BJMS
www.batnajms.net

Batna Journal of Medical Sciences 2026;13(6):xx
https://doi.org/10.48087/BJMS.2026.1306xx

ORIGINAL ARTICLE

Patient-Reported Unmet Palliative Care Needs as Indicators of Systemic Gaps in Cancer Care: a Tertiary Hospital Study in Guinea

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ABSTRACT

Background: Cancer outcomes remain poor in low-resource settings where palliative care is insufficiently integrated into oncology services. In Guinea, limited evidence exists to guide policy development. This study assessed patient-reported unmet palliative care needs as indicators of systemic gaps in oncological care within the Guinean context. **Methods:** A cross-sectional study was conducted from August to November 2022 at the Oncology Department of Donka University Hospital, Conakry. A consecutive sampling strategy was employed, including all eligible, consenting, and cognitively capable patients present during the study period. Needs were assessed using an adapted Supportive Care Needs Survey–Short Form 34 (SCNS-SF34) and analyzed descriptively. **Results:** Among the 177 patients (mean age 49.3 years; 75.7% female), breast (38.4%) and cervical (14.1%) cancers prevailed, with 92.6% of cases diagnosed at locally advanced or metastatic stages. Informational needs were the most frequent: 88.1% of participants required a better understanding of palliative care, and 80.8% sought more information regarding treatments. Physical symptoms were prevalent, particularly pain (83.6%) and fatigue (70.1%). Psychosocial distress was substantial, characterized by fear (85.3%) and difficulty discussing the illness (80.2%). Furthermore, 84.7% of patients reported high care-related costs, and 49.7% felt their concerns were inadequately addressed. Sexuality-related needs were identified by 25.4% of the cohort. **Conclusion:** The high burden of unmet needs across informational, physical, psychosocial, and financial domains highlights systemic deficiencies rather than isolated clinical gaps. Strengthening national policy frameworks, improving access to essential medicines, enhancing provider training, and integrating palliative care early into oncology services are critical priorities for Guinea and similar low-resource settings.

Keywords: Palliative care, Cancer, Unmet needs, Policy Gaps.

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Received: 02 Mar 2026
Accepted: 04 May 2026

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1. INTRODUCTION

Cancer represents a growing global public health challenge, with an estimated 10 million deaths in 2022, nearly 70–80% of which occurred in low- and middle-income countries (LMICs) [1]. In these settings, late-stage diagnosis, limited access to treatment, and weak health system capacity contribute to persistently high mortality rates [2]. Beyond disease-directed therapies, the inability of health systems to adequately address pain, psychological distress, functional decline, and social vulnerability is increasingly recognized as a major source of avoidable suffering and inequity [3].

Palliative care is therefore considered an essential component of comprehensive cancer control. The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families through the prevention

and relief of suffering, ideally integrated early alongside curative treatment [4,5]. The WHO model highlights four key pillars: appropriate national policies, access to essential medicines (particularly opioids), education and training of the health workforce, and integrated service delivery [6]. Weakness in any of these areas results in fragmented care and unmet needs.

Despite global commitments to universal health coverage, access to palliative care remains highly unequal. Nearly 80% of the 56.8 million people requiring palliative care annually live in LMICs, yet only a minority receive adequate services [4]. In sub-Saharan Africa, weak policy frameworks, regulatory barriers to opioid access, limited workforce training, and poor integration into oncology services constrain provision. As a result, cancer patients frequently experience uncontrolled symptoms, psychological distress, insufficient information, and financial hardship, reflecting systemic and policy-level gaps rather than isolated clinical failures [7–9].

In contexts where formal palliative care policies and monitoring systems are underdeveloped, patient-reported unmet needs can serve as proxy indicators of health system performance [10,11]. High levels of unmet physical, psychosocial, informational, or care-related needs signal gaps in service organization, workforce capacity, financing mechanisms, and governance. This approach has been increasingly used in global health research to inform policy development in settings where routine health system indicators are scarce or incomplete [11].

Guinea illustrates these challenges. Although cancer incidence and mortality are rising, oncology services remain centralized in Conakry, and no structured national palliative care program is currently implemented [12]. At Donka National Hospital, the country's main referral center, care focuses primarily on surgery and chemotherapy, while palliative services are delivered in an ad hoc and poorly coordinated manner. Access to essential medicines, including opioids, remains limited, and palliative care training is not systematically integrated into medical and nursing curricula. Consequently, policymakers lack empirical evidence to guide the development of equitable, patient-centered palliative care strategies. The present study, therefore, aimed to assess patient-reported unmet palliative care needs as indicators of potential systemic gaps in cancer care in a tertiary hospital setting in Guinea.

2. METHODS

Study Design and Setting

This was a cross-sectional descriptive study conducted from August 11 to November 11, 2022, in the Oncology Department of Donka University Hospital, Conakry, the main tertiary referral hospital in Guinea.

Study Population

The study included patients with a confirmed diagnosis of cancer, either newly diagnosed or already under follow-up, regardless of treatment status, who provided written informed consent. Patients were eligible if they were clinically stable and cognitively able to understand and respond to the questionnaire. Patients with severe clinical deterioration (e.g., altered consciousness, significant cognitive impairment, or extreme physical weakness) preventing participation in an interview were excluded. Patients who declined participation or had incomplete key data were also excluded.

Sampling

A consecutive sampling strategy was applied: all eligible and cognitively capable patients present during the study period were systematically approached. No prior sample size calculation was performed, as the study aimed to include the entire accessible population within the study timeframe. Completion of the questionnaire was required for inclusion.

Data Collection

Data were collected through a combination of medical record review and structured face-to-face interviews conducted by trained investigators within the oncology department. Interviews were carried out confidentially and respectfully to ensure participant comfort and privacy. Sociodemographic information included age, sex, educational level, marital status, place of residence, and employment status. Clinical and treatment-related variables comprised cancer type, stage, performance status, body mass index, comorbidities, and treatments received. Additional palliative care-specific variables captured the timing of palliative care initiation, the setting in which it was provided, and the type of healthcare provider involved.

Patient-reported unmet palliative care needs were assessed using an adapted and pretested version of the Supportive Care Needs Survey-Short Form 34 (SCNS-SF34). The instrument covers five domains: physical and daily living (pain, fatigue, lack of energy, and difficulty performing daily activities), informational (understanding of disease, treatment, side effects, and role of palliative care), psychological and socioeconomic (fear, anxiety, distress, communication difficulties, and financial concerns), sexuality (sexual function and intimacy concerns), and care and support (perceived quality of care, emotional support, and communication with healthcare

providers). The SCNS-SF34 was carefully adapted through expert review to ensure cultural and linguistic relevance and was pretested to confirm clarity, comprehension, and feasibility in the local context. To accommodate differences in literacy, the questionnaire was administered through interviewer-assisted structured interviews. Items were read verbatim when necessary, and neutral explanations were provided to ensure participants understood the questions without influencing their responses.

Investigators received standardized training on both ethical conduct and questionnaire administration. Interviews were conducted consistently and lasted approximately 20-30 minutes. All data were anonymized, verified for completeness, and securely entered into a database before analysis.

Bias Management

Selection bias was minimized through systematic inclusion of all eligible patients during the study period. However, patients with severe clinical deterioration were excluded due to their inability to participate in self-reported assessments. This may have introduced selection bias by underrepresenting the most severely ill patients, who are also more likely to experience high levels of unmet palliative care needs. To reduce information bias, data collectors were trained in standardized questionnaire administration and interview techniques. Interviews were conducted in a private setting to reduce social desirability bias. Daily checks ensured completeness and consistency of collected data.

Data Analysis

Data analysis was performed using SPSS software, version 21. Categorial variables were expressed as frequencies and percentages; continuous variables as means (standard deviation).

SCNS-SF34 scores, based on a five-point Likert scale (1 = no need/not applicable to 5 = high need), were dichotomized as follows: Unmet Need: score 3–5 (moderate to very high); No need: score 1–2 (no/low).

Domain-level prevalence was calculated as the mean proportion of patients reporting unmet needs per domain. For exploratory bivariate analysis, a summary variable ("high unmet need") was created: patients reporting at least one item ≥3 in any domain were classified as having high unmet need. Associations with sociodemographic and clinical factors were tested using chi-square or Fisher's exact tests; crude ORs with 95% CIs were calculated. Significance was set at $p < 0.05$. Although multivariable analyses were initially considered, preliminary models were not retained due to the distribution of variables and sample characteristics. Therefore, only bivariate analyses are presented.

Ethical Considerations

This study was conducted in accordance with the principles of the Declaration of Helsinki and was approved by the Scientific Committee of Kofi Annan University. All patient data were handled confidentially. Written informed consent was obtained from all participants before inclusion, including consent for the publication of data in anonymized form.

3. RESULTS

Sociodemographic Characteristics

A total of 177 patients were included in the study. The mean age was 49.3 (16.1) years, ranging from 15 to 96 years. The majority of patients were female (75.7%), married (67.2%), and had no formal education (59.3%). More than half resided in Conakry (55.4%) (Table 1).

Clinical and therapeutic characteristics

Breast cancer was the most frequent (38.4%), followed by cervical cancer (14.1%). The majority of patients were diagnosed at a locally advanced stage (48%) or metastatic stage (44.6%). Most patients were underweight (67.2%). Regarding treatment, 54.8% of patients had not yet initiated anticancer therapy, and chemotherapy was the most commonly used treatment modality (37.3%) (Table 2).

Palliative Care and Assessment of Needs

Palliative care was initiated within one to two months after diagnosis in 45.8% of patients, within three months in 36.7%, and after more than three months in 14.1%. Care was most commonly started on an outpatient basis (52.5%), followed by the hospital setting (41.8%) and at home (5.1%). Management was primarily provided by general practitioners (48.0%) and oncologists (42.4%), with minimal involvement of palliative care volunteers (1.1%) and other specialists (1.1%). Table 3 summarizes the prevalence of unmet palliative care needs by domain and the corresponding mean domain burden.

Table 1. Sociodemographic Characteristics of the Study Population.

Characteristic	Category	n	%
Age Group (years)	15–29	11	6,2
	30–44	57	32,2
	45–59	50	28,3
	60–74	56	31,6
	≥ 75	3	1,7
Sex	Male	43	24.3
	Female	134	75.7
Marital Status	Married	119	67.2
	Single	14	7.9
	Widowed	39	22.0
	Divorced	5	2.9
Education Level	No schooling	105	59.3
	Primary	19	10.7
	Secondary	30	16.9
	University	23	13.0
Occupation	Homemaker	70	39.5
	Merchant / Vendor	39	22.0
	Farmer / Manual / Laborer	24	13.6
	Administrator	19	10.7
	Others*	25	14.2
Origin	Conakry	98	55.4
	Outside Conakry	79	44.6

Others: police officers, teachers, tailors, hairdressers, artists, surveyors, legal professionals, drivers, students and midwives.*

Table 2. Clinical profile and treatment modalities of cancer patients.

Variables	Category	n	%
PS	≤ 2	123	69.5
	> 2	54	30.5
BMI	Underweight	119	67.2
	Normal Weight	14	7.9
	Overweight	39	22.0
	Obesity	5	2.9
Primary site	Breast	68	38.4
	Cervix	25	14.1
	Nasosinus	11	6.2
	Colorectal	11	6.2
	Liver	10	5.5
	Ovary	9	5.1
	Stomach	7	4.0
	Endometrium	7	4.0
	Larynx	7	4.0
	Vulva	5	2.8
	Others*	17	9.6
Stage	Localized	13	7.3
	Locally Advanced	85	48.0
	Metastatic	79	44.6
Start of anticancer therapy	Yes	80	45.2
	No	97	54.8
Treatment Modality	Chemotherapy	66	37.3
	Surgery	34	19.2
	Radiotherapy	9	5.1
	Hormone Therapy	1	0.6

Others: nasopharynx, gums, pharynx, tonsils, esophagus, pancreas, small intestine, and anal canal. A single patient could have received more than one type of anticancer therapy*

Table 3. Prevalence of Unmet Palliative Care Needs by Domain and Mean Domain Burden.

Domain	Category	Unmet Need n (%)	Mean domain burden (%)
Physical Needs			
	Pain	148 (83.6)	
	Physical Fatigue	124 (70.1)	
	Weight Loss	117 (66.1)	
	Anorexia	80 (45.2)	
	Malnutrition	66 (37.3)	
	Dehydration	65 (36.7)	
	Insomnia	58 (32.8)	36.6
	Dyspnea	56 (31.6)	
	Edema (General and Local)	52 (29.4)	
	Wound / Swelling / Ulceration	46 (26)	
	Hair Loss (Alopecia)	13 (7.3)	
	Body Image Changes	11 (6.2)	
	Body Odor	7 (4.0)	
Daily Activities			
	Overall Loss of Autonomy	147 (83.1)	
	Household Chores	106 (59.9)	
	Walking / Mobility	64 (36.2)	
	Cooking	54 (30.5)	39.6
	Going to the toilet alone	42 (23.7)	
	Washing oneself alone	40 (22.6)	
	Dressing oneself alone	38 (21.5)	
Information Needs			
	Role of Palliative Care	156 (88.1)	
	Treatment	143 (80.8)	
	My Diagnosis	124 (70.1)	
	Cause of my Cancer	104 (58.8)	
	Diet / Nutrition	102 (57.6)	66.2
	Prognosis	99 (55.9)	
	Disease Progression	97 (54.8)	
	Side Effects	96 (54.2)	
	Sexuality	60 (33.9)	
Psychological and socioeconomic needs			
	Support from Relatives is the same as before	9 (5.1)	
	Fear (General)	151 (85.3)	
	Talking about the illness with relatives	142 (80.2)	
	Frustration from no longer being able to do activities	135 (76.3)	
	Anxiety / Distress	110 (62.1)	
	Difficulty accepting the illness	102 (57.6)	
	Fear of Pain / Physical Suffering	95 (53.7)	50.3
	Difficulty showing emotions	95 (53.7)	
	Difficulty making decisions	94 (53.1)	
	Depressed Mood	86 (48.6)	
	Fear of Financial Difficulties	45 (25.4)	
	Current financial distress	42 (23.7)	
	Feeling discriminated against	30 (16.9)	
	Fear of Death	30 (16.9)	
Sexuality Needs			
	Desire to have sex	45 (25.4)	20.9
	Having an active sex life	29 (16.4)	
Satisfaction with Care			
	Need for specific care	155 (87.6)	
	Staff are attentive	30 (16.9)	
	Inappropriate Care provided	143 (80.8)	47.0
	Pain management by the care team	43 (23.7)	
	Response to concerns	88 (49.7)	
	High cost of care	150 (4.7)	

Needs are considered "present" for Likert scale scores of 3 to 5 (moderate to very high need). For the "Response to concerns" item, the 49.7% percentage indicates the proportion of patients whose concerns were not met by the healthcare team (dissatisfaction).

Physical and Functional Domains

The mean burden of unmet physical symptoms was 36.6%. Pain (83.6%), fatigue (70.1%), and weight loss (66.1%) were the most frequently reported symptoms. Functional limitations showed a higher mean burden (39.6 %), with 83.1% reporting loss of autonomy and 59.9% requiring assistance with household tasks.

Informational Domain

This domain demonstrated a high mean burden of 66.2%. Patients primarily sought information about the role of palliative care (88.1%), treatments (80.8%), and diagnosis (70.1%).

Psychosocial and Socioeconomic Domain

Psychological and socioeconomic needs exhibited a mean burden of 50.3%. Fear was reported by 85.3% of patients, difficulty discussing the illness by 80.2%, and frustration related to loss of activities by 76.3%. Anxiety affected 62.1% of participants. Financial distress was reported by 23.7%, while 25.4% feared future financial hardship.

Sexuality Domain

This domain showed a lower but notable mean burden (20.9%). 25.4% of patients expressed a need regarding sexual desire, and 16.4% regarding maintaining an active sexual life.

Care and support Domain

This domain shows a mean prevalence of 47.0%. Although most patients perceived staff as attentive, 87.6% expressed a need for specific supportive care, 84.7% reported high care-related costs, and nearly half (49.7%) indicated that their concerns were not adequately addressed.

Bivariate Analysis of High Unmet Need

High unmet needs were significantly associated with lack of formal education (OR = 4.67; p = 0.002), poor performance status (OR = 5.24; p = 0.001), underweight status (OR = 3.56; p = 0.009), advanced/metastatic stage (OR = 5.52; p = 0.006), and absence of treatment initiation (OR = 4.32; p = 0.003) (table 4).

Table 4. Bivariate analysis of factors associated with high unmet palliative care needs.

Variables	Category	Unmet Needs		OR (95% CI)	*P-value*
		High n (%)	Low/No (%)		
Sex	Male	10 (23.3)	33 (76.7)	Reference	–
	Female	100 (74.6)	34 (25.4)	0.35 (0.14–0.85)	0.017
Education level	No schooling	80 (76.2)	25 (23.8)	4.67 (1.75–12.48)	0.002
	Any schooling	30 (32.6)	62 (67.4)	Reference	–
PS	≤2	45 (36.6)	78 (63.4)	Reference	–
	>2	40 (74.1)	14 (25.9)	5.24 (2.43–11.30)	0.001
BMI	Underweight	80 (67.2)	39 (32.8)	3.56 (1.35–9.40)	0.009
	Others	30 (36.6)	52 (63.4)	Reference	–
Stage at diagnosis	Early	7 (53.8)	6 (46.2)	Reference	—
	Advanced/metastatic	142 (86.6)	22 (13.4)	5.52 (1.63–18.6)	*0.006*
Treatment started	Yes	20 (25.0)	60 (75.0)	Reference	–
	No	90 (92.8)	7 (7.2)	4.32 (1.63–11.47)	0.003

4. DISCUSSION

This study highlights a substantial burden of patient-reported unmet palliative care needs among cancer patients in Guinea, pointing to systemic and organizational constraints rather than isolated clinical shortcomings. Its originality lies in providing the first multidimensional, patient-reported assessment of supportive and palliative care needs in this context, where empirical data remain scarce. Structural health system limitations, restricted access to essential medicines, and socioeconomic vulnerability likely contribute to observed disparities in care. These findings also support the use of patient-reported outcomes as practical, context-relevant indicators of health system performance in low-resource settings. Rather than reflecting isolated clinical shortcomings, the observed patterns of unmet needs across multiple domains suggest broader structural and organizational limitations in cancer care delivery.

Although nearly half of patients initiated palliative care within two months of diagnosis, a substantial proportion experienced delayed initiation. In the absence of structured national referral pathways or integration guidelines, timing appears largely dependent on individual clinical judgment. Early integration of palliative care has been shown to improve quality of life [13]. Strengthening national frameworks for systematic early referral may therefore help reduce preventable suffering and disparities in cancer care.

Informational needs represented the highest burden, revealing major communication gaps. Most patients reported insufficient understanding of palliative care, treatment, and diagnosis. Limited educational attainment may further hinder comprehension and participation in decision-making. Similar challenges have been described in other sub-Saharan African contexts [14]. Educational level is known to influence treatment adherence and healthcare utilization [15]. These findings underscore the need for structured patient education programs and communication training within oncology services.

Psychological and socioeconomic needs constituted the second-highest burden. Fear, emotional distress, and difficulty discussing illness were highly prevalent, suggesting insufficient integration of psycho-oncology support. Financial concerns, although reported by approximately one quarter of patients, likely underestimate the overall economic impact given reliance on family support systems. Previous studies in comparable settings have documented the compounding psychological and financial strain associated with advanced cancer [16–19]. Together, these results reflect substantial emotional and economic vulnerability.

Care and support needs also revealed important gaps. Despite generally positive perceptions of staff attentiveness, nearly half of patients felt their concerns were not adequately addressed, and most reported high out-of-pocket expenses. These findings point to limitations in responsiveness and financial protection mechanisms, which may negatively affect patient experience and equity in access to supportive services.

Physical and functional needs remained considerable, consistent with the high proportion of advanced-stage disease. Loss of autonomy, pain, and fatigue were particularly prevalent. Effective symptom control remains central to palliative care [20–22]. However, access to opioids in Guinea is limited, reflecting regulatory and supply constraints documented in the region [23]. Restricted availability of essential analgesics contributes to avoidable suffering and underscores the need for improved procurement systems and provider training. Fatigue management similarly requires multidisciplinary approaches integrating medical, psychological, and social interventions [24,25]. Sexuality-related needs were less frequently reported but remain clinically relevant. Cultural norms and limited provider training may restrict open discussion of intimacy concerns, potentially leading to underreporting. Addressing sexuality as part of holistic palliative care supports patient dignity and overall well-being [26,27].

Exploratory bivariate analysis identified subgroups at increased risk of high unmet needs, including patients with low educational attainment, poor performance status, underweight status, advanced or metastatic disease, and absence of treatment initiation. As the analysis was unadjusted and cross-sectional, associations should not be interpreted causally. Nevertheless, these findings help identify clinically and socially vulnerable groups who may require prioritized supportive interventions. Lower reporting of unmet needs among men may reflect gender differences in perception or disclosure rather than true differences in burden.

These findings should be interpreted in light of several limitations. The cross-sectional design provides only a snapshot of unmet needs and does not allow conclusions about causality or changes over time. Being a single-center study in a tertiary referral hospital, the findings reflect the experiences of patients in a specialized care setting and may not be generalizable to all cancer patients in Guinea. Patients with severe clinical deterioration were not included, which may have led to underestimation of unmet needs among the most severely ill. Data were self-reported, which could introduce recall or social desirability biases, particularly for sensitive topics such as psychological distress and sexuality. The SCNS-SF34 was carefully adapted to the local cultural and linguistic context and pretested to ensure clarity, comprehension, and feasibility among participants. While formal psychometric validation in this population was not performed, the adaptation and pretesting support the appropriateness of the instrument for capturing patients' perceived unmet needs.

Despite these limitations, the study provides important empirical insights in a context where evidence is scarce. It highlights priority areas for improving cancer care, including earlier integration of palliative care, enhanced patient communication and education, better access to essential symptom-control medications, and targeted support for socially and clinically vulnerable patients. Future multicenter and longitudinal studies are needed to further explore determinants of unmet needs and inform equitable cancer care policies.

5. CONCLUSION

This study presents the first systematic assessment of patient-reported unmet palliative care needs among cancer patients in a tertiary hospital setting in Guinea. The high burden of unmet needs across informational, physical, psychosocial, and care-related domains suggests underlying health system constraints rather than solely individual-level gaps in care. While the findings are not nationally representative, they offer important indications of priority areas for health system strengthening, including earlier integration of palliative care, improved access to essential medicines, enhanced provider training, and more effective patient-centered communication. Addressing these gaps is critical to improving the quality and equity of cancer care in Guinea and similar low-resource settings.

Acknowledgments: The authors extend their sincere thanks to Dr. Mohamed Konaté, Dr. Kadiatou Peredio Sow, Dr. Aïssatou Baldé, and Dr. Dramane Camara for their invaluable contributions and dedicated efforts in completing this study.

Competing interests: The authors declare that they have no competing interest.

Funding: This research received no external funding.

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