dialects), SeSotho, SeTswana, Luganda and Runyoro). Translation was carried out by the participating sites and cross-checked by staff fluent in both English and the relevant local language. The University of KwaZulu Natal carried out the Natal Zulu translation and the University of Cape Town the isiXhosa translation.

Research nurses read out the questionnaire items and entered the patient's self-report response on their behalf. Self-complete was not used due to limited literacy, and all questionnaires were completed using research nurses to enter responses to reduce any potential bias through using a mixture of self-complete and researcher-completion. To ensure only a single data collection method was used (thereby reducing potential bias). Time to complete the MSAS-SF was recorded. Research nurses then entered data into purpose-designed Excel spreadsheets, subsequently imported into SPSS for analysis.

2.4. *Analysis*

Descriptive analysis was undertaken for patient characteristics and MSAS-SF scores. For each item within MSAS-SF, the prevalence and associated burden were calculated. Subscales of global, physical and psychological distress were calculated using the original subscales and calculation methods of the MSAS-SF (i.e. not including the additional African items). The total number of 7-d period prevalent symptoms was also calculated for each respondent, and the mean and standard deviation for the sample. Physical and psychological symptoms are reported separately and in descending order of prevalence.

2.5. *Role of the funding source*

The funding source had no role in study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the paper for publication.

3. Results

3.1. *Sample characteristics*

One hundred and twelve cancer patients were recruited. The mean age was 56.6 years (SD = 15.8), and 72 (64.3%) were female. The place of care and recruitment was as follows: home care *n* = 94 (83.9%), inpatient *n* = 8 (7.1%), outpatient 9 (8.0%), daycare *n* = 1 (1.9%). Patients had been under palliative care for a median 52 weeks. Respondents' home location was: urban *n* = 49 (43.8%); peri-urban *n* = 31 (27.7%); rural *n* = 32 (28.6%). Of the 112 patients, *n* = 73 (65.2%) were responsible for children (mean number of children responsible for was 3.7, SD = 2.8).

Of the 112 recruited cancer patients, 22 (19.6%) had an underlying diagnosis of HIV disease, and 10 of these were accessing antiretrovirals. Their ECOG functional status scores were near normally distributed: fully active *n* = 18 (16.1%); restricted *n* = 31 (27.7%); ambulatory *n* = 25 (22.3%); limited self-care *n* = 24 (21.4%); completely disabled *n* = 14 (12.5%). The cancer primaries were: breast N = 24, cervix N = 21, lung N = 14, prostate *N* = 11, Kaposi's Sarcoma *N* = 7, stomach *N* = 6, colorectal *N* = 6, oesophagus *N* = 5, liver *N* = 4, lymphoma *N* = 2, pancreas *N* = 2, bladder *N* = 1, brain *N* = 1, Hodgkin's disease *N* = 1, skin *N* = 1, lymphangiosarcoma *N* = 1, ovary *N* = 1, multiple myeloma *N* = 1 (missing *N* = 3).

The symptom 7-d period prevalence and associated burden are reported in Table 1. The mean number of symptoms was 18 (SD = 6.6). The five most prevalent symptoms were pain (87.5%), lack of energy (77.7%), feeling sad (75.9%), feeling drowsy (72.3%), worrying (69.6%). The symptoms reported as having the most severe burden (i.e. scored 'very much') are important clinically. The five most prevalent severe symptoms were as follows: pain *n* = 26 (23.2%), sexual problems *n* = 24 (21.4%), weight loss *n* = 21 (18.8%), I don't look like myself *n* = 21 (18.8%) and lack of energy *n* = 20 (17.9%). The mean Global Distress Index was 1.61 (SD = 0.70), the Physical Distress Index was 1.41 (SD = 0.75) and the Psychological Distress Index was 1.33 (SD = 0.76). The MSAS-SF took a mean 19.9 min to complete (SD = 6.5).

4. Discussion

The data presented in this paper are the first to determine the symptom prevalence and burden amongst advanced cancer patients in Sub-Saharan Africa. It is interesting to note that pain and psychological problems were three of the five most common symptoms, found in more than two out of three patients. These data can inform the planning and delivery of appropriate care for Africans with advanced cancer.

We have compared our findings to available MSAS data reporting cancer patient studies: 66 hospitalised metastatic and Stage IV lymphoma cancer patients in the USA[17]; 296 veterans with advanced cancer in the USA who had presented with at least one symptom[18]; 256 patients with colorectal cancer in China[19]; 30 patients with advanced lung or pancreatic cancer in the USA.[20] The comparison demonstrates that our sample's reported mean number of 18 symptoms was far higher that reported in other studies at 8.0–13.3 (inset A–D). The mean Distress Indices in our sample are also appreciably higher than that reported in other studies for Global Distress (1.61 versus 0.82, respectively) (inset C), Physical Distress (1.41 versus 0.57–1.29) (inset B and C) and Psychological Distress (1.33 versus 0.87–1.19) (inset B and C). These data carry important implications for clinical care and services. The prevalence of multidimensional symptoms underlines the importance of holistic approaches to assessment and management of patient problems, taking account of multiple and potentially interacting symptoms and locally appropriate intervention to reduce distress. Further research is needed to understand the complexity of symptoms alongside public health systems research to ensure that opioids and other essential drugs are available.

The comparative data should be understood in the context of setting – i.e. the prevailing malignancies, the availability of palliative care services and symptom controlling drugs and culture. Culture determines the ways that patients understand cancer, and the patient's emotional response to the disease.[21] Therefore, clinical protocols must deliver interventions that are feasible, acceptable and appropriate

Table 1 – Seven-day period prevalence using Memorial Symptom Assessment Scale $n = 112$.

Symptom	Prevalence	Missing	Burden (total: 100%)						
			Not present	Not at all	A little bit	Somewhat	Quite a bit	Very much	Missing
Physical problems									
Pain	87.5% (N = 98)	0	12.5% (N = 14)	1.8% (N = 2)	17.0% (N = 19)	17.9% (N = 20)	27.7% (N = 31)	23.2% (N = 26)	0
Lack of energy	77.7% (N = 87)	0	22.3% (N = 25)	0.9% (N = 1)	15.2% (N = 17)	17% (N = 19)	26.8% (N = 30)	17.9% (N = 20)	0
Difficulty walking*	75.0% (N = 84)	0	25.0% (N = 28)	1.8% (N = 2)	16.1% (N = 18)	11.6% (N = 13)	12.5% (N = 14)	16.1% (N = 18)	0
Feeling drowsy/tired	72.3% (N = 81)	0	27.7% (N = 31)	2.7% (N = 3)	23.2% (N = 26)	12.5% (N = 14)	19.6% (N = 22)	14.3% (N = 16)	0
Dry mouth	64.3% (N = 72)	0	35.7% (N = 40)	7.1% (N = 8)	20.5% (N = 23)	14.3% (N = 16)	12.5% (N = 14)	9.8% (N = 11)	0
'I don't look like myself'	61.6% (N = 69)	1	37.5% (N = 42)	1.8% (N = 2)	13.4% (N = 15)	11.6% (N = 13)	16.1% (N = 18)	18.8% (N = 21)	0.9% (N = 1)
Weight loss	58.0% (N = 65)	0	42.0% (N = 47)	1.8% (N = 2)	17.0% (N = 19)	7.1% (N = 8)	13.4% (N = 15)	18.8% (N = 21)	0
Difficulty moving*	56.3% (N = 63)	0	43.8% (N = 49)	0	16.1% (N = 18)	11.6% (N = 13)	12.5% (N = 14)	16.1% (N = 18)	0
Numbness/tingling hands or feet	51.8% (N = 58)	0	47.3% (N = 53)	4.5% (N = 5)	11.6% (N = 13)	12.5% (N = 14)	13.4% (N = 15)	10.7% (N = 12)	0
Shortness of breath	50.9% (N = 57)	0	49.1% (N = 55)	2.7% (N = 3)	13.4% (N = 15)	8.9% (N = 10)	12.5% (N = 14)	13.4% (N = 15)	0
Hunger*	48.2% (N = 54)	0	51.8% (N = 58)	5.4% (N = 6)	17.0% (N = 19)	8.9% (N = 10)	4.5% (N = 5)	12.5% (N = 14)	0
Difficulty seeing*	48.2% (N = 54)	0	51.8% (N = 58)	0.9% (N = 1)	21.4% (N = 24)	10.7% (N = 12)	8.0% (N = 9)	7.1% (N = 8)	0
Lack of appetite	47.3% (N = 53)	0	52.7% (N = 59)	2.7% (N = 3)	17% (N = 19)	10.7% (N = 12)	9.8% (N = 11)	7.1% (N = 8)	0
Cough	46.4% (N = 52)	0	53.6% (N = 60)	1.8% (N = 2)	16.1% (N = 18)	8.9% (N = 10)	11.6% (N = 13)	8.0% (N = 9)	0
Muscle aches*	45.5% (N = 51)	0	54.5% (N = 61)	2.7% (N = 3)	10.7% (N = 12)	11.6% (N = 13)	6.3% (N = 7)	14.3% (N = 16)	0
Swelling arms/legs	43.8% (N = 49)	0	56.3% (N = 63)	0.9% (N = 1)	8.0% (N = 9)	7.1% (N = 8)	12.5% (N = 14)	15.2% (N = 17)	0
Dizziness	42.9% (N = 48)	0	57.1% (N = 64)	0	11.6% (N = 13)	10.7% (N = 12)	10.7% (N = 12)	9.8% (N = 11)	0
Itching	42.9% (N = 48)	0	57.1% (N = 64)	1.8% (N = 2)	13.4% (N = 15)	12.5% (N = 14)	7.1% (N = 8)	8% (N = 9)	0
Difficulty concentrating	42.9% (N = 48)	0	57.1% (N = 64)	2.8% (N = 2)	11.6% (N = 13)	13.4% (N = 15)	7.1% (N = 8)	8.9% (N = 10)	0
Constipation	42.0% (N = 47)	0	58.0% (N = 65)	1.8% (N = 2)	15.2% (N = 17)	7.1% (N = 8)	8.0% (N = 9)	9.8% (N = 11)	0
Difficulty sleeping	42.0% (N = 47)	0	58.0% (N = 65)	0	8.9% (N = 10)	12.5% (N = 14)	9.8% (N = 11)	10.7% (N = 12)	0
Nausea	41.1% (N = 46)	0	58.9% (N = 66)	1.8% (N = 2)	13.4% (N = 15)	8.0% (N = 9)	8.9% (N = 10)	8.9% (N = 10)	0
Changes food taste	40.2% (N = 45)	0	59.8% (N = 67)	1.8% (N = 2)	17.9% (N = 20)	6.3% (N = 7)	6.3% (N = 7)	8.0% (N = 9)	0
Feeling bloated	39.3% (N = 44)	0	60.7% (N = 68)	0	13.4% (N = 15)	5.4% (N = 6)	13% (N = 11.6)	8.9% (N = 10)	0
Sweats	38.4% (N = 43)	0	61.6% (N = 69)	1.8% (N = 2)	15.2% (N = 17)	5.4% (N = 6)	13.4% (N = 15)	2.7% (N = 3)	0
Sexual problems	38.4% (N = 43)	0	61.6% (N = 69)	1.8% (N = 2)	7.1% (N = 8)	0.9% (N = 1)	7.1% (N = 8)	21.4% (N = 24)	0
Changes in skin	38.4% (N = 43)	0	61.6% (N = 69)	4.5% (N = 5)	14.3% (N = 16)	2.7% (N = 3)	4.5% (N = 5)	12.5% (N = 14)	0
Problems urinating	35.7% (N = 40)	0	64.3% (N = 72)	0	8.0% (N = 9)	5.4% (N = 6)	5.4% (N = 6)	17.0% (N = 19)	0
Difficulty hearing*	33.9% (N = 38)	0	66.1% (N = 74)	0.9% (N = 1)	19.6% (N = 22)	3.6% (N = 4)	5.4% (N = 6)	4.5% (N = 5)	0

Table 1 – (*continued*)

Symptom	Prevalence	Missing	Burden (total: 100%)						
			Not present	Not at all	A little bit	Somewhat	Quite a bit	Very much	Missing
Bad smell/odour*	24.1% (*N* = 27)	0	75.0% (*N* = 84)	0.9% (*N* = 1)	8.0% (*N* = 9)	2.7% (*N* = 3)	4.5% (*N* = 5)	8.9% (*N* = 10)	0
Hair loss	23.2% (*N* = 26)	0	76.8% (*N* = 86)	5.4% (*N* = 6)	9.8% (*N* = 11)	3.6% (*N* = 4)	1.8% (*N* = 2)	2.7% (*N* = 3)	0
Vomiting	23.2% (*N* = 26)	0	76.8% (*N* = 86)	0.9% (*N* = 1)	6.3% (*N* = 7)	8.0% (*N* = 9)	3.6% (*N* = 4)	4.5% (*N* = 5)	0
Difficulty swallowing	22.3% (*N* = 25)	0	77.7% (*N* = 87)	0.9% (*N* = 1)	12.5% (*N* = 14)	5.4% (*N* = 6)	0.9% (*N* = 1)	2.7% (*N* = 3)	0
Discharge from genitals*	17.0% (*N* = 19)	0	83.0% (*N* = 93)	0.9% (*N* = 1)	2.7% (*N* = 3)	3.6% (*N* = 4)	0.9% (*N* = 1)	8.9% (*N* = 10)	0
Sores/lumps on genitals*	15.2% (*N* = 17)	0	84.8% (*N* = 95)	0.9% (*N* = 1)	0.9% (*N* = 1)	1.8% (*N* = 2)	5.4% (*N* = 6)	6.3% (*N* = 7)	0
Mouth sores	11.6% (*N* = 13)	0	88.4% (*N* = 99)	0.9% (*N* = 1)	0.9% (*N* = 1)	4.5% (*N* = 5)	1.8% (*N* = 2)	3.6% (*N* = 4)	0
Diarrhoea	15.2% (*N* = 17)	0	84.8% (*N* = 95)	0.9% (*N* = 1)	4.5% (*N* = 5)	2.7% (*N* = 3)	3.6% (*N* = 4)	3.6% (*N* = 4)	0
			Not present	Rarely	Occasionally	Frequently	Almost constantly	Missing	
Psychological problems									
Feeling sad	75.9% (*N* = 85)	0	24.1% (*N* = 27)	16.1% (*N* = 18)	34.8% (*N* = 39)	11.6% (*N* = 13)	13.4% (*N* = 15)	0	
Worrying	69.6% (*N* = 78)	0	30.4% (*N* = 34)	19.6% (*N* = 22)	19.6% (*N* = 22)	17.9% (*N* = 20)	12.5% (*N* = 14)	0	
Feeling irritable	66.1% (*N* = 77)	0	33.9% (*N* = 38)	17.9% (*N* = 20)	25.9% (*N* = 29)	12.5% (*N* = 14)	9.8% (*N* = 11)	0	
Feeling nervous	47.3% (*N* = 53)	0	52.7% (*N* = 59)	23.2% (*N* = 26)	13.4% (*N* = 15)	7.1% (*N* = 8)	3.6% (*N* = 4)	0	

Note: Items no tin original MSAS-SF are noted with an asterisk.

to patient needs and beliefs. A qualitative study has been published describing the main problems of advanced cancer patients in Kenya, and found their problems to be principally physical.[22] It is difficult to determine prevalence using qualitative methods, and our data support their finding that the problems are mainly physical. However, the interaction between fatigue syndromes (the two most prevalent physical problems in our study alongside pain) and mental health should be recognised. Lastly, we note that pain was the most prevalent problem despite notional availability of morphine for pain relief in each of our study settings, which reflects the challenges of drug availability and use in Africa.[14]

There are a number of limitations to this study. Firstly, we have collected data in two countries – these are widely recognised as the two African countries with the most advanced provision of palliative care. Further studies are required in other African countries. As the recruited patients were receiving palliative care it could be hypothesised that these patients have a lower prevalence and burden of pain and other symptoms compared to other cancer patients, therefore our data may be conservative. Conversely, it is possible that only those patients with severe and apparently refractory symptoms were able to access palliative care. In order to participate, patients were required to be well enough to engage in self-report data collection, which may bias our data against those with significant disease progression and nearing the end of life (who may have a higher prevalence and burden of symptoms). As palliative care services are not widely available in Africa, there may be additional confounding factors in relation to the characteristics of patients who successfully access palliative care, thus introducing bias into the results. Lastly, the MSAS-SF has not been fully validated in Africa, although it is the most commonly used tool in international studies, and we utilised the additional items generated in an African study of MSAS items.

Systematic reviews of the evidence clearly demonstrate that palliative care improves outcomes (particularly pain and symptom control) for patients with progressive disease.[23–25] However, outcome evidence is required amongst Sub-Saharan African populations, particularly in the light of our findings which show a relatively high symptom prevalence and burden in patients receiving palliative care and at all stages of functional status. Further studies are also required to determine valid measurement methods and the prevalence/burden of symptoms of children in Sub-Saharan Africa. We recommend further study to determine additional domains of need for patients with advanced cancer (e.g. physical, psychological, spiritual, social) using tools that have been validated in African settings, two of which are currently available.[26,27]

The current and projected cancer epidemiological data suggest the need for good quality advance care planning for affected families. In low and middle income countries prolonged ill health of poor families can increase the proportion of income spent on health care and drive families into extreme poverty. Holistic assessment and advance planning of the whole family unit affected by the disease are required.

The current focus on care in advanced HIV in Sub-Saharan Africa must be equally concerned with cancer care. Our data show that the burden of cancer is currently high at the patient level, and if the epidemiological projections are correct, the burden of advanced malignant disease will become a significant public health and clinical challenge. The management of advanced cancer will become a crucial issue in the health responses to meet the Millennium Development Goals.

5. Author contributions

The study was conceived by RH and IJH, design input by all authors, analysis conducted by RH and LS, all authors commented on further analysis and interpretation, and on draft manuscript.

Conflict of interest statement

The authors declare that they have no conflicting interests.

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