Cancer Management and Research

Elevate Series

Open Access Full Text Article

ORIGINAL RESEARCH

Addressing the Neglected Burden of Cancer Cachexia: A Quasi-Experimental Study at Uganda Cancer Institute

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Background: Cancer cachexia is a debilitating syndrome contributing to significant morbidity and mortality. Despite its impact on survival and quality of life, it remains under-recognized and undertreated, particularly in low- and middle-income countries (LMICs) where structured care models are scarce.

Objective: This study evaluated impact of a structured educational intervention on patient knowledge, emotional coping, and practice outcomes at Uganda Cancer Institute (UCI).

Methods: A longitudinal quasi experimental with a pre and post study design was used to enroll 484 patients with cancer cachexia. The intervention consisted of structured educational sessions delivered in-person and via SMS, and data were collected using a questionnaire aligned with international cachexia tools and guidelines. Analysis was performed in STATA (v18) with descriptive statistics.

Results: Awareness of cancer cachexia increased to 94.2% following the intervention. Improvements were noted in nutrition-impacting symptoms and emotional well-being including reductions in eating-related distress (15–25%), family conflict (14–17%) and body image concerns (23–29%). In contrast, declines were observed in coping ability (37%), self-rated health (42%), and quality of life (35%) reflecting awareness paradox. While weight-loss and sarcopenia improved (9–13%), physical strength and activity levels decreased (6–8%) due to disease progression reflected in a higher proportion of patients with worsened ECOG and advanced malignancies (61.7%).

Conclusion: Tailored interventions can enhance awareness and self-care in cancer cachexia, even in LMICs. Sustainable impact requires early detection and integration into multimodal care with institutional support.

Keywords: cancer cachexia, knowledge, attitude, practices, Uganda, cachexic patients

Background

Cancer cachexia remains one of the most devastating yet under-recognized syndromes, afflicting 80% of patients with advanced malignancies and contributing to over 20% of cancer-related deaths.[1] It is a multifactorial syndrome marked not only by ongoing skeletal muscle wasting and weight loss but also emotional and functional impairment that cannot be fully reversed just by conventional nutritional support.[2,3]

Despite decades of evidence linking cancer cachexia to poor outcomes, the syndrome continues to evade routine oncology care and remains under-recognized and under-treated globally, particularly in many low- and middle-income countries (LMICs), where oncology care systems are often ill-equipped to address its complex multifactorial nature leading to delays in recognition and timely care.[4–6] Early recognition of cachexia is crucial as part of comprehensive oncology care because of its prognostic significance and treatment outcomes.[7] Both patients and caregivers have expressed a sense of hopelessness and need for information, underscoring its role in guiding evidence-based practices to optimize care.[8,9] In Uganda, patients frequently navigate their illness trajectories with limited knowledge of cachexia, inadequate counseling, and little access to interdisciplinary support, even as the syndrome profoundly impacts their quality of life and treatment tolerance while oncology teams face structural barriers including lack of systematic screening, limited access to nutritionists, physiotherapists, and psychosocial services, and resource constraints that restrict multimodal care.[10]

https://doi.org/10.2147/CMAR.S576718
Received: 25 October 2025
Accepted: 13 February 2026
Published: 24 March 2026

In high-income settings, interventions rooted in multimodal care and patient-centered education have shown promise in improving symptom control and psychosocial outcomes.[11] Global consensus now underscores the urgency of addressing cancer cachexia through coordinated, transdisciplinary strategies that combine medical, nutritional, psychosocial, and rehabilitative components, with an emphasis on cultural relevance and patient engagement.[12] Previous studies in other contexts have shown that structured educational and multimodal interventions can improve symptom control, nutritional management, and psychosocial outcomes[13] supporting the rationale for evaluating a tailored educational intervention in the Ugandan setting. Evidence from other LMIC and regional contexts also supports the feasibility and effectiveness of structured, multidisciplinary management models when adapted to local healthcare realities,[14] further reinforcing the need for culturally sensitive, resource-appropriate strategies in African oncology care.

Understanding how patients perceive, cope with, and act upon cachexia is critical to designing sustainable interventions that are both clinically effective and culturally attuned. This study offers one of the first explorations of cancer cachexia from the patient perspective in a Ugandan cancer center, shedding light on prevailing gaps in knowledge, shifting attitudes, and lived experiences of care. By evaluating the impact of a structured educational intervention with multi-modal approach on patients' understanding, emotional resilience, and self-care practices within a resource-limited context, this research aims to lay the groundwork for integrated, context-specific strategies to address this neglected burden and yet life-altering condition.

Methods

Study Setting and Participants

This study employed a longitudinal quasi experimental design with a pre and post study approach from November 2023 to May 2025, carried out at the Uganda Cancer Institute (UCI), a leading tertiary facility in Kampala providing comprehensive oncology services to patients from across the country. UCI attends to approximately 8000 cancer patients annually, with an estimated 80% experiencing varying degrees of cachexia.

The study enrolled a total of 484 participants were recruited at baseline, inclusion required age $\geq$ 18 years and a clinical diagnosis of cancer cachexia (defined as $\geq$5% weight loss in 6 months, or BMI <20 with >2% weight loss, or sarcopenia with weight loss). Exclusion criteria involved inability to consent. Simple randomization was done using the REDCap randomization module to ensure representative inclusion.

Data Collection

Data acquisition was conducted by a qualified nurse and a clinician using a structured, interviewer-administered questionnaire developed using domains from multiple sources including Edmonton scale,[15] Eating related distress survey,[16] Functional Assessment of Anorexia Cachexia Therapy (FAACT) questionnaire,[17,18] ASCO,[19] ESMO[20] and GLIM[21] international guidelines on cachexia diagnosis and management capturing multidimensional aspects and adapted to the Ugandan context through literature and expert review and pilot tested in a small group of patients for clarity and appropriateness. The questionnaire captured objective items and subjective perceptions related to knowledge, attitudes, and practices (KAP) on a wide range of domains: demographic characteristics, understanding of cachexia (definition, mechanisms, and clinical presentation), associated symptoms, and management outcomes.

The educational intervention consisted of structured in-person sessions led by trained nurses, nutritionists and psychologists, covering topics including cachexia awareness, nutrition, symptom management, rehabilitation exercises, and psychosocial coping strategies. Each session lasted approximately 60 minutes and was delivered once per week for three months. Additionally, SMS messages contained concise educational content and reminders were sent twice weekly over the same period. All in-person sessions and SMS content were standardized using a pre-defined protocol and validated message scripts to ensure consistency across participants.

Data Management and Analysis

All responses were recorded in REDCap and subsequently analyzed using STATA v18. Objective responses were scored dichotomously (1 for correct, 0 for incorrect). Subjective evaluations were rated on a 5-point Likert scale, ranging from 1

(very low) to 5 (very high). Responses were interpreted correct/wrong based on 50% cut-off or using modified Bloom's criteria: scores above 80% were deemed "good," 60–80% as "moderate," and below 60% as "poor."[22]

For Likert-scale, multiple responses were consolidated (eg, "agree" and "strongly agree" combined). Descriptive analysis included frequency distributions, percentages, medians, and interquartile ranges to summarize categorical and continuous variables.

Results

Demographics

A total of 484 patients were surveyed pre-intervention. Of these, 164 (33.9%) had died and 78 (16.1%) of these had gastrointestinal cancer, besides this 42 (8.7%) were lost to follow-up by the time of post-intervention assessment. The remaining 278 patients alive, participated in the post-intervention evaluation for comparison of knowledge, attitudes, and practices related to cancer cachexia (Figure 1).

The median patient age remained comparable between groups. Breast cancer was the most prevalent diagnosis in both groups, and over 57% of participants were female. Most patients were receiving chemotherapy. A majority had attained at most secondary education [140 (28.9%) pre- vs 104 (37.4%) post-intervention] followed by primary education [135 (27.9%) pre- vs 57 (20.5%) post-intervention].

At baseline, 60.95% presented with localized cancer, while 35.95% had metastatic disease. In contrast, among post-intervention participants, there was a higher proportion of patients with advanced disease, with only 38.27% presenting with localized cancer and 61.73% having metastatic cancer. Performance status, as measured by the ECOG score, also showed notable changes. Pre-intervention, 66.74% had an ECOG of 2, 15.7% had ECOG 1 and 8.06% had ECOG 0. Post-intervention, the proportion of patients with ECOG 2 remained high (60.07%), but there was a considerable increase in patients with a score of 1 (38.85%) and a sharp decline in those fully active (ECOG 0), which dropped to just 1.08% (Table 1). These shifts may reflect both disease progression and functional decline consistent with the clinical burden of cancer cachexia.

Knowledge: Advancing Awareness, but Complexity Breeds Confusion

Substantial improvements were observed in patient knowledge regarding cancer cachexia following the intervention. Prior to the intervention, 90.3% of patients had heard of malnutrition, but only 1.65% were familiar with the term "cachexia." Post-intervention, awareness of malnutrition rose to 100%, while knowledge of cachexia increased dramatically to 94.2%. The sources of cachexia knowledge shifted notably after the intervention: nurses (36.2%), nutritionists (32.1%), and psychologists (30.8%).

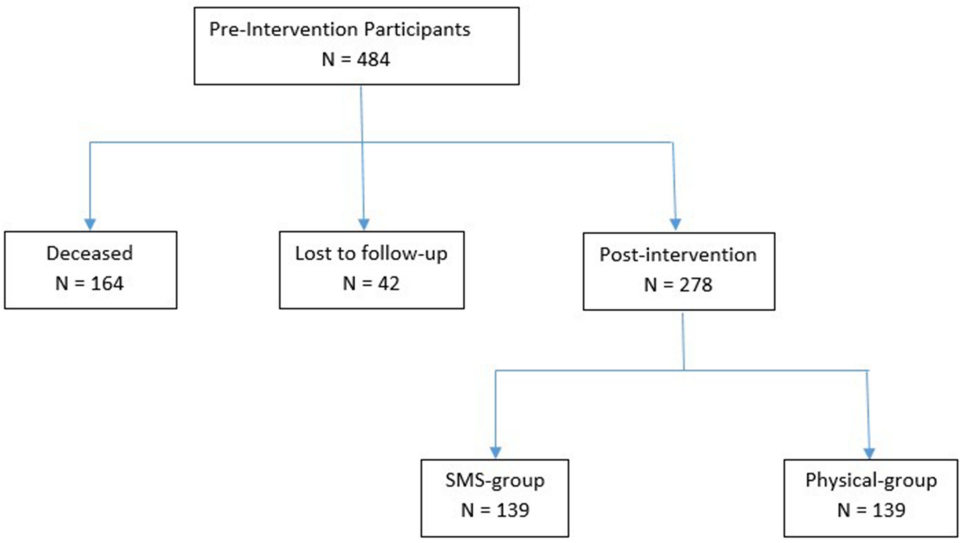

Figure 1 Participant flow diagram illustrating enrollment, attrition, and follow-up of study participants (N = 484).

https://doi.org/10.2147/CMAR.S576718

Table 1 Participant Demographics and Cachexia Awareness

Variable	Category	Pre-Intervention (n=484)		Post-Intervention (n=278)	
		Freq. (n)	%	Freq. (n)	%
Age (Median, IQR)	Median	47		46	
	IQR	38 to 57		39 to 53	
Gender	Female	281	58.06	159	57.19
	Male	203	41.94	119	42.81
Region	Western	135	27.89	76	27.34
	Eastern	124	25.62	54	19.42
	Central	121	25.00	102	36.69
	Northern	78	16.12	43	15.47
	Southern	26	5.37	3	1.08
Education level	Primary	135	27.89	57	20.50
	Secondary	140	28.93	104	37.41
	Tertiary Institution	83	17.15	77	27.70
	University	85	17.56	30	10.79
	None	41	8.47	10	3.60
Cancer Type	Breast	146	30.17	109	39.35
	Gastrointestinal	104	21.49	26	9.39
	Sarcoma	81	16.74	61	22.02
	Prostate	76	15.70	53	19.13
	Cardiothoracic	33	6.82	1	0.36
	Gynaecological	25	5.17	–	–
	Haematological	15	3.10	15	5.42
	Head and Neck	2	0.41	9	3.25
	ENT	2	0.41	3	1.08
Cancer Stage	Local	295	60.95	106	38.27
	Metastatic/Disseminated	174	35.95	171	61.73
	Unstaged	15	3.10	–	–
ECOG Performance Status	0	39	8.06	3	1.08
	1	76	15.70	108	38.85
	2	323	66.74	167	60.07
	3	42	8.68	–	–
	4	4	0.83	–	–

(*Continued*)

Table 1 (Continued).

Variable	Category	Pre-Intervention (n=484)		Post-Intervention (n=278)	
		Freq. (n)	%	Freq. (n)	%
Cancer Treatment	Chemotherapy	441	91.12	262	77.06
	Hormonal Therapy	29	5.99	59	17.35
	Radiotherapy	59	12.19	11	3.24
	Surgery	20	4.13	7	2.06
	Palliative	7	1.45	0	0.00
	No Treatment	19	3.93	1	0.29
	Other	1	0.33	0	0.00
Setting	Outpatient	447	92.36	278	100.00
	Inpatient	36	7.44	–	–
	Home Care	1	0.21	–	–
Comorbidity	None	349	72.11	185	67.27
	Others	34	7.02	39	14.18
	Heart Disease	31	6.40	26	9.45
	ISS	27	5.58	1	0.36
	Renal Disease	21	4.34	11	4.00
	Liver Disease	12	2.48	3	1.09
	Diabetes	8	1.65	8	2.91
	COPD	2	0.41	2	0.73
Have you heard of the word malnutrition?	Yes	437	90.29	278	100.00
	No	47	9.71	0	0.00
If yes, source of hearing malnutrition?	Doctor	79	16.32	34	4.59
	Nurse	117	24.17	243	32.79
	Nutritionist	48	9.92	160	21.59
	Psychologist	22	4.55	87	11.74
	Internet	57	11.78	58	7.83
	Social Media	149	30.79	47	6.34
	Mass	209	43.18	52	7.02
	Community	99	20.45	60	8.10
	School	8	1.65	–	–
Have you heard of the word cachexia?	Yes	8	1.65	259	94.18
	No	476	98.35	16	5.82

(*Continued*)

Table 1 (Continued).

Variable	Category	Pre-Intervention (n=484)		Post-Intervention (n=278)	
		Freq. (n)	%	Freq. (n)	%
If yes, source of hearing cachexia?	Doctor	2	41.0	33	4.65
	Internet	2	41.0	6	0.85
	Community	1	21.0	–	–
	Nutritionist	1	21.0	228	32.11
	Psychologist	1	21.0	168	23.66
	Social Media	1	21.0	7	0.99
	Mass	–	–	10	1.41
	Other	–	–	1	0.14

Patients demonstrated good baseline knowledge with strong retention of structured, action-oriented educational content, particularly in areas involving nutritional support, symptom recognition, rehabilitation, quality of life, and the need for multimodal management approaches. SMS-based educational content performed well especially in delivering clear and actionable messages, such as encouraging referrals to dietitians or promoting exercise.

Despite these improvements, knowledge gaps persisted in more complex or sensitive topics, including biological mechanisms underlying cachexia, misconceptions around palliative feeding, and understanding of psychosocial care needs (Table 2). These domains likely require deeper engagement, repeated reinforcement, and individualized education strategies to achieve comparable comprehension.

Emotional Relief and Realism (Growth vs Weight)

The intervention also led to marked improvements in patient attitudes, particularly in emotional and psychosocial domains. Participants reported notable reductions in fear of death (19%), disease progression (20%), anxiety (0.99 points), and depression (0.99 points). Concerns related to body image also improved by 23–29%, and family-related conflict over meals dropped by 14–17%. Nevertheless, while emotional resilience and family cohesion improved, certain

Table 2 Knowledge of Cancer Cachexia

	Question	Group	Strongly Disagree (n, %)	Disagree (n, %)	Neutral (n, %)	Agree (n, %)	Strongly Agree (n, %)	Median (IQR)
Pathophysiology	Loss of appetite is common in patients with advanced cancer and may be the result of the cancer process itself	Pre-Intervention	(189, 40)	(86, 18)	(7, 1.5)	(95, 20)	(95, 20)	2 (1–4)
		SMS	(90, 66)	(36, 26)	(1, 1)	(7, 5)	(3, 2)	1
		Physical	(83, 61)	(40, 29)	(5, 4)	(5, 4)	(4, 3)	1
	Trying to force a patient to eat is usually counterproductive, potentially leading to increased nausea/vomiting	Pre-Intervention	(47, 10)	(113, 24)	(12, 3)	(216, 46)	(83, 18)	4 (2–4)
		SMS	(34, 25)	(77, 56)	(10, 7)	(16, 12)	(0, 0)	2
		Physical	(65, 47)	(47, 34)	(4, 3)	(20, 15)	(1, 1)	2
Palliative care	In most patients with advanced cancer and cachexia, providing additional calories by feeding tubes and/or intravenously does not improve outcomes	Pre-Intervention	(161, 34)	(149, 32)	(28, 6)	(69, 15)	(64, 14)	2 (1–4)
		SMS	(51, 37)	(65, 47)	(12, 9)	(8, 6)	(1, 1)	2
		Physical	(66, 48)	(48, 35)	(6, 4)	(17, 12)	(0, 0)	2

(*Continued*)

Table 2 (Continued).

	Question	Group	Strongly Disagree (n, %)	Disagree (n, %)	Neutral (n, %)	Agree (n, %)	Strongly Agree (n, %)	Median (IQR)
Psychosocial & Caregiver Support	Trying to make a patient eat, when they have marked appetite loss, can lead to increased patient distress and decreased interactions with caregivers	Pre-Intervention	(32, 7)	(111, 24)	(61, 13)	(200, 42)	(68, 14)	4 (2–4)
		SMS	(59, 43)	(36, 26)	(18, 13)	(24, 18)	(0, 0)	2
		Physical	(67, 49)	(46, 34)	(10, 7)	(13, 9)	(1, 1)	2
	For caregivers, it may be best to listen to and support the patient in a variety of other ways instead of trying to talk them into eating more	Pre-Intervention	(9, 2)	(64, 14)	(42, 9)	(225, 48)	(131, 28)	4 (4–5)
		SMS	(43, 31)	(36, 26)	(9, 7)	(30, 22)	(19, 14)	2
		Physical	(43, 31)	(10, 7)	(10, 7)	(50, 37)	(24, 18)	4
Quality of Life	Symptom, distress, and functional status management (eg, pain, dyspnea, fatigue, sleep disturbance, mood, nausea, or constipation) are an essential component of care	Pre-Intervention	(6, 1.3)	(9, 2)	(7, 1.5)	(109, 23)	(340, 70)	5 (4–5)
		SMS	(9, 7)	(6, 4)	(0, 0)	(33, 24)	(89, 65)	5
		Physical	(0, 0)	(1, 1)	(1, 1)	(41, 30)	(94, 69)	5
Rehabilitation / Physical Function	Physical exercise is safe and recommended in patients with cancer cachexia	Pre-Intervention	(1, 0.2)	(1, 0.2)	(11, 2)	(138, 29)	(319, 66)	5 (4–5)
		SMS	(0, 0)	(0, 0)	(5, 4)	(41, 30)	(91, 66)	5
		Physical	(0, 0)	(0, 0)	(0, 0)	(43, 31)	(94, 69)	5
Evidence-Based Nutritional Management/ multi-disciplinary management	Referral to a registered dietitian may provide patients and caregivers with additional opportunities to discuss concerns and challenges related to nutrition, appetite, and meal planning	Pre-Intervention	(2, 0.4)	(2, 0.4)	(14, 3)	(118, 25)	(334, 69)	5 (4–5)
		SMS	(0, 0)	(1, 1)	(0, 0)	(41, 30)	(95, 69)	5
		Physical	(0, 0)	(0, 0)	(0, 0)	(54, 39)	(83, 61)	5
	Tailored information by healthcare professionals (doctors, nurses, and dietitians) about the role of nutritional support according to the stage of cachexia is fundamental to achieving treatment goals	Pre-Intervention	(3, 0.65)	(3, 0.65)	(7, 1.5)	(125, 27)	(326, 67)	5 (4–5)
		SMS	(0, 0)	(0, 0)	(0, 0)	(35, 26)	(101, 74)	1
		Physical	(0, 0)	(0, 0)	(0, 0)	(37, 27)	(100, 73)	1

challenges persisted. Coping fatigue and existential distress remained prevalent, underscoring the need for ongoing psychological and palliative care beyond initial education.

A paradoxical trend emerged in patients' self-perceptions of health and quality of life. Perceived ability to cope with illness declined from moderate to poor levels significantly (from 79% pre-intervention to 47% post-intervention), while perceived overall health and quality of life decreased to poor levels by 42% and 35%, respectively (Table 3).

Symptom Improvement vs Functional Decline: A Divergent Outcome

A majority of nutrition-impacting symptoms significantly improved post-intervention. Patients reported reductions in food intake changes (21%), early satiety (7%), food aversions (5–7%), constipation (10%), and abdominal pain (9%), suggesting enhanced symptom recognition and improved dietary guidance. However, some domains remained challenging primarily driven by cachexia-related anorexia typically resistant to behavioral change alone. The average nausea and appetite scores decreased slightly by 0.17 and 0.31 points respectively, and the proportion of patients reporting pain that interfered with eating increased from 10% to 20%. Additionally, fatigue-related eating difficulty rose, indicating that fatigue and pain remained significant barriers to adequate nutrition.

Physical outcomes showed a mixed picture. While overall appearance and weight-related indicators (including weight loss and sarcopenia) improved by 9–13%, physical strength declined, with handgrip strength decreasing by 6% and physical activity limitations increasing by 8% (Table 4).

Table 3 Psychosocial Distress and Quality of Life Symptoms

Theme	Symptom	Pre-Intervention						Post-Intervention					
		Not at All (n, %)	Little (n, %)	Neutral (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)	Not at All (n, %)	Little (n, %)	Neutral (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)
Concerns about Weight and Appearance	I am worried about my weight	(34, 7)	(186, 39)	(50, 11)	(141, 30)	(63, 13)	3(2 to 4)	(57, 21)	(152, 55)	(10, 4)	(42, 15)	(13, 5)	2(2 to 2)
	I am concerned about how thin I look	(29, 6)	(210, 45)	(34, 7)	(133, 28)	(62, 13)	3(2 to 4)	(67, 25)	(158, 58)	(13, 5)	(28, 10)	(6, 2)	2(2 to 2)
	The amount I eat is sufficient to meet my needs	(240, 51)	(54, 11)	(37, 8)	(104, 22)	(39, 8)	2(1 to 4)	(160, 58)	(29, 11)	(5, 2)	(59, 22)	(21, 8)	1(1 to 4)
Emotional and Psychological Well-being	I feel sad generally	(258, 55)	(28, 6)	(65, 14)	(88, 19)	(34, 7)	1(1 to 3)	(142, 52)	(38, 14)	(16, 6)	(54, 20)	(24, 9)	1(1 to 4)
	Did you feel irritable?	(270, 57)	(39, 8)	(79, 17)	(58, 12)	(25, 5)	1(1 to 3)	(195, 71)	(31, 11)	(11, 4)	(14, 5)	(23, 8)	1(1 to 2)
	I worry about dying	(289, 61)	(24, 5)	(36, 8)	(82, 17)	(44, 9)	1(1 to 3)	(190, 69)	(57, 21)	(8, 3)	(12, 4)	(7, 3)	1(1 to 2)
	I am losing hope in the fight against my illness	(290, 61)	(20, 4)	(48, 10)	(71, 15)	(43, 9)	1(1 to 3)	(226, 82)	(23, 8)	(6, 2)	(11, 4)	(8, 3)	1(1 to 1)
	I worry that my condition will get worse	(279, 59)	(24, 5)	(40, 8)	(97, 20)	(35, 7)	1(1 to 3)	(197, 72)	(49, 18)	(7, 3)	(15, 5)	(6, 2)	1(1 to 2)
Coping and caregiver support	I get emotional support from my family/friends	(29, 6)	(12, 3)	(13, 3)	(155, 33)	(267, 56)	4(4 to 5)	(8, 3)	(8, 3)	(9, 3)	(129, 47)	(120, 44)	4(4 to 5)
	I am satisfied with how I am coping with my illness	(27, 6)	(48, 10)	(26, 5)	(286, 60)	(90, 19)	4(3 to 4)	(36, 13)	(99, 36)	(12,4)	(73, 27)	(54, 20)	3(2 to 4)
	I am satisfied with family communication about my illness	(12, 3)	(13, 3)	(21, 4)	(213, 45)	(218, 46)	5(4 to 5)	(9, 3)	(5, 2)	(1, 0)	(101, 37)	(158, 58)	4(4 to 5)
	I feel close to my partner (or the person who is my main support)	(23, 5)	(13, 3)	(23, 5)	(238, 50)	(180, 38)	4(4 to 5)	(17, 6)	(7, 3)	(8, 3)	(106, 39)	(136, 50)	4(4 to 5)
	My family or friends are pressuring me to eat	(333, 70)	(37, 8)	(26, 6)	(46, 10)	(31, 7)	1(1 to 2)	(240, 89)	(18, 7)	(2, 1)	(9, 3)	(1, 0)	1(1 to 1)
	My family has accepted my illness	(12, 3)	(13, 3)	(25, 5)	(210, 44)	(216, 45)	4(4 to 5)	(1, 0)	(4, 1)	(3, 1)	(102, 37)	(164, 60)	4(4 to 5)
Financial Impact	Because of my physical condition, I have trouble meeting the needs of my family	(2, 0.4)	(19, 4)	(7, 1)	(69, 15)	(376, 79)	4(4 to 5)	(2, 1)	(33, 12)	(1, 0)	(55, 20)	(183, 67)	5(4 to 5)
	Has your physical condition or medical treatment caused you financial difficulties?	(7, 1)	(6, 1)	(11, 2)	(106, 22)	(347, 73)	5(4 to 5)	(4, 1)	(3, 1)	(1, 0)	(99, 36)	(167, 61)	5(4 to 5)
Functional status	I am forced to spend time in bed	(361, 76)	(43, 9)	(31, 7)	(24, 5)	(17, 4)	1(1 to 2)	(253, 92)	(12, 4)	(0, 0)	(4, 1)	(5, 2)	1(1 to 1)
	Do you need help with eating, dressing, washing yourself, or using the toilet?	(366, 77)	(31, 7)	(28, 6)	(32, 7)	(19, 4)	1(1 to 3)	(257, 94)	(15, 5)	(0, 0)	(1, 0)	(1, 0)	2(2 to 2)
Treatment	I am bothered by side effects of treatment	(262, 56)	(28, 6)	(8, 2)	(67, 14)	(106, 23)	1(1 to 4)	(76, 28)	(105, 38)	(3, 1)	(41, 15)	(49, 18)	2(1 to 4)
Quality of Life	How would you rate your overall quality of life during the past week?	(2, 0.4)	(35, 7)	(103, 22)	(319, 67)	(14, 3)	4(3 to 4)	(1, 0)	(62, 23)	(116, 42)	(87, 32)	(7, 3)	3(3 to 4)
	How would you rate your overall health during the past week?	(14, 3)	(37, 8)	(89, 19)	(314, 66)	(22, 5)	4(3 to 4)	(2, 1)	(67, 24)	(125, 46)	(71, 26)	(9, 3)	3(2 to 4)

https://doi.org/10.2147/CMAR.S576718

Table 4 Symptoms Experienced in 6 months

Theme	Symptom	Pre-Intervention						Post-Intervention					
		Not at All (n, %)	Little (n, %)	Neutral (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)	Not at All (n, %)	Little (n, %)	Neutral (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)
Appetite/ Nutrition	Change in taste	(146, 31)	(236, 49)	(41, 9)	(46, 10)	(8, 2)	2(1.5 to 2)	(121, 44)	(138, 50)	(1, 0)	(11, 4)	(3, 1)	2(1 to 2)
	Dry mouth	(401, 85)	(41, 9)	(9, 2)	(21, 4)	(2, 0.4)	1(1 to 1)	(247, 90)	(25, 9)	(1, 0)	(1, 0)	(0, 0)	1(1 to 1)
	Early satiety	(355, 75)	(54, 11)	(20, 4)	(41, 9)	(5, 1)	1(1 to 2)	(200, 73)	(63, 23)	(2, 1)	(8, 3)	(0, 0)	1(1 to 2)
	Food intake changes	(68, 14)	(230, 48)	(19, 4)	(139, 29)	(21, 4)	3(2 to 4)	(76, 28)	(161, 59)	(4, 1)	(30, 11)	(3, 1)	2(1 to 2)
	Nausea/Vomiting	(157, 33)	(242, 51)	(34, 7)	(12, 5.6)	(2, 0.9)	2(1 to 2)	(100, 37)	(159, 58)	(4, 1)	(10, 4)	(1, 0)	2(1 to 2)
	No appetite, just did not feel like eating	(294, 62)	(39, 8)	(15, 3)	(44, 9)	(83, 17)	1(1 to 4)	(176, 64)	(28, 10)	(2, 1)	(43, 16)	(24, 9)	1(1 to 3)
	Put off eating by food smells	(364, 76)	(41, 9)	(34, 7)	(33, 7)	(4, 1)	1(1 to 2)	(234, 85)	(32, 12)	(1, 0)	(7, 3)	(0, 0)	1(1 to 1)
	Put off eating by quantity	(365, 77)	(47, 10)	(29, 6)	(29, 6)	(4, 1)	1(1 to 2)	(244, 89)	(21, 8)	(2, 1)	(7, 3)	(0, 0)	1(1 to 1)
	Texture of food unpleasant	(239, 51)	(172, 36)	(28, 6)	(29, 6)	(5, 1)	1(1 to 2)	(224, 82)	(42, 15)	(1, 0)	(7, 3)	(0, 0)	1(1 to 1)
	Too tired to eat	(351, 74)	(61, 13)	(26, 6)	(26, 6)	(8, 2)	1(1 to 2)	(219, 80)	(26, 9)	(4, 1)	(15, 5)	(10, 4)	1(1 to 1)
Weight Loss/ Sarcopenia	Change in physical appearance (muscle mass/wasting/sarcopenia)	(7,1.5)	(218, 46)	(8, 1.7)	(78, 23)	(166, 35)	4(2 to 5)	(6, 2)	(138, 51)	(7, 3)	(82, 30)	(40, 15)	2(2 to 4)
	Weight loss < 1%	(150, 32)	(66, 14)	(81, 17)	(124, 26)	(51, 11)	3(1 to 4)	(153, 56)	(40, 15)	(14, 5)	(57, 21)	(9, 3)	1(1 to 3)
	Weight loss 1–5%	(3, 0.6)	(32, 7)	(63, 13)	(195, 41)	(177, 38)	4(4 to 5)	(7, 3)	(34, 12)	(44, 16)	(159, 58)	(29, 11)	3(3 to 4)
	Weight loss >5%	(7, 1.5)	(28, 6)	(49, 10)	(191, 40)	(198, 42)	4(4 to 5)	(3, 1)	(33, 12)	(39, 14)	(160, 59)	(38, 14)	4(3 to 4)
	Weight loss preventing usual activities	(113, 24)	(191, 40)	(37, 8)	(88, 19)	(43, 9)	2(1 to 2)	(78, 28)	(128, 47)	(5, 2)	(49, 18)	(14, 5)	2(1 to 2)
Pain/Palliative care	Abdominal pain	(299, 63)	(102, 21)	(27, 6)	(39, 8)	(8, 2)	2(1 to 2)	(224, 82)	(46, 17)	(0, 0)	(4, 1)	(0, 0)	1(1 to 1)
	Other pain	(343, 76)	(39, 9)	(21, 5)	(39, 8)	(11, 2)	1(1 to 2)	(261, 95)	(12, 4)	(0, 0)	(1, 0)	(0, 0)	1(1 to 1)
	Unable to eat because in pain	(329, 69)	(52, 11)	(44, 9)	(39, 8)	(11, 2)	1(1 to 2)	(179, 66)	(36, 13)	(4, 1)	(27, 10)	(27, 10)	1(1 to 2)

(*Continued*)

https://doi.org/10.2147/CMAR.S576718

Table 4 (Continued).

Theme	Symptom	Pre-Intervention						Post-Intervention					
		Not at All (n, %)	Little (n, %)	Neutral (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)	Not at All (n, %)	Little (n, %)	Neutral (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)
Functional Decline	Have you noticed any loss of handgrip force?	(6, 1)	(30, 6)	(36, 8)	(268, 56)	(137, 29)	4(3 to 4)	(1, 0)	(2, 1)	(1, 0)	(170, 62)	(100, 37)	4(4 to 5)
	Have you noticed any decrease in the physical activities that you normally carry out during the day?	(10, 2)	(20, 4)	(29, 6)	(286, 60)	(132, 28)	4(4 to 4)	(7, 3)	(3, 1)	(0, 0)	(170, 62)	(94, 34)	4(4 to 5)
	Did you have to put more effort on climbing stairs?	(13, 3)	(16, 3)	(14, 3)	(275, 58)	(160, 33)	4(4 to 5)	(2, 1)	(5, 2)	(2, 1)	(171, 63)	(93, 34)	4(4 to 5)
	Have you felt tired after walking approximately half a kilometer?	(8, 2)	(17, 4)	(6, 1)	(276, 58)	(167, 35)	4(4 to 5)	(2, 1)	(4, 1)	(2, 1)	(171, 63)	(92, 34)	4(4 to 5)
	Shortness of breath	(396, 83)	(34, 7)	(19, 4)	(27, 6)	(1, 0.2)	1(1 to 1)	(231, 84)	(33, 12)	(3, 1)	(6, 2)	(1, 0)	1(1 to 1)
Gastrointestinal symptoms	Diarrhea	(380, 80)	(70, 15)	(9, 2)	(17, 4)	(0,0)	1(1 to 2)	(195, 71)	(72, 26)	(1, 0)	(6, 2)	(0, 0)	1(1 to 2)
	Constipation	(178, 38)	(216, 46)	(17, 4)	(55,12)	(6, 1)	1(1 to 2)	(120, 44)	(142, 52)	(3, 1)	(7, 3)	(1, 0)	2(1 to 2)
	Difficulty drinking	(399, 84)	(25, 5)	(30, 6)	(16, 3)	(6, 1)	1(1 to 2)	(249, 91)	(18, 7)	(0, 0)	(7, 3)	(0, 0)	1(1 to 1)
	Difficulties swallowing	(359, 76)	(53, 11)	(24, 5)	(30, 6)	(8, 2)	1(1 to 2)	(179, 65)	(75, 27)	(3, 1)	(11, 4)	(6, 2)	1(1 to 2)
	Mouth sores (stomatitis)	(160, 34)	(248, 52)	(17, 4)	(48, 10)	(2, 0.4)	2(1 to 2)	(105, 38)	(158, 58)	(1, 0)	(10, 4)	(0, 0)	2(1 to 2)
	Feeling too full (early satiety merged with above)	(375, 80)	(47, 10)	(16, 3.4)	(30, 6)	(3,0.6)	1(1 to 2)	(204, 75)	(56, 21)	(1, 0)	(12, 4)	(0, 0)	1(1 to 1)
	Willing but not able to eat	(345, 73)	(55, 12)	(24, 5)	(36, 8)	(9, 2)	1(1 to 2)	(211, 77)	(41, 15)	(1, 0)	(19, 7)	(2, 1)	1(1 to 1)

https://doi.org/10.2147/CMAR.S576718

Behaviorally, there were several positive shifts in dietary practices. Distress associated with eating declined by 15–25%, and adherence to structured meal routines improved, with three-meal-per-day consistency rising 80.6%. Patients also reported less confusion regarding food choices and nutritional requirements, with a 15–20% decrease in related uncertainty (Table 5).

Discussion

This study provides a comprehensive evaluation of the impact of a structured intervention on patients' knowledge, attitudes, and practices (KAP) regarding cancer cachexia at Uganda Cancer Institute (UCI). The intervention produced notable gains in nutritional awareness, emotional resilience, and symptom relief. However, these were tempered by persistent challenges particularly related to disease progression, knowledge retention, emotional burden and physical function decline. This underscores the multifactorial nature of cancer cachexia while reflecting the complex interplay between patient education, health literacy, emotional response and the realities of care in a low-resource oncology setting.

Unlike reports from Norway where cachexia prevalence was high among lung and gastrointestinal cancers[23,24] our cohort was dominated by breast cancer with most participants being female, also differing from findings in the United States.[25] However our distribution closely aligns with a national population-based cancer survey in Uganda, which documented similar trends in the country's cancer spectrum.[26]

Of 484 patients enrolled, 33.9% died before post-intervention assessment. This high attrition highlights the aggressive course and mortality burden of cancer cachexia, which coincides with late-stage presentation[27,28] a common occurrence in Uganda across various cancers owing to multiple barriers.[29–31] Similar trends have been observed in the USA, where cachexia amplified systemic strain with longer hospital stays and higher costs besides increased mortality, emphasizing the urgency of early recognition and preventive strategies.[32] These findings reinforce the importance of early recognition and systematic regular nutritional risk screening, as patients with depleted reserves are more vulnerable to treatment-related toxicities, reduced tolerance, poorer outcomes, and increased mortality. Proactive detection before advanced stages could mitigate attrition and optimize treatment outcomes.[7]

The most striking finding was the surge in awareness of cancer cachexia from 1.65% to 94.2% post-intervention. Pre-intervention, patients overwhelmingly recognized malnutrition but lacked familiarity with the term or clinical implications of cachexia, reflecting global trends in patient reports of nutritional issues but under-recognition of cachexia as a clinical entity,[33] especially in LMICs. This underscores the need for patient education alongside systemic reforms.[34] Patients retained practical actionable concepts on nutritional support, rehabilitation, symptom control, quality of life and multimodal care. Gains likely stemmed from active engagement in care processes and the relevance of these topics to daily experiences. Nutritionist- and psychologist-led sessions and SMS-delivered content proved particularly effective in bridging knowledge gaps, demonstrating the value of targeted, accessible education and capacity of structured strategies in resource-limited settings.[35,36]

Despite greater awareness, overall knowledge accuracy dropped from seven correct domains pre-intervention to five in the physical group and four in the SMS group. The decline was notable in complex and emotionally laden areas like pathophysiology, irreversibility, and psychosocial misconceptions. Rather than indicating true decline, this may reflect information overload and transition from superficial confidence to deeper but uncertain understanding, as patients questioned ingrained inaccurate cultural beliefs.[37] Confronting counterintuitive truths such as the limited impact of feeding in late-stage cachexia created cognitive dissonance, signaling the start of behavioral change likely requiring deeper engagement to achieve comparable comprehension.[23]

Improved health literacy also brought emotional strain. Greater insight into treatment limitations may have triggered psychological resistance, especially when conflicting with family or cultural expectations. Without counseling and emotional support, patients may disengage from distressing content. Therefore, emotionally difficult information requires empathetic delivery, counseling and family-inclusive dialogue to foster understanding and acceptance.[38]

Low educational attainment further constrained comprehension of abstract or nuanced concepts. In such contexts, rote learning and cultural intuition may override conceptual change, unless new information is actively integrated into existing mental frameworks through practical application or sustained engagement. Without system-level reinforcement, supportive follow-up or culturally adapted training, divergent concepts may not have been assimilated meaningfully and thus more susceptible to degrade over time or revert to experiential intuitive reasoning.[39,40] These findings emphasize the

Table 5 Eating-Related Concerns and Dietary Support

Category	Symptom	Pre-Intervention						Post-Intervention					
		Not at All (n, %)	A Little (n, %)	Somewhat (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)	Not at All (n, %)	A Little (n, %)	Somewhat (n, %)	Quite a Bit (n, %)	Very Much (n, %)	Median (IQR)
Eating Difficulty and Distress	Although I know that I have to eat enough, I cannot do that	(259, 55)	(67, 14)	(30, 6)	(61, 13)	(56, 12)	1(1 to 3)	(100, 37)	(101, 37)	(1, 0)	(34, 12)	(38, 14)	2(1 to 4)
	I do not know why I cannot eat enough	(41, 9)	(242, 51)	(45, 9)	(90, 19)	(57, 12)	2(2 to 3)	(40, 15)	(163, 60)	(12, 4)	(42, 15)	(16, 6)	2(2 to 3)
	I want attention to be paid to my eating-related distress	(44, 9)	(233, 49)	(26, 5)	(92, 19)	(80, 17)	2(2 to 4)	(33, 12)	(172, 63)	(10, 4)	(44, 16)	(15, 5)	2(2 to 3)
	I feel that a lack of nutrition makes my condition worse	(12, 3)	(245, 52)	(31, 7)	(76, 16)	(111, 23)	2(2 to 4)	(36, 13)	(170, 62)	(10, 4)	(41, 15)	(16, 6)	2(2 to 2)
Dietary needs	I wonder what kinds of food I can eat	(19, 4.01)	(246, 51.9)	(37, 7.81)	(99, 20.89)	(73, 15.4)	2(2 to 4)	(38, 14)	(169, 62)	(8, 3)	(45, 16)	(13, 5)	2(2 to 2)
	I wonder which nutrients I should preferentially consume	(14, 2.95)	(240, 50.53)	(26, 5.47)	(93, 19.58)	(102, 21.47)	2(2 to 4)	(29, 11)	(176, 64)	(9, 3)	(45, 16)	(15, 5)	2(2 to 3)
	I wonder how I can eat more	(17, 4)	(251, 52.73)	(31, 7)	(88, 18)	(89, 18.7)	2(2 to 4)	(37, 14)	(167, 61)	(12, 4)	(39, 14)	(18, 7)	2(2 to 3)
	I feel that more medical support about my daily diet is needed	(13, 2.73)	(221, 46.43)	(26, 5.46)	(97, 20.38)	(119, 25)	3(2 to 4)	(36, 13)	(170, 62)	(12, 4)	(34, 12)	(22, 8)	2(2 to 2)
Family-Related Eating Conflict	I am burdened by the meals that my family serves me	(285, 60)	(42, 8.84)	(35, 7.37)	(47, 9.89)	(66, 13.89)	1(1 to 3)	(222, 81)	(26, 9)	(4, 1)	(6, 2)	(16, 6)	1(1 to 1)
	I have experienced conflict about my meals with my family	(289, 60.84)	(44, 9.26)	(32, 6.74)	(37, 7.79)	(73, 15.37)	1(1 to 3)	(226, 82)	(26, 9)	(4, 1)	(4, 1)	(14, 5)	1(1 to 1)
	I feel that I disregard the effort that my family shows by making my meals	(282, 59.37)	(46, 9.68)	(34, 7.16)	(48, 10.11)	(65, 13.68)	1(1 to 3)	(221, 81)	(28, 10)	(4, 1)	(7, 3)	(14, 5)	1(1 to 1)
	I feel sad because I cannot enjoy dinner with my family	(275, 57.89)	(42, 8.84)	(32, 6.74)	(50, 10.53)	(76, 16)	1(1 to 3)	(203, 74)	(35, 13)	(2, 1)	(13, 5)	(21, 8)	1(1 to 2)

https://doi.org/10.2147/CMAR.S576718

need for iterative, emotionally sensitive, culturally tailored, simplified and personalized educational messages, reinforced by counseling and multidisciplinary care within a supportive clinical environment.[41,42]

The intervention yielded marked improvement in emotional and psychosocial attitudes indicating better emotional alignment. These findings suggest that even brief psychoeducational support can foster better family communication, reduce patient distress, and enhance emotional well-being. However, a deeper emotional cost became evident and accompanied by declines in perceived coping ability, self-rated health and quality of life. This apparent contradiction of symptom relief with worsening self-perception can be explained by the "awareness paradox," where realistic disease insight replaces hopeful denial, especially in low-literacy settings. As documented in psycho-oncology, this shift reflects psychological acceptance and adaptation seen in palliative care rather than increased distress.[29,43] It may stem from the mismatch between knowledge and feeling empowered to change its course, and more critical self-assessment of prognosis and function reflecting the emotional cost of realistic insight.[44] Persistent health system constraints and financial strain outside the scope of this intervention may compound this effect.

Encouragingly, symptom management improved, with reduced burden, better adherence to structured meals and less eating-related distress and dietary confusion consistent with findings from an Australian observational study following multidisciplinary care.[13] However pain related eating difficulties doubled to 20%, pointing to unaddressed pain syndromes as a potential obstacle to nutritional progress attributed to administrative, professional, and economic impediments.[45] Besides, fatigue-related eating issues worsened, and mean appetite scores declined slightly diverging from Bland's consistent improvements likely due to resource constraints and limited care in our context. Functional-capacity also continued to deteriorate echoing evidence that muscle loss predicts mortality, even with supportive care.[46] Although sarcopenia and weight loss parameters improved, strength, endurance, and physical activity did not, likely due to advancing disease and worsening ECOG scores, as seen in prior Ugandan studies highlighting the progressive clinical burden of cancer cachexia.[43] Our findings align with Swedish data showing that cachexic patients with weight loss, inflammation, fatigue, and low grip strength had poorer quality of life, reduced performance, and shorter survival in palliative settings.[47]

These results reinforce that cachexia's inflammatory and metabolic processes resist late-stage interventions. Nutritional education alone is essential but insufficient to reverse progression.[48,49] This calls for early detection and proactive, multimodal supportive care,[50,51] integrating physiotherapy, pharmacologic appetite stimulants, palliative care, pain control, and rehabilitation to address the syndrome's complexity.[13,52]

Strengths

This study is the first at the Uganda Cancer Institute to evaluate a structured, tailored educational intervention for cancer cachexia in a large, diverse patient cohort representative of national cancer trends. The use of SMS delivery methods, coupled with nutritionist- and psychologist-led sessions, allowed scalable, context-relevant engagement. By assessing multidimensional outcomes—including knowledge, attitudes, practices, psychosocial well-being, symptom burden, and functional status—it provides a holistic picture of intervention impact and unique insights for designing integrated, multimodal cachexia management strategies in low-resource settings.

Limitations

Key limitations include the single-center design, which may limit generalizability beyond similar LMIC oncology settings, and the high attrition rate reflecting advanced disease and reducing post-intervention sample size. The relatively short follow-up period restricted assessment of long-term knowledge retention and sustained behavioral change. Self-reported measures may have introduced potential recall and social desirability bias.

Conclusion

This study highlights the potentially broad and positive impact of targeted low-cost scalable educational interventions including SMS and in-person sessions, in improving patient knowledge, emotional coping, and self-care practices related to cancer cachexia in a low-resource setting. Despite these gains, persistent functional decline and overall quality of life burden due to the progressive physical deterioration, and the emotional weight of increased illness awareness limited the overall benefit.

This emphasizes the pressing need for early detection and management of cancer cachexia and to move beyond standalone interventions towards a multimodal interdisciplinary framework that includes nutritional, medical, physical rehabilitation, and psychosocial support for sustainable improvements. Practical and institutional implications include the routine integration of nutritional screening, structured patient education, and ongoing psychosocial support into oncology services, with dedicated structural and administrative backing to ensure sustainability.

Albeit these challenges, the intervention's success underscores the feasibility and impact of embedding patient-centered, low-cost strategies into routine oncology care in LMIC context. Further research should focus on controlled studies, long-term follow-up and evaluation of sustained patient-centered outcomes to strengthen the evidence base and inform policy and practice in similar resource-limited settings.

Data Sharing Statement

The data that support the findings of this study are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request.

Ethical Approval

The study adhered to ethical principles in the Declaration of Helsinki. Approval was secured from Uganda Cancer Institute-Research and Ethics Committee (UCI-2022-69) and Uganda National Council for Science and Technology (HS3194ES).

Consent to Participate and Confidentiality

Written informed consent was obtained from all participants and for participants who were not able to read or write the consent process was conducted in Luganda (the local language) and informed consent was obtained from the appropriate representative. Participation was voluntary with their right to withdraw at any stage. To protect participant confidentiality, unique codes were used in place of names, and all collected data were handled with strict confidentiality.

Acknowledgment

We would like to thank the patients who participated in this study and shared their valuable time and insights. We also appreciate the support of the research team for facilitating data collection and providing a conducive environment for this work. Finally, we acknowledge the funder and institutional support that made this research possible.

Author Contributions

Darshit Dave: conceptualized and designed the study, supervised data collection, performed data analysis and interpretation, drafted and revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Angucia Bridget: contributed to study design, performed data management, data analysis and interpretation, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Caroline Komukama: contributed to study design, coordinated the study, supervised data collection, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Andrew Kahwa: contributed to data collection, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Sanjanaa Srikant: conceptualized and designed the study, assisted in data analysis, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Alice Pakileto: contributed to data collection, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Ezra Anecho: contributed to study design, managed the project, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Nixon Niyonzima: contributed to study design, supervised the project, revised the manuscript, approved the final version, and is accountable for all aspects of the work.

Funding

This research was supported by Pfizer Inc. USA. The funder had no role in the study design, data collection, analysis, interpretation, or manuscript writing.

Disclosure

The authors have no competing interests.

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