Unplanned attendances of cancer patients to an outpatient unit in a low-income country: A prospective study from Sudan

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Background: Studies of unplanned attendances of cancer patients to outpatient oncology units in limited-resource settings are rare.

Aim: The primary aim of the study was to determine the cause of unplanned visits of cancer patients to an outpatient clinic in a limited-resource setting. A secondary aim was to provide an overview of the demographic, clinical characteristics and outcomes of this cohort of patients.

Setting: Outpatient clinic at National Cancer Institute, Sudan.

Methods: This prospective cross-sectional study was conducted between October 2018 and February 2019. Clinical data of patients who presented without an appointment during the study period were reviewed.

Results: Out of 5957 patients' attendances to the outpatient clinic during the study period, 70% were planned and 30% were unplanned. A total of 642 patients made the unplanned visits to the outpatient department. Only 501 of these patients met the criteria for inclusion in the study. The purpose of the unplanned visits included: clinical assessment (75%), giving results of investigations when patients missed their planned appointment (20%) and refilling of prescription medication (5%). Most of the patients were females (64.5%), and the most common tumour site was the breast (26.7%), followed by the gastrointestinal tract (18.4%). The majority (63.5%) of the patients had loco-regional disease and 24.5% had stage IV disease. At the time of this study, only half of the cases were on active oncological treatment. The most frequent presenting complaints at unplanned visits were uncontrolled pain (39%), vomiting (11%) and fever (9%). Ninety-five patients (19%) were hospitalised after an unplanned presentation.

Conclusions: Thirty percent of patients' attendances to the outpatient oncology clinic were unplanned. Uncontrolled pain was the most frequent symptom (39%) that prompted patients to attend the outpatient unit without an appointment. We recommend that the adequacy of cancer pain management in our setting should be systematically evaluated and that effective cancer pain management programs should be developed to prevent unplanned visits prompted by uncontrolled pain.

Keywords: unscheduled visits; unplanned presentations; appointments and schedules; pain; developing countries.

Introduction

Worldwide, approximately 18.1 million new cancer cases and 9.6 million cancer deaths occurred in 2018.¹ The World Health Organisation (WHO) estimates that by 2040, this will increase to 29.5 million new cancer diagnoses and 16.5 million cancer-related deaths annually.² Approximately 70% of cancer deaths in the world occur in low- and middle-income countries (LMICs), a fact that has forced health authorities in LMICs to acknowledge cancer as a high-priority health problem.¹ Unfortunately, these health systems often have a high burden of other equally pressing health issues to contend with including infectious diseases, violence, malnutrition and mother and child health.³

Sudan is a low-income country in sub-Saharan Africa with a population of approximately 40 million people. Approximately half of the population is living below the poverty line. The Sudanese government spends about 8.43% of its annual gross domestic product (GDP) on healthcare.⁴ Healthcare in Sudan is delivered at three levels. At the apex are teaching, general and specialised hospitals providing secondary and tertiary healthcare. In the secondary level

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are the rural hospitals providing secondary care and diagnostic facilities. Primary level care is provided through primary healthcare unit, dressing stations and family health centres. Despite the significant burden of communicable diseases, cancer has been amongst the top 10 causes of hospital admissions in Sudan and ranks as the third leading cause of death after malaria and pneumonia.⁵ The National Health Insurance Fund (NHI) covers approximately 43.8% of the population of Sudan. Membership of NHI is compulsory for the formal sector, whilst it is voluntary for the informal sector and small companies. The subscriber unit is the family and beneficiaries include the principal member, spouse, children and parents. The insured and non-insured cancer patients are treated in the same public hospitals. Khartoum Oncology Hospital and the National Cancer Institute in Wad Medani are the only two specialised state cancer centres in the country providing both chemotherapy and radiation therapy treatments to cancer patients. More recently, the government has established five new chemotherapy units attached to five state hospitals. Geographic distribution of cancer treatment centres in Sudan is shown in Figure 1. Chemotherapy, radiation therapy and supportive medications are available without cost to Sudanese citizens at public cancer centres regardless of insurance status. However, for the many cancer patients without adequate health insurance coverage, limited personal finances can be a significant barrier to accessing surgical interventions and diagnostic investigations. For cancer patients receiving treatment at the NCI, charity organisations such as Sudanese Zakat Chamber, which is a form of Islamic charity, and The Friends of Cancer Patients Society are covering expenses for investigations for uninsured patients with limited personal finances.

In Sudan, the management of cancer patients faces major challenges: weak healthcare infrastructure, low numbers of oncology healthcare professional and a paucity of comprehensive cancer treatment centres.⁶ Moreover, the majority of cancer patients have locally advanced or metastatic disease at presentation.^{7,8,9,10,11,12} These challenges along with lack of access to palliative care services may result in higher numbers of unplanned attendances to outpatient units for palliation of uncontrolled symptoms, management of treatment-related side effects and end of life care. Therefore, outpatient units are often overcrowded and waiting periods for care can be long and uncomfortable. Unplanned attendances also add to the strain on human resources. A previous study assessing the nature of unscheduled visits by cancer patients in South Africa showed that pain was the most common presenting complaint and the majority of patients had locally advanced or metastatic diseases.¹³ In a Canadian cohort of cancer survivors, Lebel and colleagues found a correlation between fear of cancer recurrence and unplanned outpatient or emergency room visits.¹⁴

There is limited data published on unplanned visits to oncology outpatient departments in Africa¹³ and to our knowledge there is no previous study on this subject

conducted in Sudan. Therefore, this study was undertaken to assess the prevalence, main reasons for and outcomes of unplanned visits of cancer patients to the outpatient clinic at the National Cancer Institute (NCI), Sudan. The information obtained from this study may aid in improving the provision of high-quality care to cancer patients and potentially avoid unplanned visits and hospital admission.

Methods

Setting

The National Cancer Institute (NCI) is an 80-bed hospital affiliated to the University of Gezira specialising in the diagnosis and treatment of cancer patients. It is located in Wad Medani city, the capital of Gezira state, which serves the whole Gezira state and nearby states.

Consultations at outpatient oncology clinics are by appointment. These clinics, general oncology clinic, provide specialist consultation to cancer patients with all tumour sites during week days from 8:00 AM to 15:00 PM. The trained receptionist makes appointments in a diary and patients get cards to keep track of their appointment. There is no system to send out reminders to patients telephonically or by a message system.

Study design

We performed a prospective, cross-sectional study to evaluate the prevalent, reasons for and outcomes of unplanned visits to the outpatient oncology clinic at NCI over a 4-month period from October 2018 to February 2019.

The primary aim of the study was to determine the cause of unplanned visits. The complaints that prompted patients to attend for clinical assessment were subdivided as follows: symptoms related to progression of disease or uncontrolled advanced disease, symptoms secondary to side effects of cancer treatment and symptoms related to medical comorbidities. A secondary aim was to provide an overview of the demographic, clinical characteristics and outcomes of this cohort of patients.

Data collection

All cancer patients who had been treated at the NCI and made unplanned visits, which are non-booked clinic visits by patients, to the outpatient unit during the study period were identified. Patients < 16 years of age and patients who refused to participate were excluded from the study. A predesigned paper-based questionnaire containing 26 questions was developed by the principal investigator. The questionnaire was submitted to a panel of three experts to review the content accuracy and internal validity. It was then piloted on 10 patients and modifications were made according to the suggestions. Questionnaire was completed by a research assistant based on patients' answers. The data collected included: Demographics (age, sex and residence), reason(s) for attendance, clinical variables (presenting complaints,

FIGURE 1: Geographic distribution of cancer treatment centres in Sudan.

primary cancer site, stage and comorbidities), treatment variables, dates of previous unplanned visits and outcome of the visit. Patients were interviewed once during the study period. Medical records were used to obtain specific information only when necessary. Verbal consent was obtained from patients prior to their inclusion in the study.

Statistical analysis

Data were entered into and analysed using Statistical Package for Social Science (SPSS) version 24. Categorical variables are presented as frequencies and percentages and continuous data are presented as means (standard deviation) or median values (range) depending on normality.

Ethical consideration

Ethical approval for this prospective study was obtained from the ethical committee at the Faculty of Medicine, University of Gezira. All data were collected anonymously. Ethical Clearance was received on 15-10-2018.

Results

Out of 5957 patient attendances to the outpatient unit at the NCI during the study period, 4170 (70%) were planned and 1787 (30%) were unplanned attendances. The 1787 unplanned visits were made by a total of 642 patients. Of these, 501 patients met the criteria for inclusion in this study.

TABLE 1: Demographic and clinical characteristics ($N = 501$).

Clinical feature	Frequency	Percentage
Gender		
Male	178	35.5
Female	323	64.5
Residence		
Rural	368	73.5
Urban	133	26.5
Marital status		
Married	360	71.9
Single	65	13.0
Widowed	57	11.4
Divorced	19	3.8
Occupation		
Employed	202	40.3
Unemployed	299	59.7
Health insurance		
Yes	380	75.8
No	121	24.2
Primary cancer diagnosis		
Breast	134	26.7
Gastrointestinal tract	92	18.4
Head-neck	70	14.0
Gynaecological	69	13.7
Urology	48	9.6
Leukemia	28	5.6
Lymphoma	23	4.6
Lung	10	2.0
Other	28	5.6
Comorbidities		
No	402	80.2
Yes	99	19.8
Disease status		
Local regional	318	63.5
Metastatic	122	24.5
Clear from disease	61	12.0

The reasons for exclusion were refusal to participate (56 patients) and age below 16 years (85 patients). The general characteristics of the study population are presented in Table 1. The mean and median ages were 55.5 years (SD 14.9) and 52 years (range 19–95 years), respectively. The male to female ratio was 1:2. The most common tumour site was breast (26.7%), followed by gastrointestinal tract (18.4) and head and neck (14%). Nearly two-thirds (63.5%) of the cohort had loco-regional disease, 24.5% had metastatic disease and 12% were clear of disease at the time of inclusion in this study. Among patients with stage IV cancer, bone was the most frequent site of metastasis (45%) as shown in Figure 2.

Nearly all (99.2 %) the patients making unplanned attendances were self-referrals. The reasons given for the unplanned visits were the following: needing clinical assessment ($n = 376$, 75%), wanting results of investigations after missing their scheduled appointment ($n = 98$, 20%) and needing prescription refilled ($n = 27$, 5%). Of 376 patients who presented for clinical assessment: 270 (72%) had cancer-related symptoms, 69 (18%) had chemotherapy and/or radiotherapy related side-effects, and 37 (10%) had complaints related to other medical conditions such as

FIGURE 2: Distribution of patients with stage IV disease ($n = 122$) according to sites of metastases. **FIGURE 3:** Frequency of unplanned visits to outpatient unit by cancer patients (501) during the study period.

malaria, lower urinary tract infections (LUTI) and peptic ulcer disease. Only 56% of patients who visited the outpatient unit for clinical assessment had new symptoms and/or signs. The majority (59%) of the study population had a history of previous unplanned visits to the outpatient unit during the study period as shown in Figure 3.

Amongst the 27 patients who presented to the outpatient unit unplanned needing prescription refilled, a total of 19 (60%) filled an opioid analgesic prescription and 8 (40%) filled oral hormonal therapy prescription. The majority of (90%) patients needing prescriptions refilled had locally advanced or metastatic disease and only 10% were clear at time of study. All clear patients needing prescription filled oral hormonal therapy.

Diabetes mellitus (8.8%) and hypertension (8.8%) were the most frequent comorbidities occurring in our study population. Asthma and coronary artery disease were found in 2% and 1%, respectively. Out of 99 patients who had comorbidities, the reasons of unplanned visits in 30% were complaints related to their comorbidities or other medical conditions such as malaria and LUTI.

Of the 253 (50.5%) patients making unplanned visits who were on active oncological treatment, 97 (38.3%) were on chemotherapy, 90 (35.6%) on radiotherapy and 66 (26.1%)

TABLE 2: Most common presenting complaint of cancer patients prompting unplanned visits to the outpatient unit at the National Cancer Institute, Sudan.

Chief complaints	Frequency	Percentage (%)
Pain	197	39
Vomiting	56	11
Fever	48	9
Cough	27	5
Diarrhoea	26	5
Lower urinary tract symptoms	26	5
Fatigue	17	3
Other complaints	19	4
Abdominal distension	14	3
Constipation	14	3
Neurological disturbance	13	3
Skin rash or ulceration	12	2
Anorexia	11	2
Dyspnoea	11	2
Oral mucositis	10	2
Numbness	6	1
Dysphagia	3	1

TABLE 3: Distribution of patients according to sites and types of pain.

Site of pain	Types of pain				Totals	
	Acute		Chronic		N	%
	n	%	n	%		
Abdomen	30	42	50	40	80	41
Bone	19	26	45	36	64	32
Chest	4	5	15	12	19	10
Headache	12	17	6	5	18	9
Others	7	10	9	7	16	8
Total	72	100	125	100	197	100

on hormone therapy. The reasons given for the unplanned visits in this group of patients: needing clinical assessment ($n = 209$), wanting results of investigations after missing their scheduled appointment ($n = 26$) and needing prescriptions refilled ($n = 18$). The symptoms that prompted unplanned attendances among patients on active oncological treatment were tumour-related symptoms in 127 patients, treatment-related side-effects in 69 patients and complaints related to other medical conditions in 13 patients. Pain was the most frequently reported symptoms ($n = 98$), followed by emesis ($n = 35$). Only small number of patients were diagnosed with febrile neutropenia ($n = 5$) and spinal cord compression ($n = 2$).

The most frequently reported symptoms were pain ($n = 197$, 38.6%), gastrointestinal tract symptoms ($n = 124$, 24.3%) and fever ($n = 48$, 9.4%) as shown in Table 2. The distribution of patients according to sites and types of pain is shown in Table 3. Dermatitis and emesis were the most frequent cancer treatment-related side-effects that prompted unplanned attendances (Table 4).

Overall, 95 patients (19%) were admitted to the hospital for further management, 396 patients (79%) were sent home and 10 patients (2%) were referred to other hospitals for further management. Reasons for hospital admission, in order of frequency, were gastrointestinal symptoms (38%), pain (26%), infections (12%), respiratory tract symptoms (9%),

TABLE 4: Breakdown of symptoms secondary to cancer treatments that prompted unplanned visits by patients to the outpatients unit.

Symptoms	Number
Chemotherapy-related side-effect	
Emesis	17
Neutropenia	5
Numbness	4
Diarrhoea	3
Anaemia	3
Oral mucositis	1
Total	33
Radiotherapy-related side-effect	
Dermatitis	15
Oral mucositis	8
Diarrhoea	7
Emesis	5
Burning micturition	4
Total	36
Grand total	69

neurological symptoms (6%), urine retention (3%), anaemia (2%), fatigue (2%), bleeding (1%) and oral mucositis (1%).

Of the 521 prescriptions issued during unplanned visits, analgesic medications were the most common (25%), followed by antibiotics (22%), proton pump inhibitors (15%), hormonal medications such as tamoxifen, aromatase inhibitors and anti-androgens (12%), intravenous fluids (10%) and antiemetics (8%). The average numbers of medicine prescribed for patient per unplanned visit was 1.2. Twenty out of thirty-two patients who had three or more medications prescribed per visit had comorbidities. Some patients with comorbidities needed a separate prescription for their long-term medications that are not available in the hospital pharmacy.

Discussion

As far as we know, this is the first study that assessed the prevalence, main reasons and the outcomes of unplanned visits by cancer patients to an outpatient oncology clinic in Sudan. We found that 30% of patients' attendances to the outpatient unit at the NCI during the study period were unplanned. These unplanned attendances add to the burden on already limited health resources and divert human resources, which are needed to manage patients making planned attendances.

Approximately two-thirds of our patients were female, which is similar to studies conducted in South Africa¹³ and Italy.¹⁵ This could be because breast cancer and gynaecological malignancies were the most common tumour sites in those countries. Studies from Turkey¹⁶ and the USA¹⁷ however, reported a higher proportion of male patients. This could be a reflection of a higher percentage of lung cancer cases in these countries, which are associated with male rather than female patients. The mean age (51.5 years) reported in this study is younger than that reported in similar studies conducted in South Africa (56.5 years), Italy (63 years) and Turkey (64.5 years).^{13,15,16} The younger mean age in this study is likely because of the higher proportion of breast cancer patients in this cohort. Sudanese women with breast cancer

are on average younger compared with their counterparts from high-income countries.^{9,18}

More than two-thirds (73.5%) of our study population were from remote rural places and most of them were unemployed. Therefore, for them the financial implications of travelling to access healthcare at the NCI could be a huge burden. In our setting, cancer treatment is free for Sudanese patients at cancer treatment centres. Nevertheless, cancer patients need to pay for healthcare services at the primary and secondary healthcare levels. This might be a possible explanation of why a large proportion of our patients were self-referred and bypassing the primary care level and seek healthcare at cancer centre. Moreover, an effective patients' referral system in Sudan is lacking. Thus, implementing efficient referral systems between healthcare facilities in rural areas and cancer treatment centres, providing access to free healthcare services for cancer patients at primary healthcare facilities, involving general practitioners at primary and secondary healthcare levels in the follow-up of cancer patients and encouraging patients to visit their local facilities may help reduce unnecessary visits to specialised cancer centres. Studies from high-income countries documented that a large proportion of cancer patients have concerns about primary care physicians' expertise to conduct a thorough follow-up assessment for specific cancer issues or often felt that these physicians were unwilling to take on this responsibility.^{19,20}

In this study, uncontrolled pain was the most frequent symptom (39%) that prompted patients to make an unplanned visit to the outpatient unit. This finding is consistent with similar single institution studies from South Africa, Taiwan and Italy.^{13,21,22} Despite the existence of guidelines for cancer pain management, a systematic literature review of 26 studies from Asia, Europe and the United States showed that 43% of cancer patients do not receive adequate pain relief.²³ In this study, the abdomen and bones were the most frequently reported sites of pain. A possible explanation is the high frequency of bone and liver metastasis as shown in Figure 1. Moreover, approximately one in five patients with cancer in this study had gastrointestinal tract (GIT) malignancies. In Sudan, common analgesics that are available for cancer patients are paracetamol, nonsteroidal anti-inflammatory drugs, tramadol and immediate-release morphine. Although pain medications at NCI are dispensed free of charge to cancer patients, the cost of travel represents a huge burden for the patients and their caregivers. In our limited resource setting, home care or hospice palliative care services are not available. Therefore, further studies are needed to find out the individual and organisational reasons for the high frequency of unplanned visits to outpatient unit by cancer patients with pain. Moreover, the adequacy of cancer pain management in our setting should be systematically evaluated.

Patients on active oncological treatment made about 50% of our cohort. These patients are at high risk of experiencing

considerable treatment-related toxicities. At the study site, there is no dedicated clinic to follow patients on radiation therapy or chemotherapy. This may explain the higher frequency of this group of patients in this study. Therefore, avoidance of unplanned visits among patients on chemotherapy or radiation therapy may be possible by establishing a dedicated clinic to provide proactive follow-up and support to these patients.

In this study, 20% of patients visited the outpatient unit unplanned after missing their scheduled appointment. In various multispecialty clinics, the rate of missing planned appointment range from 15% to 30%.^{24,25,26} Transportation problems and patients' forgetfulness are reported as main reasons for missing appointment.²⁶ It has been shown that reminder system such as text and voice message reminders in outpatient clinics are effective in improving patients' attendance across a range of healthcare settings and patient populations.^{27,28} Moreover, covering expense for transportation for poor patients may help alleviating the problem of transportation. Whether these factors are effective in reducing the rate of patients missing their appointment in our setting is unknown. Therefore, studies are needed to identify the burden and determinants of the missing planned appointment in our limited resource setting. The findings of these studies can help decision maker to develop strategies that are effective at improving appointment attendances.

We found a high rate of patients with multiple unplanned visits (59%), including 12% of patients reporting five or more visits in the prior 3 months. This group of patients might have substantial unmet health needs. Therefore, further studies are warranted to find out possible reasons for this phenomenon. Moreover, the high rate of multiple unplanned visits highlights the importance of palliative care in oncology. Thus, improvement in the care of cancer patients with more pro-active palliative care can help to reduce this rate.

In this study, the rate of hospital admission was 19%. Aprile et al. reported a 7% rate of hospital admission after an unplanned attendance in cancer patients.¹⁵ A study from Argentina reported 31% admission rate.²⁹ Another study from Australia showed a very high rate (83%) of hospital admissions.³⁰ A possible explanation for variations in admission rates after an unplanned attendance by cancer patients could be because of the differences in study population. The study of McKenzie et al. included patients on chemotherapy,³⁰ whereas this study included patients under active treatment (chemotherapy, hormonal or radiotherapy) and patients not on active treatment. The factors predicting hospital admission are beyond the scope of this study. However, previous studies suggest that predictors for hospitalisation include the number of symptoms, selected toxicities, distance from the hospital and visits near the end of life.^{15,31} Further research should

focus on exploring the factors predicting hospital admission following unplanned attendances in our limited resource setting.

There are some limitations in this study. Firstly, symptoms have not been graded for severity. Secondly, although the data were prospectively collected and included a fairly large sample of cases from the only referral oncology institute in central Sudan, our study is a single institution so our findings and recommendations should therefore be generalised with the necessary caution.

Conclusion

This study shows high prevalence of unplanned visits by cancer patients to outpatient oncology unit of the NCI, located in central Sudan. Even though this is a single institution study, the NCI is the only oncology referral institute in central Sudan; therefore, the current data are the best indicator of the prevalence, main reasons for and outcomes of unplanned visits of cancer patients to outpatient oncology clinics within this region. Our analysis confirmed the significant magnitude of the phenomenon. The majority of the unplanned visits in this study were not true emergencies and fall within the scope of palliative management. Moreover, unplanned attendances add to the burden on already limited health resources. Therefore, dedicated strategies to avoid such visits are urgently needed. Uncontrolled pain was the most frequent symptom that prompted unplanned visit to the outpatient oncology unit. We therefore recommend that the adequacy of cancer pain management in our setting should be systematically evaluated and that effective cancer pain management programmes should be developed to reduce unplanned visits with pain as a presenting problem.

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Competing interests

The authors declare that they have no conflict of interest.

Authors' contributions

M.M.A.E. was the project leader. M.M.A.E., S.I.H.T., and M.M.A.M contributed to the design and implementation of the research, analysis of the results and writing of the manuscript.

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Data availability statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

Disclaimer

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