



Prevalence and Determinants of Distress at the Start of Chemotherapy among Adult Cancer Patients in Two Tertiary Hospitals in Kenya

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Abstract

BACKGROUND

Chemotherapy is considered the cornerstone in the treatment of many cancers, but it also comes with its challenges. The distress experienced by patients at the commencement of chemotherapy is a critical aspect of their cancer journey, with profound implications for their overall well-being and treatment outcomes. This study aimed to assess the prevalence and determinants of distress before the first dose of chemotherapy among adult cancer patients in two tertiary hospitals in Kenya.

METHODOLOGY

This was a cross-sectional study. A total of 438 patients who were scheduled for the first dose of chemotherapy were interviewed using a structured questionnaire. Those who were not able to give consent, those who were only on oral chemotherapy and those who were not chemotherapy naïve were excluded. Distress was measured using the Distress thermometer with a cutoff point of four. Data analysis was performed using SPSS V26.

RESULTS

The study participants interviewed were predominantly women (63%), older than 50 (53%), unemployed (87%), married (65%), Christian (99%), lived less than 100 Kilometers (55%), lived with family (90%), educated up to the primary level (49%), and had insurance (92%). The most prevalent cancers were reproductive organ tumours, and 43% of the participants had stage four disease. A total of 89 % of the participants were clinically distressed (DT \geq 4). In a chi-square analysis, there was a significant relationship between unemployment (P=0.003), residence (P=0.002), income level (P=0.001), insurance status (P=0.004), living conditions (P=0.003), education level (P=0.001), tumour type (P=0.004), goal of therapy (P=0.001) and stage of disease (P=0.000) with clinical distress. On a multi-variate regression analysis, the strongest predictors were the cancer stage with (aOR: 8.4 P=0.000), education level (aOR: 8.3 P=0.001) along with unemployment (aOR: 4.1 P=0.003) and goal of therapy (aOR: 6.32 P=0.001)

CONCLUSION

The prevalence of distress at the start of chemotherapy is high, and interventions should be initiated before chemotherapy. Sociodemographic and disease characteristics should be considered when developing targeted interventions to manage distress among patients starting chemotherapy.

Keywords: Distress, Chemotherapy, Adult Patients

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Introduction

Cancer remains a significant global health challenge, affecting millions of individuals and their families in low- and middle-income

countries (LMICs)¹. Chemotherapy, one of the primary treatment modalities for various types of cancer, is known to trigger distress². The distress experienced by patients at the commencement of



chemotherapy is a critical aspect of their cancer journey, with profound implications for their overall well-being and treatment outcomes. Understanding the prevalence and sociodemographic determinants of distress in this vulnerable population is crucial for developing targeted interventions and providing personalized support.

Cancer-related distress is defined as “an unpleasant experience of an emotional, psychological, social, or spiritual nature that interferes with the ability to cope with cancer treatment which may extend from common normal feelings of vulnerability, sadness, and fears, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis”³. It may manifest as anxiety, depression, fear, or uncertainty, often exacerbated by the uncertainties associated with chemotherapy's side effects and efficacy⁴. This distress can hinder treatment adherence, compromise quality of life, and even influence clinical outcomes⁵.

The prevalence of distress at the initiation of chemotherapy varies across various diagnoses and individual patient characteristics⁶. Sociodemographic factors such as age, gender, socioeconomic status, and disease characteristics play a pivotal role in shaping how patients cope with the emotional burden of cancer and its treatment. Previous research has indicated that these determinants can influence distress levels and coping mechanisms^{6,7,8}. However, a comprehensive understanding of the interplay between patient sociodemographic factors, disease characteristics and distress during chemotherapy initiation is needed to effectively tailor support services in Kenya cancer treatment centres. In Kenya, psychosocial issues surrounding cancer are risk factors for psychiatric disorders, with about 50% of cancer patients suffering from either a minor or a major psychiatric disorder¹.

This study aimed to investigate the prevalence and determinants of distress experienced by cancer patients at the onset of chemotherapy. These insights will not only inform healthcare providers but also guide the development of targeted interventions and support systems to alleviate distress during chemotherapy and enhance the overall well-being of cancer patients.

Methodology

Study design

This was a cross-sectional study conducted at the Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH) cancer treatment centres. KNH is the National referral hospital located in Nairobi while MTRH is a referral hospital located in Eldoret serving the North Rift and Western Kenya regions. The study included adult cancer patients starting their first dose of chemotherapy, both inpatients and outpatients, who consented to participate. Excluded were patients too ill to consent, those on oral chemotherapy only, and those on secondary chemotherapy due to recurrence or failure of the first line of treatment.

Sample size

Purposive sampling was used to select patients who met the criteria until the required sample was achieved as this study targeted cancer which is a rare disease within the general population.

The formula $n = 2(\sigma)^2 (Z_{1-\alpha/2} + Z_{1-\beta})^2 / d^2$ was used to determine the sample size. In this formulae n was the sample size required in each group; α the selected level of significance; $Z_{1-\alpha/2}$ the value from the standard normal distribution holding $1-\alpha/2$ below it; $1-\beta$ the selected power; $Z_{1-\beta}$ the value from the standard normal distribution holding $1-\beta$ below it, and d is the effect size at 1.43⁹.

The standard deviation (σ) used in this study was 5.1¹⁰. The level of significance was 95%, and the power was set at 80%. Thus:



$n = \{2 (5.1)^2 [1.96+0.84]\} / 1.43^2 = 199$
(+ 10% to account for loss to follow-up)

n=219 patients in the treatment group in KNH and 219 patients in the control group in MTRH. The total number interviewed for this phase of the study was 438 patients.

Study variables

Independent variables were patient characteristics- Age, gender, marital status, religion, employment status, residence (distance from the treatment centres), income level, insurance ownership status, living conditions, dependents, and education level. Distance from the treatment centres. Disease characteristics- tumour type/site, the goal of chemotherapy, stage of disease, co-morbidity, performance status. The dependent variable was distress levels as measured using the Distress Thermometer

Ethical considerations

Ethical clearance was obtained from the Kenyatta National Hospital- University of Nairobi Ethics Research Committee (KNH-UoN ERC P732/09/2021), Moi Teaching and Referral Hospital/Moi University Institutional Research Ethics Committee (MTRH/MU IREC 065/2021) and National Commission for Science, Technology and Innovation (NACOSTI/P/22/15984). Permission for was obtained from both hospitals and written informed consent secured from each participant.

Table 1:

Sociodemographic Characteristics of the Participants

Characteristic		n	%
Age	18-28	35	8
	29-38	60	13.7
	39-48	109	24.9
	>50	234	53.4
	Total	438	100.0
Sex	Men	162	37
	Women	276	63.0
	Total	438	100.0
Marital	Married	285	65.1
	Single	75	17.1
	Divorced	23	5.3
	Widowed	55	12.6
	Total	438	100.0

Patients with distress levels above four on the distress thermometer were referred to a counsellor or counselled on-site.

Data collection and analysis

A structured questionnaire was used to collect data. The National Comprehensive Cancer Network (NCCN) Distress thermometer V2 2020 was used to measure the distress levels with a cutoff point of 4. The European Cooperative Oncology Group (ECOG) scale was used to measure the performance status before the participants received their first dose of chemotherapy^{9,10}. Data were then entered in Excel, coded and cleaned. SPSS Version 26 was used for analysis chi-square to assess the relationship between various patient characteristics and clinical distress status (no distress vs. distressed) and multivariate logistic regressions

Results

Sociodemographic characteristics

A total of 438 participants were included in the study, 219 drawn from Kenyatta National Hospital (KNH) and 219 from MTRH. The overall characteristics of the patients are summarized in Table 1. The majority of participants were over 50 years old (53.4%), predominantly women (63%), and mostly married (65.1%).



Table 1 Cont.:

Characteristic		n	%
Religion	Christian	435	99.3
	Islam	3	0.7
	Total	438	100.0
Employed	No	384	87.7
	Yes	54	12.3
	Total	438	100.0
Residence	> 100 KM	195	44.5
	< 100 KM	243	55.5
	Total	438	100.0
Income	< 30000	419	95.9
	31000- 60000	15	3.4
	> 60000	3	0.7
	Total	437	100.0
Insurance	No	34	7.8
	Yes	404	92.2
	Total	438	100.0
Living	Alone	18	4.1
	With Family	397	90.6
	Others	23	5.3
	Total	438	100.0
Dependents	No	111	25.3
	Yes	327	74.7
	Total	438	100.0
Education	Primary	215	49.2
	Secondary	161	36.8
	Tertiary	61	14
	Total	437	100.0
Tumour type	Blood	22	5.0
	Reproductive	180	41.1
	Upper GIT	96	21.9
	Lower GIT/Urinary/Prostate	50	11.4
	Skin	16	3.7
	Respiratory	50	11.4
	Pancreatic/Liver/GB/Endocrine/Adrenal	15	3.4
	Bone	9	2.1
	Total	438	100.0
Goal	Adjuvant	200	45.8
	Neo-adjuvant	133	30.4
	Palliative	104	23.8
	Total	437	100.0
Stage	One	35	9.5
	Two	57	15.4
	Three	116	31.4
	Four	161	43.6
	Total	369	100.0
Comorbidity	No	318	72.8
	Yes	119	27.2
	Total	437	100.0



Nearly all were Christians (99.3%) and unemployed (87.7%) at the time of the study. More than half lived within 100 KM of the treatment centre (55.5%) and had an income below 30,000 (95.9%). Most had insurance (92.2%) and lived with family (90.6%). A majority had dependents (74.7%), and nearly half had primary education (49.2%).

The most common tumour type was reproductive (41.1%), followed by upper gastrointestinal (21.9%), and other types (11.4% each). The main treatment goal was adjuvant (45.8%), with most participants in advanced stages (43.6% in stage four, 31.4% in stage three). Most did not have comorbidities (72.8%).

Performance status of the study participants as measured with the ECOG scale

The majority of the participants (68.5%) reported a good performance status at the commencement of the first dose of chemotherapy.

Prevalence of distress

The cutoff point for distress levels was 4; therefore, patients were either not clinically

distressed ($DT < 4$) or clinically distressed ($DT \geq 4$). As presented in Table 3, 89.3% (391) of the participants were clinically distressed while 10.7% (47) of the participants were not clinically distressed.

Significant associations with clinical distress were found for employment, residence distance, income level, insurance ownership status, living conditions, dependents, education level, tumour type/site, goal of chemotherapy, stage of disease, and performance status. No significant associations were found for age, sex, marital status, religion, and comorbidity.

Multivariate logistics regression on variables associated with distress

Multivariate logistic regression analysis was conducted on significantly associated variables ($p < 0.05$) with distress. All the variables were predictors of distress but at different magnitudes. The strongest predictor was the cancer stage with (aOR: 8.4; CI:2.9-10.31) followed by the education level (aOR: 8.3; CI: 3.1- 12.14) with both variables being eight times more likely to have distress than their counterparts as shown on Table 5.

Table 2:

Performance Status of the Participants Before the Start of Chemotherapy as Measured by ECOG

Characteristics	Frequency (n)	Percentage (%)
Fully active	130	29.7
Restricted in physically strenuous activities	170	38.8
Ambulatory and capable of Selfcare up to 50% waking hours	90	20.6
Capable of only limited self-care, confined to bed/wheelchair for >50% of waking hours	43	9.8
Completely disabled, cannot carry any Selfcare (SC)	5	1.1
Total	438	100.0

Table 3:

Distribution of Distress Levels in the Study Population

Distress status	n	%
Distressed Clinically ($DT \geq 4$)	391	89.3
Not Distressed ($DT < 4$)	47	10.7
Total	438	100.0



Discussion

This study recorded a distress prevalence of 89.3% which is higher than in studies performed in Brazil (59.5%)¹¹ and Ethiopia (64.5%)¹². The distress at the beginning of chemotherapy is a possible reaction to an event before the person adapts to the situation and may reduce as the patient progresses further into the treatment¹³. However, distress levels should not be ignored, as they may affect the overall patients' clinical outcomes. Additionally, initial

distress may be a predictor of later distress and should be managed and interventions, if any, should be as close as possible to the time of diagnosis¹⁴

Age, gender, marital status and religion were associated insignificantly with clinical distress. Studies in North America, Malaysia and Pakistan showed an association between these demographic factors and distress^{15,16,17}. While a study in Spain showed no correlation between demographic characteristics and disease characteristics and distress.¹⁸

Table 4:

Cross-tabulation of Distress and Socio-Demographic Characteristics of the Patients

	Variable	No Distress	Distressed	Total	Chi-square	P-value
Age	>50 years	24 (51.1%)	210 (53.7%)	234	0.118	0.731
	<50 years	23 (48.9%)	181 (46.3%)	204		
Sex	Male	16(34.0%)	146(33.7%)	162	0.196	0.658
	Female	31(66.0%)	245(62.7%)	276		
Marital Status	Otherwise	13(27.7%)	140(35.6%)	153	1.225	0.268
	Married	34(72.3%)	251(64.2%)	285		
Religion	Christian	46(97.9%)	389(99.5%)	435	1.611	0.204
	Islam	1(2.1%)	2(0.5%)	3		
Employed	No	39(83.0%)	345(88.2%)	384	1.073	0.003
	Yes	8(17.0%)	46(11.8%)	54		
Residence	>100km	17(36.2%)	178(45.5%)	195	1.486	0.002
	<100km	30(63.8%)	213(54.5%)	243		
Income	>30K	3(6.45)	15(3.8%)	19	0.683	0.001
	<30K	44(93.6%)	375(96.2%)	419		
Insurance	Yes	5(10.6%)	29(7.4%)	420	0.608	0.004
	No	42(89.4%)	362(92.6%)	18		
Living Conditions	Otherwise	45(95.7%)	375(95.9%)	420	0.958	0.003
	Family	2(4.2%)	16(4.1%)	18		
Dependents	No	10(21.3%)	101(25.8%)	111	0.460	0.000
	Yes	37(78.7%)	209(74.2%)	327		
Education	>Primary	27(57.4%)	195(50%)	222	0.931	0.001
	Primary	20(42.6%)	195(50%)	215		
Tumour Type	Others	28(53.2%)	233(59.6%)	258	0.710	0.004
	Reproductive	22(46.8%)	158(40.4%)	180		
Goal of Therapy	Others	28(59.6%)	210(53.7%)	238	0.583	0.001
	Adjuvant	19(40.4%)	181(43.3%)	200		
Disease stage	≥3	36(76.6%)	310(79.3%)	346	0.183	0.00
	<3	11(23.4%)	81(20.7%)	92		
Co-Morbidity	No	32(66.0%)	287(73.6%)	319	1.233	2.267
	Yes	16(34.0%)	103(26.4%)	119		
Performance Status	Poor	7(14.9%)	129(33.0%)	136	6.419	0.011
	Good	40(85.1%)	262(67.0%)	302		

A significant majority of participants were unemployed (88%). Participants who were employed were 4.1 times more clinically distressed compared to the unemployed. A study reported that employed cancer patients showed higher levels of anxiety, depression and somatisation¹⁹. Likewise, those with higher income showed higher odds of experiencing psychosocial distress, possibly because people with higher income may have financial commitments and life plans which would get disrupted by cancer diagnosis and treatment.

More participants lived within 100 KM of the treatment Centers (56%) while (45%) lived further away. Those who lived more than 100 km were 2.3 (0.17-8.64) times more likely to have clinical distress as compared to those who lived near the cancer treatment centre. Distance from the cancer treatment centres has been one of the

factors associated with the burden among cancer patients due to indirect cost, the discomfort of public transport or the time taken to travel for treatment. Cancer patients who had to travel longer distances to treatment centres showed poorer outcomes^{20,21}. The travelling costs contributed to financial toxicity among cancer patients and those who relied on public transportation were likely to experience delays in completing cancer therapies which may lead to increased distress and decreased quality of life^{22,23}

Nearly half of the participants (49%) had a primary education level. Lower education levels were significantly associated with clinical distress, with those having lower education being 8.3 times more likely to experience distress compared to those with higher education.

Table 5:
Multivariate Logistics Regression on Variables Associated with Distress

	Variable	Distress Level (%)	cOR (95% CI)	P-value	aOR (95% CI)	P-Value
Employed	Yes	87.70%	3 (0.53-29.22)	0.000	4.1 (0.11-0.44)	0.003
	No	12.30%	RC		RC	
Residence	>100 KM	44.50%	4 (0.97-40.1)	0.000	2.3 (0.17-8.64)	0.002
	<100 KM	55.50%	RC			
Income	>30k	4.10%	6.2 (4.9-12.6)	0.000	2.2 (2.34-10.45)	0.001
	<30k	95.90%	RC		RC	
Insurance	No	7.80%	2 (1.44-24.34)	0.000	1.2 (1.99-46.3)	0.012
	Yes	92.20%	RC		RC	
Living Condition	Otherwise	95.90%	4 (1.44-7.77)	0.001	3.1 (2.1-9.22)	0.003
	Family	4.10%	RC		RC	
Dependents	Yes	25.30%	3 (1.24-8.22)	0.004	2.1 (2.55-10.11)	0.000
	No	74.70%	RC		RC	
Education	>Primary	50.80%	RC		RC	
	Primary	49.20%	4 (5.14-11.11)	0.000	8.3 (3.12-12.14)	0.001
Tumour Type	Others	58.90%	RC		RC	
	Reproductive	41.10%	6 (1.32-9.22)	0.000	2.1 (2.34-10.45)	0.004
Goal of Therapy	Others	54.30%				
	Adjuvant	45.70%	3 (1.55-8.21)	0.001	6.32 (3.1-11.33)	0.001
Stage	≥3	79.00%	2 (2.14-9.43)	0.001	8.4 (2.9-10.31)	0.000
	<3	21.00%	RC		RC	
Performance Status	Poor	31.10%	3 (0.53-29.22)	0.000	3.2 (1.2-4.8)	0.011
	Good	68.90%	RC			

Notes: RC = Reference Category; cOR = crude OR; aOR = adjusted OR



Health literacy, which involves understanding and using health information to make informed decisions, is often lower among patients with less education, making it harder for them to grasp complex medical information and treatment plans, leading to confusion, anxiety, and helplessness. Poor health literacy can hinder patients' active participation in their care, contributing to a loss of control and increased distress^{24, 25}.

The majority of the participants owned health insurance coverage (92 %). Those without health insurance coverage were 1.2 more times likely to experience distress compared to those with health insurance coverage. Financing has been one of the major issues burdening cancer patients in Kenya²⁶. Similarly, the Lack of insurance has been attributed to financial distress during chemotherapy^{27,28,29}. Sharp *et al.* demonstrated that cancer patients experiencing financial difficulties reported lower quality of life and higher levels of distress. Financial problems were closely linked to emotional distress, as patients worried about the affordability of their care and future financial security³⁰. Lack of insurance also means higher out-of-pocket expenditure to access chemotherapy treatment which is an unfavorable method of healthcare financing due to the associated economic burden³¹

Patients living otherwise (alone, with friends) were 3.1 times to experience distress compared to those who lived with family.

The lack of social support during cancer treatment has been linked has been linked to higher distress^{32, 33}. The NCCN guideline strongly links living alone and lack of family support to distress during cancer treatment (NCCN 2019). Those participants with dependents had a 2.1 likelihood of experiencing distress compared to those without primary dependents NCCN guidelines link having dependents especially young children during treatment to increased distress³⁴.

The majority of participants interviewed were predominantly women with reproductive health cancers, including breast and cervical cancer, which is in keeping with the Kenya cancer registry data³⁵. Participants with a reproductive system tumour diagnosis were 2.1 times more likely to experience distress compared to participants with other types of tumours. Patients with reproductive system cancers face unique challenges such as fertility and sexual function, body image issues, the impact of hormonal changes, and the emotional and social implications of their disease and treatment³⁶ that could contribute to higher levels of distress during chemotherapy.

Participants undergoing adjuvant chemotherapy were 6.32 times more likely to experience higher distress levels compared to those receiving neoadjuvant or palliative chemotherapy. Adjuvant therapy implies that patients have already undergone primary treatments like surgery or radiation. Adding chemotherapy introduces new challenges and exacerbates their already strained coping mechanisms³⁷.

The majority of the participants had advanced-stage cancer, with 44% in stage four and 31 % in stage three. Early-stage cancers (one and two) made up a smaller portion (25%). Previous studies in Kenya have shown that the majority of cancer patients are diagnosed with late-stage disease²⁰. Disease had the strongest odds with clinical distress with those diagnosed with advanced stages being 8.4 times more likely to experience higher levels of distress compared to those diagnosed with early-stage disease. This could be related to the severe signs and symptoms of the disease at an advanced stage and the patients were aware that a disease could metastasize^{38,39}. A study in Brazil showed that the tumour site and disease stage impact the quality of life of the individual with a late stage of disease more likely to trigger distress⁴⁰ and so was a study done in Malaysia⁴¹.



Participants with a poorer performance status were 3.2 times more likely to experience distress at the beginning of chemotherapy treatment compared to those who had a better performance status score. This could be because these patients were in a worse state of health both physically and mentally ⁴². The findings of a study assessing psychosocial distress among outpatient chemotherapy patients in Australia established that performance status was a key predictor of distress. ⁴³

Study limitations

The sampling method used was the purpose sampling method and therefore the results may not be generalized to other cancer treatment centres in the country.

Conclusion

The prevalence of distress is high among Kenyan patients with strong predictors of this distress being; having dependents, stage of disease and distance from the treatment centres. These findings underscore the critical importance of comprehensive psychosocial support and interventions for patients starting chemotherapy.

Recommendations

Addressing distress not only enhances the overall well-being of patients but also has the potential to positively impact treatment adherence and outcomes. Distress screening should be an integral part of clinical intervention during chemotherapy and interventions for distress management should be initiated early. Future research should focus on tailoring interventions to meet the unique needs of these individuals, ultimately striving to improve their quality of life during chemotherapy.

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Data Availability. All data sets are available from the corresponding author on request.

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