Received: 8 January 2025 | Revised: 21 January 2026 | Accepted: 5 February 2026

DOI: 10.1002/ijc.70390

RESEARCH ARTICLE

Cancer Epidemiology

IJC INTERNATIONAL JOURNAL of CANCER | UICC

Patient- and caregiver-reported barriers to radiotherapy for cancer in sub-Saharan Africa—A survey of population-based registries

Eric Sven Kroeber[1] | Tamara König[1] | Ole Stöter[1] | Biying Liu[2] | Phoebe Mary Amulen[3] | Margaret Borok[4] | Gladys Chesumbai[5] | Eric Chokunonga[4] | Ima-Obong Ekanem[6] | Mahine Ivanga[7] | Bakarou Kamaté[8] | William Muller[9] | Abidemi Omonisi[10] | Jean-Félix Peko[11] | Mathewos Assefa[12] | Furaha Serventi[13] | Markus Wallwiener[14] | Mazvita Muchengeti[15] | Pablo Sandro Carvalho Santos[1] | Donald Maxwell Parkin[2,16,17] | Eva Johanna Kantelhardt[1,16] | Nikolaus Christian Simon Mezger[1]

[1]Global and Planetary Health Working Group, Center of Health Sciences, Medical Faculty of the Martin Luther University Halle-Wittenberg, Halle (Saale), Germany

[2]The African Cancer Registry Network, INCTR African Registry Programme, Oxford, UK

[3]Kampala Cancer Registry, Kampala Cancer Registry, Department of Pathology—College of Health Sciences, Makerere University, Kampala, Uganda

[4]Zimbabwe National Cancer Registry, College of Health Sciences, University of Zimbabwe, Harare, Zimbabwe

[5]Eldoret Cancer Registry, Moi Teaching and Referral Hospital, Eldoret, Kenya

[6]Department of Pathology, Calabar Cancer Registry, University of Calabar Teaching Hospital, Calabar, Nigeria

[7]Institut de Cancérologie de Libreville, Registre du Cancer du Gabon, Libreville, Gabon

[8]Bamako Cancer Registry, L'Hôpital National du Point G, Bamako, Mali

[9]Mbeya Cancer Registry, Mbeya Referral Hospital, Mbeya, Tanzania

[10]Ekiti Cancer Registry, Department of Medicine, Ekiti State University Teaching Hospital, Ado-Ekiti, Nigeria

[11]Brazzaville Cancer Registry, Service de Carcinologie et Radiotherapie, Centre Hospitalier Universitaire de Brazzaville, Brazzaville, Republic of the Congo

[12]Addis Ababa City Cancer Registry, Radiotherapy Center, Tikur Anbessa Hospital, Addis Ababa University, Ethiopia

[13]Moshi Cancer Registry, Kilimanjaro Christian Medical Centre, Cancer Care Centre, Moshi, Tanzania

[14]Department of Gynaecology, Martin Luther University Halle-Wittenberg, Halle, Germany

[15]National Cancer Registry, National Health Laboratory Service, Johannesburg, South Africa

[16]Nuffield Department of Population Health, University of Oxford, Oxford, UK

[17]Surveillance Unit, International Agency for Research on Cancer, Lyon, France

Correspondence
Eric Sven Kroeber, Global and Planetary Health Working Group, Medical Faculty of the Martin Luther University Halle-Wittenberg, Magdeburger Str. 8, 06112 Halle (Saale),

Abstract

Although radiotherapy is an essential part of comprehensive cancer care, access is heavily limited in most sub-Saharan African (SSA) countries. Patients' barriers to care

Abbreviations: AFCRN, African Cancer Registry Network; CI, confidence interval; HDI, human development index; ICD, International Statistical Classification of Diseases and Related Health Problems; LMIC, low- and middle-income countries; OR, odds ratio; SSA, sub-Saharan Africa.

Eva Johanna Kantelhardt and Nikolaus Christian Simon Mezger contributed equally to the work.

Germany.
Email: eric.kroeber@uk-halle.de

Funding information
German Federal Ministry of Education and Research, Grant/Award Number: 01KA2220B; Else Kroener-Fresenius-Foundation, Grant/Award Number: 2018_HA31SP; Science for Africa Foundation, Grant/Award Number: Del-22-008

can be grouped as availability, accessibility, accommodation, affordability, and acceptability. We aimed to assess cancer patient- and caregiver-reported barriers in nine SSAn countries (Republic of the Congo, Ethiopia, Gabon, Kenya, Mali, Nigeria, Tanzania, Uganda, and Zimbabwe). We conducted a telephone-based survey among 553 randomly selected patients with breast, cervical, colorectal, and prostate cancer, Kaposi sarcoma and non-Hodgkin lymphoma diagnosed between 2018 and 2019 registered in population-based registries of the African Cancer Registry Network. We inquired about receipt of radiotherapy and barriers irrespective of recalling a recommendation. Among all categories, 21.6% (*Use of alternative medicine*) to 39.6% (*Cost of treatment*) of patients reported severe barriers. Most common was problematic *Cost of treatment* (69.0% overall). A high share of patients from Congo, Kenya, Nigeria, and Tanzania reported barriers. Higher education and wealth were associated with reduced problems in all categories except increased problems with *Fear* and *Use of alternative medicine*. Receipt of radiotherapy was associated with fewer problems with *Availability of transport* (odds ratio [OR]: 0.34; 95% confidence interval [CI], 0.13–0.88) and *Trust in healthcare workers* (OR: 0.44; 95% CI, 0.24–0.8), and increased *Fear* (OR: 2.33; 95% CI, 1.33–4.05). Seeing that one-third of the patients reported severe problems in all dimensions, shortage of radiotherapy units is not the only problematic aspect of access to radiotherapy. Improvements in affordability, patient–healthcare worker communication, and psychosocial support are needed.

KEYWORDS
access to health care, cancer care, radiotherapy, sub-Saharan Africa

What's New?

Low- and middle-income countries have over 70% of the global cancer burden but 10% of the world's radiotherapy capacities. This population-based multi-country study explores the barriers to access experienced by cancer patients in sub-Saharan Africa. Cost of treatment and knowledge/awareness were the most frequently reported barriers. Higher education/wealth was associated with reduced barriers, except for fear and use of alternative medicine. Radiotherapy recipients reported fewer issues with transport availability and trust in healthcare workers but increased fears. Beyond the shortage of radiotherapy units, the findings highlight the need for patient-centered improvements in affordability, patient–healthcare worker communication, and psychosocial support.

1 | INTRODUCTION

Cancer is the second leading cause of mortality globally.[1] Projections for sub-Saharan Africa (SSA) show a doubling from about half to 1 million yearly deaths by 2030.[2] Improving cancer care is central to achieving the United Nations 2030 Sustainable Development Goal 3.4 of reducing the burden of non-communicable diseases.[3] Radiotherapy is an essential part of comprehensive cancer care.[4] Low- and middle-income countries (LMIC) have 10% of the world's radiotherapy capacities despite having over 70% of the global cancer burden. In 2020, about half the African countries had at least one radiotherapy facility, with most countries lagging far behind the calculated needed radiotherapy units[5] often worsened by low utilization rates,[6] poor quality control, safety, maintenance, and a lack of trained personnel.[7] There are typically fewer than five (and often zero) nuclear medicine specialists per million inhabitants in SSA countries.[8] Key fields of action to improve radiotherapeutic care include cancer control plans, human resources, sustainable financing, alignment with universal health coverage, and patient access.[9,10]

Pechansky and Thomas structure patients' access to healthcare in the five domains availability, affordability, accessibility, accommodation, and acceptability.[11] Availability includes the availability of facilities, equipment, and qualified providers.[12,13] Accessibility depends on the distance to a healthcare facility, existing transportation infrastructure and costs and is made more difficult by rural residency.[10,12] Affordability comprises the costs of medical treatment, as well as secondary costs resulting from being absent from home (e.g., lost wages and childcare) that are aggravated by common out-of-pocket

payments and insufficient insurance systems.[14] Accommodation encompasses systemic factors including referral systems and waiting times, as well as individual factors like the availability of a caregiver.[10] Acceptability comprises a preference for alternative and traditional medicine, fear of treatment and stigma, knowledge and awareness of the cancer and healthcare options including existing patient information and education, as well as trust in healthcare workers.[14,15]

According to our research, the existing literature gives insight into cancer care barriers in general, specific entities and settings, and to broader LMIC contexts. The aim of this study is to assess patient- and caregiver-reported barriers to radiotherapy for common cancer entities in SSA. Population-based cancer registries are a feasible study framework as they systematically collect cancer data in defined populations.

2 | MATERIALS AND METHODS

2.1 | Study design, population, and data source

We conducted a cross-sectional survey of population-based cancer registries of the African Cancer Registry Network (AFCRN) in nine SSA countries (Brazzaville, Republic of the Congo; Libreville, Gabon; Addis Ababa, Ethiopia; Eldoret, Kenya; Kilimanjaro and Moshi, Tanzania; Kampala, Uganda; Harare, Zimbabwe; Bamako, Mali; Calabar and Ekiti, Nigeria). Each registry covers a city population, except Zimbabwe's and Gabon's, which contain national data. Patients were residents of the respective registry's catchment areas. We gathered data for adult patients with cancers of female breast (International Statistical Classification of Diseases and Related Health Problems [ICD]-10[16]: C50), cervix (C53), colorectum (C18-20), prostate (C61), Kaposi sarcoma (C46), or non-Hodgkin lymphoma (C82-85, C96), diagnosed in 2018 and 2019. Of 5951 patients registered in the study period we randomly drew a feasibility sample of 60 samples per registry (10 per cancer entity, planned sample size $n = 660$). The AFCRN office who has access to the databases of all cancer registries randomly selected patient and created a list of patients to contact for each registry. In total, 968 were contacted, of which 321 were not reached by phone and 11 refused to participate. We excluded patients with a wrong cancer entity ($n = 2$), metastatic status at the time of diagnosis ($n = 1$), and incomplete data in the questionnaire ($n = 57$), yielding 553 patients included for data analysis and a response rate of 57.1%. Some cancer entities had low incidence in several registries, leading to a reduced sample size (Supporting Information S1: Supplements A and B).

Radiotherapy machines were existent in all countries except for the Republic of the Congo. Gabon was the only country in which the calculated demand of megavoltage units was matching the number of megavoltage units in the country (1.13/1000 cancer cases),[5] even though other literature suggests a higher demand (2.5/1000 cancer cases).[17] In all other countries, the available machines were well below the demand (Supporting Information S1: Supplement B).[5]

2.2 | Data collection

The data collection was conducted between January 2021 and June 2022 during the COVID-19 pandemic by cancer registry staff members of the local (AFCRN) registries. The AFCRN coordinates population-based cancer registries in SSA to guarantee comparable cancer registration standards, facilitate capacity building, and provide cancer patient data for policy makers. Administration and data collector training was organized online in collaboration with the AFCRN office. All data collectors had a previous training on cancer registration as part of their position in the cancer registry, which included training on telephone-based follow-up and were familiar with contacting patients or caregivers. Basic data were retrieved from the registries' CANREG software (by the International Agency for Research on Cancer), including date of diagnosis, last contact, the basis of diagnosis, tumor topography and morphology, age, and contact telephone number. Then, patients were interviewed via telephone after receiving oral consent documented on the paper-based questionnaire. In cases when the patient was not available (e.g., due to being deceased), we included their caregivers, usually close relatives, to respond to the questionnaire on behalf of the patient. In cases of unreachability or refusal to participate, a new patient with the same entity was randomly picked. The data was entered into EpiData Software and exported as a Microsoft Excel sheet.

2.3 | Questionnaire design

The questionnaire was iteratively developed based on a literature review identifying barriers to access of cancer care in SSA by an interdisciplinary team. The tool was initially prepared in English. The translation to French was done by bilingual native speakers followed by a back-translation by a third person who has not been involved in the previous process to ensure consistency. Adaptations were made upon discussion. By providing the questionnaire in English and French, we ensured that the instrument was accessible in the two most common official languages. Data collectors were trained to use local languages only when necessary. In cases where interviewers had to translate, their familiarity with both medical terminology and local languages helped maintain accuracy. We piloted the survey among 20 patients in Zimbabwe leading to minor adaptations.

The main target variable was patient-reported access to radiotherapy with three answering options ("not recommended, not received," "recommended, not received," and "recommended, received"). Due to the ongoing coronavirus disease 2019 (COVID-19) pandemic, we were not able to access patient files and get deeper insight into the treatment procedures and verify recommendation and radiotherapy receipt status. We conducted a sensitivity analysis stratifying the cohort according to the radiotherapy status. Secondary targets were patient-reported barriers to radiotherapy based on the concept of specific dimensions of patient access to healthcare irrespective of their recall of a recommendation. Eleven items were asked on a three-step Likert scale corresponding to not problematic,

TABLE 1 Access to care dimensions.

Dimension of the barrier	Definition	Items (not/intermediately/severely problematic)
Availability	The presence of a health facility offering radiotherapeutic treatment.	• *Availability of a radiotherapy facility*
Accessibility	Patients' prospects to reach the geographical location of the health facility offering radiotherapy including the availability of resources (e.g., financial means and time to use public transport).	• *Availability of transport* • *Cost of transport*
Affordability	The financial abilities of a patient to afford treatment and associated costs (e.g., hospitalization, absence from home and work, childcare, etc.).	• *Cost of treatment* • *Cost of absence from home*
Accommodation	The extent health providers and their services are organized to fulfill the needs, preferences, and constraints of the patient.	• *Leaving home for treatment* • *Waiting time*
Acceptability	The patient's views and beliefs concerning health personnel and facilities as well as attitudes of the health personnel toward the patient.	• *Fear* • *Knowledge/awareness* • *Use of alternative medicine* • *Trust in healthcare workers*

Note: According to Pechansky et al.[10] (for further information, see Supporting Information S1: Supplement E).

intermediately problematic and very problematic[11] (Table 1, Supporting Information S1: Supplement H).

2.4 | Statistical analysis

All statistical analyses were conducted using Statsmodels 0.14.4 in Python.[18] Multivariate ordinal regressions (logit distribution) were fitted to each of the 11 factors of the five dimensions of access to care, having age, sex, country's human development index[19] (HDI), responding person in the interview, cancer entity and a combined score for problems with "education & wealth" as explanatory variables. Due to collinearity, variables "education level" and "perceived wealth" were merged, all other explanatory variables were deemed independent from each other ($r^2 < 0.4$). Survival status was excluded as an explanatory variable due to collinearity with responding person in the interview. A logistic regression was computed for a subset of patients who recalled a radiotherapy recommendation ($n = 172$). Imputation (using the median value) was performed for "education level" of two patients (0.3% of samples), based on their sex and age. The results of the logistic regression were depicted using forest plots drawn with the zEpid library for Python.[20]

3 | RESULTS

Of a total of 553 patients, 59.9% were female. The mean age was 54.6 years (range 20–102). We included 118 cervical cancer (21.3%), 116 breast cancer (21.0%), 89 colorectal cancer (16.1%), 108 prostate cancer (19.5%), 49 Kaposi's sarcoma (8.9%), and 73 non-Hodgkin lymphoma (13.2%) patients. Almost half (46.3%) reported being poor or very poor. Regarding education, 11.8% were illiterate while 31.9% had higher education. Of the responders, 313 were family members/caregivers (56.6%) and 241 were patients (43.4%). One fifth (19.2%, $n = 106$) received radiotherapy and 67.3% ($n = 372$) did not recall a recommendation (Table 2).

3.1 | Overall access to radiotherapy

Patients reported severe problems among all categories: least in *Use of alternative medicine* (21.6%) and most among *Cost of treatment* (38.7%). The most mentioned barriers (intermediate + severe) were problems with *Cost of treatment* (69.0%) and *Knowledge/Awareness* (62.7%) (Figure 1, details in Supporting Information S1: Supplements C and D).

3.2 | Factors influencing dimensions of access to radiotherapy

Lower education & wealth were associated with increased problems in 9 out of 11 barriers and lower country HDI in 8. Being male was associated with increased problems in *Availability of a radiotherapy facility*, *Cost of transport*, and *Availability of transport*. Cancer entities did not show strong associations with problems reported except for Kaposi sarcoma (*Affordability*) and cervical and prostate cancer (*Fear*; Table 3). Caregiver responses led to increased report of Fear (odds ratio [OR]: 1.60; 95% confidence interval [CI], 1.13–2.28), and reduced Trust in healthcare workers (OR: 0.70; 95% CI, 0.49–0.99). In a sensitivity analysis among participants who were recommended radiotherapy ($n = 179$), associations with education and wealth largely persisted, whereas associations with HDI were less consistent and attenuated in sensitivity analyses (Supporting Information S1: Supplements F and G).

3.3 | Barriers according to radiotherapy recommendation and receipt

Among patients who recalled a recommendation ($n = 181$), 58.6 percent received radiotherapy ($n = 106$; Table 4). Half (47.2%) of those who did not have a radiotherapy recommendation reported the *Availability of a radiotherapy facility* to be severely problematic

TABLE 2 Patient characteristics.

		Type of cancer													
		Breast		Cervix		Colorectum		Prostate		Kaposi		NHL		Total	
		n	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%	*n*	%
Total		116		118		89		108		49		73		553	
Sex	Female	116	100.0	118	100.0	42	47.2	0	0.0	19	38.8	36	49.3	331	59.9
	Male	0	0.0	0	0.0	47	52.8	108	100.0	30	61.2	37	50.7	222	40.1
Age	<26	1	0.9	0	0.0	1	1.1	0	0.0	5	10.2	7	9.6	14	2.5
	26–35	15	12.9	9	7.6	11	12.4	0	0.0	9	18.4	9	12.3	53	9.6
	36–45	32	27.6	25	21.2	16	18.0	0	0.0	10	20.4	18	24.7	101	18.3
	46–55	33	28.4	39	33.1	21	23.6	3	2.8	14	28.6	17	23.3	127	23.0
	56–65	17	14.7	28	23.7	21	23.6	29	26.9	4	8.2	9	12.3	108	19.5
	66–75	13	11.2	15	12.7	14	15.7	45	41.7	5	10.2	8	11.0	100	18.1
	75+	5	4.3	2	1.7	5	5.6	31	28.7	2	4.1	5	6.8	50	9.0
Socioeconomic self-assessment	Very poor	12	10.3	16	13.6	9	10.1	13	12.0	6	12.2	9	12.3	65	11.8
	Poor	50	43.1	47	39.8	24	27.0	30	27.8	18	36.7	22	30.1	191	34.5
	Middle class	45	38.8	46	39.0	47	52.8	52	48.1	24	49.0	28	38.4	242	43.8
	Rich	2	1.7	0	0.0	3	3.4	7	6.5	1	2.0	2	2.7	15	2.7
	Patient could not tell/NA	7	6.0	9	7.6	6	6.7	6	5.6	0	0.0	12	16.4	40	7.2
Education	Cannot read and write	14	12.1	25	21.2	5	5.6	13	12.0	3	6.1	8	11.0	68	12.3
	Can read and write	14	12.1	15	12.7	16	18.0	19	17.6	2	4.1	13	17.8	79	14.3
	Elementary—Grade 1th–8th	21	18.1	27	22.9	16	18.0	20	18.5	15	30.6	20	27.4	119	21.5
	Secondary—Grade 9th–12th	26	22.4	23	19.5	14	15.7	14	13.0	16	32.7	18	24.7	111	20.1
	Diploma—college	24	20.7	13	11.0	22	24.7	24	22.2	10	20.4	7	9.6	100	18.1
	Bachelor's degree	14	12.1	12	10.2	11	12.4	13	12.0	2	4.1	6	8.2	58	10.5
	Master's degree	3	2.6	3	2.5	5	5.6	5	4.6	1	2.0	1	1.4	18	3.3
Country	Congo	11	9.5	11	9.3	13	14.6	10	9.3	0	0.0	12	16.4	57	10.3
	Ethiopia	10	8.6	10	8.5	10	11.2	10	9.3	0	0.0	9	12.3	49	8.9
	Gabon	12	10.3	11	9.3	13	14.6	10	9.3	9	18.4	9	12.3	64	11.6
	Kenya	8	6.9	10	8.5	5	5.6	13	12.0	8	16.3	7	9.6	51	9.2
	Mali	11	9.5	10	8.5	9	10.1	10	9.3	0	0.0	10	13.7	50	9.0
	Nigeria	25	21.6	24	20.3	14	15.7	19	17.6	0	0.0	0	0.0	82	14.8
	Tanzania	19	16.4	22	18.6	15	16.9	16	14.8	10	20.4	16	21.9	98	17.7
	Uganda	10	8.6	10	8.5	10	11.2	10	9.3	10	20.4	10	13.7	60	10.8
	Zimbabwe	10	8.6	10	8.5	0	0.0	10	9.3	12	24.5	0	0.0	42	7.6
Radiotherapy	Not recommended	55	47.4	53	44.9	74	83.1	77	71.3	47	95.9	66	90.4	372	67.3
	Recommended but not received	30	25.9	24	20.3	4	4.5	13	12.0	2	4.1	2	2.7	75	13.6
	Received	31	26.7	41	34.7	11	12.4	18	16.7	0	0.0	5	6.8	106	19.2

Abbreviations: Kaposi, Kaposi sarcoma; NA, not answered; NHL, non-Hodgkin lymphoma.

(recommended but not received: 31.5%; received: 14.2%). Patients who were recommended for radiotherapy reported fewer severe problems irrespective of radiotherapy receipt (except *Fear*). Patients who received radiotherapy commonly reported *Fear* as a problem (severe: 50.0%, intermediate: 28.3%). For those who were recommended but did not receive radiotherapy, *Cost of treatment* was the most common problem (severe: 39.2%, intermediate: 43.2%).

Patient-reported receipt of radiotherapy was associated with fewer problems with *Availability of transport* (OR: 0.34; 95% CI, 0.13–0.88) and *Trust in healthcare workers* (OR: 0.44; 95% CI, 0.24–0.8), and increased *Fear* (OR: 2.33; 95% CI, 1.33–4.05) (Figure 2).

FIGURE 1 Patient-reported barriers to radiotherapy overall and per country. Barriers to radiotherapy care dimensions across nine African population-based cancer registries according to Pechansky et al.,[11] reported as being either not problematic (green), intermediate (yellow), or severely problematic (red), $n = 553$; (A) all countries, (B) Republic of the Congo, (C) Ethiopia, (D) Gabon, (E) Kenya, (F) Mali, (G) Nigeria, (H) Tanzania, (I) Uganda, (J) Zimbabwe. RT, radiotherapy.

4 | DISCUSSION

We present, to our knowledge, the first population-based multi-country data on patient-reported barriers to radiotherapy in SSA. *Cost of treatment* and *Availability of a radiotherapy facility* were most frequently reported as severely problematic. Higher education & wealth and country HDI were associated with reporting fewer barriers. Patients reporting more problems with *Availability of transport* and

TABLE 3 Associations with barrier report.

Variable		Availability		Accessibility				Affordability			
		Availability of RT facility		Cost of transport		Availability of transport		Cost of treatment		Cost of absence from home	
		OR	(95%-CI)	OR	95%-CI	OR	95%-CI	OR	95%-CI	OR	95%-CI
Education and wealth, $n = 551$	Higher score (0–6)	**0.70**	(0.59, 0.82)	**0.59**	(0.5, 0.7)	**0.67**	(0.57, 0.79)	**0.65**	(0.55, 0.76)	**0.66**	(0.56, 0.78)
HDI, $n = 551$	Higher HDI (steps of 0.1)	**0.75**	(0.59, 0.96)	**0.69**	(0.54, 0.88)	**0.67**	(0.52, 0.85)	**0.73**	(0.58, 0.91)	**0.79**	(0.62, 0.99)
Responding person (self,[a] $n = 241$), $n = 551$	Other, $n = 310$	1.05	(0.73, 1.5)	1.00	(0.71, 1.42)	0.91	(0.64, 1.3)	0.99	(0.7, 1.4)	0.85	(0.6, 1.2)
Sex (female,[a] $n = 330$), $n = 551$	Male, $n = 221$	**2.57**	(1.48, 4.45)	**1.72**	(1.01, 2.94)	**1.92**	(1.12, 3.31)	**1.81**	(1.07, 3.05)	1.54	(0.91, 2.6)
Age, $n = 551$	Higher age	1.00	(0.99, 1.01)	0.99	(0.98, 1.01)	1.00	(0.99, 1.01)	0.99	(0.98, 1.01)	0.99	(0.98, 1.01)
Entity (NHL,[a] $n = 73$), $n = 551$	Breast, $n = 115$	0.77	(0.4, 1.48)	0.97	(0.52, 1.8)	1.00	(0.52, 1.92)	1.67	(0.89, 3.14)	0.72	(0.38, 1.35)
	Cervix, $n = 118$	0.87	(0.46, 1.66)	0.76	(0.41, 1.41)	1.00	(0.53, 1.89)	1.40	(0.75, 2.61)	0.86	(0.46, 1.6)
	Colorectum, $n = 89$	0.71	(0.38, 1.33)	0.78	(0.42, 1.43)	1.06	(0.57, 1.98)	1.09	(0.6, 1.98)	0.90	(0.49, 1.63)
	Prostate, $n = 107$	0.58	(0.29, 1.17)	0.82	(0.41, 1.62)	1.00	(0.50, 2.0)	0.97	(0.49. 1.92)	0.78	(0.39, 1.55)
	Kaposi, $n = 49$	1.34	(0.63, 2.86)	1.81	(0.87, 3.77)	2.09	(1.0, 4.35)	2.03	(0.99, 4.19)	**2.34**	(1.14, 4.83)

Variable		Accommodation				Acceptability							
		Leaving home for treatment		Waiting time		Use of alternative medicine		Fear		Knowledge/ awareness		Trust in healthcare workers	
		OR	95%-CI	OR	95%-CI	OR	95%-CI	OR	95%-CI	OR	95%-CI	OR	95%-CI
Education and wealth, $n = 551$	Higher score (0–6)	**0.72**	(0.61, 0.84)	**0.79**	(0.67, 0.92)	**0.80**	(0.66, 0.97)	1.13	(0.97, 1.31)	0.88	(0.76, 1.02)	**0.85**	(0.73, 0.99)
HDI, $n = 551$	Higher HDI (steps of 0.1)	**0.54**	(0.43, 0.69)	**0.49**	(0.39, 0.63)	**2.25**	(1.73, 2.94)	**2.15**	(1.68, 2.74)	**0.70**	(0.56, 0.88)	0.93	(0.74, 1.17)
Responding person (self,[a] $n = 241$), $n = 551$	Other, $n = 310$	0.89	(0.63, 1.26)	0.92	(0.65, 1.3)	1.02	(0.68, 1.54)	**1.60**	(1.13, 2.28)	1.05	(0.75, 1.48)	**0.70**	(0.49, 0.99)
Sex (female,[a] $n = 330$), $n = 551$	Male, $n = 221$	1.48	(0.87, 2.52)	1.39	(0.82, 2.35)	0.91	(0.49, 1.67)	0.69	(0.41, 1.16)	1.40	(0.84, 2.33)	1.60	(0.95, 2.71)
Age, $n = 551$	Higher age	1.00	(0.99, 1.02)	1.00	(0.99, 1.01)	1.00	(0.99, 1.02)	0.98	(0.97, 0.99)	1.00	(0.99, 1.01)	1.01	(1.0, 1.02)
Entity (NHL,[a] $n = 73$), $n = 551$	Breast, $n = 115$	0.82	(0.43, 1.58)	0.87	(0.46, 1.64)	0.56	(0.27, 1.17)	1.63	(0.85, 3.13)	0.97	(0.53, 1.8)	1.28	(0.67, 2.45)
	Cervix, $n = 118$	0.75	(0.40, 1.42)	0.74	(0.40, 1.37)	1.52	(0.76, 3.06)	**2.18**	(1.14, 4.14)	0.72	(0.39, 1.31)	0.97	(0.51, 1.85)
	Colorectum, $n = 89$	0.98	(0.53, 1.82)	0.86	(0.47, 1.58)	0.86	(0.43, 1.7)	1.09	(0.59, 2.0)	0.76	(0.42, 1.37)	1.16	(0.63, 2.12)
	Prostate, $n = 107$	0.71	(0.35, 1.42)	1.10	(0.55, 2.19)	0.89	(0.41, 1.91)	**2.12**	(1.06, 4.27)	0.91	(0.47, 1.78)	0.83	(0.42, 1.64)
	Kaposi, $n = 49$	1.62	(0.79, 3.32)	**2.09**	(1.02, 4.26)	**0.33**	(0.13, 0.82)	0.82	(0.4, 1.68)	1.76	(0.89, 3.49)	**2.82**	(1.39, 5.73)

Note: Multivariable ordinal regression reporting odds ratios (adjusted for all items mentioned) for factors influencing barriers to care. Odds ratios >1 indicate increased probability of increased problem report. Bold values indicate odds ratios with 95% confidence intervals excluding 1.

Abbreviations: CI, confidence interval; HDI, human development index of the country; NHL, non-Hodgkin lymphoma; OR, odds ratio; RT, radiotherapy.

[a]Reference category.

TABLE 4 Access-report according to radiotherapy receipt.

			Total ($n = 553$) *n* (%)	Not recommended ($n = 372$; 67.2%) *n* (%)	Recommended but not received ($n = 75$; 13.6%) *n* (%)	Received ($n = 106$; 19.1%) *n* (%)	Not recommended	Recommended but not received	Received
Availability	Availability of a radiotherapy facility	Severe	213 (38.7%)	175 (47.2%)	23 (31.5%)	15 (14.2%)			
		Intermediate	83 (15.1%)	43 (11.6%)	12 (16.4%)	28 (26.4%)			
		Not problematic	254 (46.2%)	153 (41.2%)	38 (52.1%)	63 (59.4%)			
Accessibility	Cost of transport	Severe	182 (33.0%)	158 (42.6%)	19 (25.7%)	5 (4.7%)			
		Intermediate	149 (27.0%)	73 (19.7%)	36 (48.6%)	40 (37.7%)			
		Not problematic	220 (39.9%)	140 (37.7%)	19 (25.7%)	61 (57.5%)			
	Availability of transport	Severe	161 (29.2%)	145 (39.1%)	13 (17.6%)	3 (2.8%)			
		Intermediate	134 (24.3%)	67 (18.1%)	35 (47.3%)	32 (30.2%)			
		Not problematic	256 (46.5%)	159 (42.9%)	26 (35.1%)	71 (67.0%)			
Affordability	Cost of treatment	Severe	218 (39.6%)	166 (44.7%)	29 (39.2%)	23 (21.7%)			
		Intermediate	162 (29.4%)	89 (24.0%)	32 (43.2%)	41 (38.7%)			
		Not problematic	171 (31.0%)	116 (31.3%)	13 (17.6%)	42 (39.6%)			
	Cost of absence from home	Severe	172 (31.2%)	152 (41.0%)	10 (13.5%)	10 (9.4%)			
		Intermediate	133 (24.1%)	69 (18.6%)	36 (48.6%)	28 (26.4%)			
		Not problematic	246 (44.6%)	150 (40.4%)	28 (37.8%)	68 (64.2%)			
Accommodation	Leaving home for treatment	Severe	168 (30.5%)	142 (38.3%)	20 (27.0%)	6 (5.7%)			
		Intermediate	149 (27.0%)	84 (22.6%)	25 (33.8%)	40 (37.7%)			
		Not problematic	234 (42.5%)	145 (39.1%)	29 (39.2%)	60 (56.6%)			
	Waiting time	Severe	180 (32.7%)	159 (42.9%)	19 (25.7%)	2 (1.9%)			
		Intermediate	155 (28.1%)	75 (20.2%)	31 (419%)	49 (46.2%)			
		Not problematic	216 (39.2%)	137 (36.9%)	24 (32.4%)	55 (51.9%)			

TABLE 4 (Continued)

			Total ($n = 553$) *n* (%)	Not recommended ($n = 372$; 67.2%) *n* (%)	Recommended but not received ($n = 75$; 13.6%) *n* (%)	Received ($n = 106$; 19.1%) *n* (%)	Not recommended	Recommended but not received	Received
Acceptability	Use of alternative medicine	Severe	108 (21.6%)	76 (22.8%)	17 (25.0%)	15 (15.3%)			
		Intermediate	78 (15.6%)	46 (13.8%)	12 (17.6%)	20 (20.4%)			
		Not problematic	314 (62.8%)	212 (63.5%)	39 (57.4%)	63 (64.3%)			
	Fear	Severe	195 (35.4%)	117 (31.5%)	25 (33.8%)	53 (50.0%)			
		Intermediate	142 (25.8%)	86 (23.2%)	26 (35.1%)	30 (28.3%)			
		Not problematic	214 (38.8%)	168 (45.3%)	23 (31.1%)	23 (21.7%)			
	Knowledge/awareness	Severe	192 (34.9%)	149 (40.2%)	22 (30.1%)	21 (19.8%)			
		Intermediate	153 (27.8%)	100 (27.0%)	22 (30.1%)	31 (29.2%)			
		Not problematic	205 (37.3%)	122 (32.9%)	29 (39.7%)	54 (50.9%)			
	Trust in healthcare workers	Severe	170 (30.9%)	131 (35.3%)	22 (30.1%)	17 (16.0%)			
		Intermediate	108 (19.6%)	70 (18.9%)	18 (24.7%)	20 (18.9%)			
		Not problematic	272 (49.5%)	170 (45.8%)	33 (45.2%)	69 (65.1%)			

Note: The bars on the right represent the shares of (left to right) not recommended, recommended but not received, received; green, not problematic; yellow intermediate; red, severely problematic.

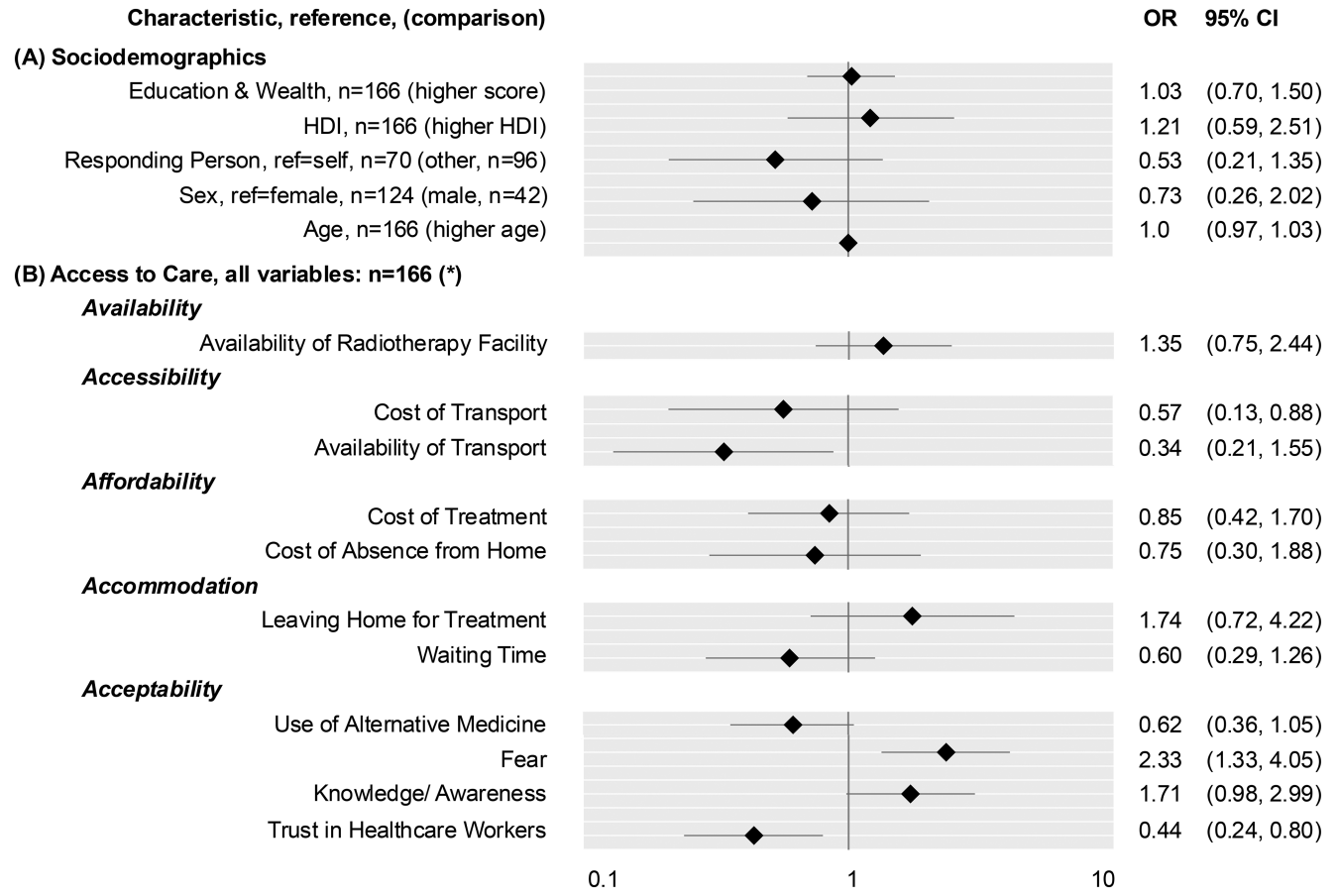

FIGURE 2 Associations with (self-reported) receipt of radiotherapy. Odds ratios >1 indicate an increased probability of receiving radiotherapy. Only patients for whom radiotherapy had been recommended ($n = 166$) were included in the analysis. *Increasingly problematic; CI, confidence interval; HDI, human development index; OR, odds ratio; (A) sociodemographic characteristics, (B) barriers to care variables according to the five access to care dimensions by Penchansky et al.

Trust in healthcare workers were associated with reduced radiotherapy receipt after a recommendation. Increased *Fear* was associated with therapy receipt.

4.1 | Availability

Availability of radiotherapy facilities is a problem in SSA.[5] In our cohort, Gabon was the only country matching the calculated demand, and most patients reported availability as unproblematic. In the Republic of the Congo, the only country without a radiotherapy facility, availability was severely problematic. Generally, we found large differences concerning self-reported problems with availability. For instance, Ethiopia (0.01 units/1000 cancer cases) and Uganda (0.03 units/1000 cancer cases)[5] both have comparably low megavoltage ratios. However, Ugandan patients from Kampala reported far fewer problems than Ethiopian patients from Addis Ababa. A reason could be a higher number of patients traveling to the capital city in Ethiopia compared to Uganda or organizational differences between both healthcare systems. Moreover, patient-reported problems with *Availability of radiotherapy facilities* can also exist if a radiotherapy unit exists in the city due to availability without usability caused by defunct machines, power outages, a lack of specialized personnel, and inadequate training capacities.[21] There is a need to improve radiotherapy availability, sustainable management of the facilities, and an exchange among LMIC stakeholders.

4.2 | Accessibility

Accessibility was also considerably problematic. Though most registries cover urban populations, more than half reported *Availability* and *Cost of transport* to be impeding. The highest share was in the Republic of the Congo where patients had to consider traveling out of the country to receive radiotherapy.[5] In Zimbabwe, half of the patients judged *Availability* and *Cost of transport* as very problematic, possibly due to the registry covering the entire country, leading to longer traveling distances.[22] Accessibility of radiotherapy is worse in rural settings with 57.5% of patients in SSA having to travel over 4 h to a radiotherapy facility.[23]

4.3 | Affordability

Though radiotherapy is regarded as a cost-effective treatment,[6] patient costs vary vastly and can create a disastrous financial burden, especially in the common out-of-pocket payment systems.[14] *Cost of treatment* was the most prevalent barrier among patients who were recommended for radiotherapy but did not receive it. Affordable payment and insurance systems that cover cancer treatment are highly important[24] and evidence-based, innovative strategies for cost reduction without reducing effectiveness such as hyperfractionation (e.g., prostate and breast cancers)[25] or artificial intelligence models[26] can be considered. The association between affordability and education and wealth highlights the need to support patients with lower financial resources. Given that local governments and the International Atomic Energy Agency facilitated considerable investments in the radiation infrastructure, treatment costs should mainly cover running and maintenance expenses and authorities should ensure that these prices remain affordable for patients.

4.4 | Accommodation

Long *Waiting times* for cancer treatment is a known problem in SSA that can lead to progression of the disease and decreased survival.[27] Reasons include lack of facilities, inadequate staffing,[12] initial non-acceptance of treatment, preference of alternative medicine,[28] defunct machines,[29] and lack of clear referral pathways.[12] The problem was especially great in Kenya, Nigeria, and Ethiopia and increased with lower HDI and lower education & wealth. An evidence-based system to support ethical triage balancing effective radiotherapy for early-stage cancer with palliative care is needed. The literature backs our finding concerning *Leaving home for treatment* by reporting burdening the family (children leaving home to act as caregivers), leaving family obligations (day-to-day care),[30] and lack of caregivers during hospital stays[31] showing the need for comprehensive patient support.

4.5 | Acceptability

Fear of cancer treatment, and especially radiotherapy, is commonly reported in SSA.[6,14,15] Increased *Fear* of radiotherapy and problems with *Trust in healthcare workers* were associated with having received radiotherapy, highlighting the importance of the acceptability of treatment. Psychosocial support can help cancer patients undergoing radiotherapeutic treatment[32] and patient education has been shown to reduce fear, for example, for vulnerable groups such as prostate and cervical cancer patients.[33] We found a considerable association of problems with *Knowledge & awareness* and *Use of alternative medicine* with non-receipt of radiotherapy. *Use of alternative medicine* in SSA is common and underreporting is usual.[34] Patients can have an ambiguous relationship with alternative treatments[35] and it has been shown to reduce treatment uptake.[15] Improving patient information, communication about alternative medicines and education of traditional healers seems advisable.

4.6 | Country differences and individual factors

A country's developmental position is associated with cancer survival, and the availability and efficiency of health services.[36] While overall, higher country HDI reduced problems reported in most dimensions, the results were inconclusive in the sensitivity analysis of patients who recalled a radiotherapy recommendation. On the individual level, our findings on the association of higher education and wealth with reduced barriers were stable in the sensitivity analysis, and congruent with the existing literature highlighting the importance of supporting individuals with lower socioeconomic resources.[37]

Males reported increased problems in all dimensions except for *Fear* and *Use of alternative medicine*. While we do not have a conclusive explanation, women generally report their own health status as worse than men, irrespective of world region or societal factors,[38] seek help earlier,[39] and are more attentive to health-related information.[40] It seems possible that information seeking is relevant, as males also reported *Knowledge & awareness* as more problematic. The alleviated problem report by male patients in cost-related items might be triggered by the men commonly occupying the role as a financial provider of the family in African societies.[41]

We found increased trust problems in male participants except for the subgroup of patients with a recommendation who did not receive radiotherapy in which women reported increased problems. Research suggests that men often exhibit lower overall trust in the healthcare system and are more likely to delay seeking care, potentially due to sociocultural norms around autonomy and self-reliance.[39] In contrast, women may be more sensitive to relational aspects of trust, such as perceived empathy and communication quality.[42]

4.7 | Factors associated with receipt of radiotherapy

Generally, a higher share of patients who did not recall a radiotherapy recommendation reported severe problems than those who recalled a recommendation. This might be explained with construal level theory[43] according to which a more abstract versus a more concrete interaction with a problem in question can lead to differences in perception. Another explanation could be existing stigmata and lack of information regarding radiotherapy.[15] Though further research would be necessary to clarify the dynamics of this highly diverse cohort, this phenomenon could be considered when planning care structures and awareness campaigns. Common reports of severely problematic *Availability of radiotherapy facilities* by patients without a recommendation could be due to a lack of information but might also reflect non-recommendation due to lacking capacities.

Meanwhile, *Fear* is a well-documented barrier to initiating radiotherapy, often linked to concerns about radiation toxicity and side

effects.[44] Interestingly, in our cohort, patients who reported more problems with *Fear* were more likely to have received treatment. Although the regression analysis builds on the premise that *Fear* is independent of undergoing treatment, we believe that the association can be explained by the experience of radiotherapy itself increasing *Fear* levels.

Fear and anxiety typically peak immediately before the start of radiotherapy and gradually decrease thereafter.[45] However, the initial treatment process, including unfamiliar procedures, physical isolation during sessions, and uncertainty about outcomes, can heighten psychological distress. Patients may also experience a loss of control or fear due to inadequate communication or emotional support.[46] In some settings, misconceptions and local terminology with negative connotations about radiotherapy may contribute further to fear. These may include beliefs that radiotherapy worsens cancer or that it involves being burned or shocked with electricity.[47] Some patients reported fear to be worse than the treatment and its side effects, and coping mechanisms include trying not to worry and seeking information.[48] Adequate healthcare worker sensitization, including tailored screening tools and psychosocial training, are necessary to help patients combat fear.[46]

The association of increased problems with *Trust in healthcare workers* and reduced treatment receipt might either be caused by patients with lower trust deliberately dismissing radiotherapy treatment or the non-receipt of the radiotherapy after a recommendation leading to a loss of trust. In either case, there is a clear need for improved patient–healthcare worker communication.

The association with *Availability of transport* demonstrates the importance of infrastructure to make care attainable especially since transportation barriers can lead to increased waiting times, advanced stages of cancer, and higher mortality rates.[49] While a feasible number of radiotherapeutic units is of utmost importance, healthcare planners and providers must take patients' perceptions into account to ensure adequate access.

4.8 | Strengths and limitations

Our study has several strengths and limitations. The questionnaire was developed by an interdisciplinary team using the existing literature. However, it is not a validated tool possibly yielding problems regarding reliability and validity. We were particularly interested in patients' perceptions; due to the nature of self-reported information, the information must be considered subjective and thus carefully interpreted. While our study focused on patients diagnosed before the COVID-19 pandemic, data were collected during the pandemic which may have introduced recall bias, potentially influencing the reports on barriers to radiotherapy which we tried to mitigate by training the data collectors to give the participants standardized instructions to recall the treatment process devoid of possible ongoing health care limitations.

The study design involved collecting data on chemotherapy, surgery, and radiotherapy access. Patients were included regardless of their radiotherapy treatment status, thus not all patients were recommended radiotherapy, meaning some study participants may have had limited direct experience. We decided to include all patients irrespective of recommendation for radiotherapy because we could not adequately assess whether the non-recommendation was based on medical guidelines or other factors, such as non-understanding, non-availability of radiotherapy capacities, or financial concerns of treating physicians. Moreover, the information on radiotherapy recommendation itself relied on patient reports, as we were unable to gain access to medical records to verify radiotherapy recommendation and treatment status due to the COVID-19 pandemic restrictions at the time of data collection. Additionally, patients who did not recall a recommendation of radiotherapy may still have had conversations about it and formed opinions that are relevant to their health care system perception and decision-making. By including all patients in the study, we aimed to explore general perceptions, knowledge gaps, and systemic factors that might influence treatment decisions. To see differences between those who recalled a radiotherapy recommendation and those who did not, we conducted a sensitivity analysis.

We decided against the use of an *unknown* or *uncertain* answering option as these can encourage respondents to dismiss questions and increase the proportion of substantive responses. Moreover, the option *not problematic* was available which was likely to be chosen if the person did not recall any problems.

The population-based approach improves representativeness in the study's defined areas. However, our cohort largely consisted of individuals from urban settings, who probably had better access than the general population.[5]

We tried to mitigate survivorship bias by including patients independently of survival status. This led to a relevant number of respondents being caregivers, which we adjusted for in the regression analysis. Interviewer bias could introduce cluster effects between countries. To mitigate, we frequently communicated with each registry and provided comprehensive data collection training.

4.9 | Conclusions

Our findings on self-reported access to radiotherapy in SSA contribute evidence on patient perspectives that are valuable for healthcare planners and providers. About one-third of cancer patients from SSA reported severe problems in all dimensions of access to radiotherapy. *Cost of treatment* and *fear* were common barriers, and socioeconomic factors played a central role. Infrastructural aspects of radiotherapy access, including availability of transport and affordability of radiotherapy, urgently need to be increased. The strong association of treatment acceptability with treatment receipt highlights the need for improved communication, health information, and psychosocial support programs.

AUTHOR CONTRIBUTIONS

Eric Sven Kroeber: Conceptualization; writing – original draft; methodology; visualization; formal analysis; validation; project administration; data curation. **Tamara König:** Conceptualization; writing – review and editing;

methodology; data curation; investigation; project administration. **Ole Stöter:** Conceptualization; investigation; writing – review and editing; methodology. **Biying Liu:** Supervision; writing – review and editing; project administration; software; resources; funding acquisition; conceptualization. **Phoebe Mary Amulen:** Resources; supervision; writing – review and editing; investigation; data curation. **Margaret Borok:** Investigation; writing – review and editing; data curation; supervision; resources. **Gladys Chesumbai:** Data curation; supervision; resources; writing – review and editing; investigation. **Eric Chokunonga:** Investigation; writing – review and editing; data curation; supervision; resources. **Ima-Obong Ekanem:** Investigation; writing – review and editing; data curation; supervision; resources. **Mahine Ivanga:** Investigation; writing – review and editing; data curation; supervision; resources. **Bakarou Kamaté:** Investigation; writing – review and editing; data curation; supervision; resources. **William Muller:** Investigation; writing – review and editing; data curation; supervision; resources. **Abidemi Omonisi:** Investigation; writing – review and editing; data curation; supervision; resources. **Jean-Félix Peko:** Investigation; writing – review and editing; data curation; supervision; resources. **Mathewos Assefa:** Investigation; writing – review and editing; data curation; supervision; resources. **Furaha Serventi:** Investigation; writing – review and editing; data curation; supervision; resources. **Markus Wallwiener:** Resources; supervision; writing – review and editing; funding acquisition. **Mazvita Muchengeti:** Supervision; writing – review and editing; methodology. **Pablo Sandro Carvalho Santos:** Conceptualization; data curation; software; formal analysis; visualization; writing – review and editing; methodology; validation. **Donald Maxwell Parkin:** Conceptualization; investigation; funding acquisition; writing – review and editing; methodology; supervision; resources. **Eva Johanna Kantelhardt:** Conceptualization; writing – review and editing; resources; supervision; data curation; methodology; funding acquisition. **Nikolaus Christian Simon Mezger:** Conceptualization; supervision; writing – review and editing; methodology; validation; project administration; investigation; data curation.

ACKNOWLEDGMENTS

We thank Charlotte Brown from Proof-Reading-Service.com Ltd. for her proofreading assistance. We acknowledge additional proofreading by Sherryl Sundell. Open Access funding enabled and organized by Projekt DEAL.

FUNDING INFORMATION

This work was supported by German Federal Ministry of Education and Research (01KA2220B; recipient: Eva Johanna Kantelhardt). Else Kroener-Fresenius-Foundation (2018_HA31SP; recipient: Eva Johanna Kantelhardt). Science for Africa Foundation under its Developing Excellence in Leadership, Training and Science in Africa (DELTAS Africa) program (Del-22-008; recipient: Eva Johanna Kantelhardt) with support from the Wellcome Trust and the UK Foreign, Commonwealth & Development Office and is part of the EDCPT2 program supported by the European Union.

CONFLICT OF INTEREST STATEMENT

There are no conflicts of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available upon reasonable request. Further information is available from the corresponding author upon request.

ETHICS STATEMENT

Ethical approval was obtained from the AFCRN research committee, the Martin Luther University Halle-Wittenberg Review Board (Reference 2020-192), and review boards responsible for each registry. Patient names were initially recorded from the registry databases for the interviews but not in the study database. Oral consent was obtained from the patient or caregiver before the telephone interview and documented on the paper-based questionnaire.

ORCID

Eric Sven Kroeber https://orcid.org/0000-0002-7201-6023
Biying Liu https://orcid.org/0000-0003-3438-683X
Mazvita Muchengeti https://orcid.org/0000-0002-1955-923X
Eva Johanna Kantelhardt https://orcid.org/0000-0001-7935-719X
Nikolaus Christian Simon Mezger https://orcid.org/0000-0002-5090-1080

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Kroeber ES, König T, Stöter O, et al. Patient- and caregiver-reported barriers to radiotherapy for cancer in sub-Saharan Africa—A survey of population-based registries. *Int J Cancer*. 2026;1-14. doi:10.1002/ijc.70390