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Colorectal cancer care in Uganda: a narrative review and case-based health needs assessment from Mbarara Regional Referral Hospital

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ABSTRACT

Colorectal cancer (CRC) is an important cause of cancer-related morbidity and mortality in both Sub-Saharan Africa (SSA) and Uganda. Despite national progress in cancer awareness and policy development, CRC care remains limited by resource constraints. CRC serves as an ideal lens for assessing health system resiliency, as it spans the care continuum. This review searched PubMed from inception through December 2025 for Uganda specific articles on CRC and analyzed 13 peer-reviewed articles to describe the current state of CRC care in Uganda, with insights from a health needs assessment (HNA) conducted at Mbarara Regional Referral Hospital (MRRH). Across Uganda, CRC diagnosis and treatment are hindered by insufficient endoscopic and pathology capacity, medication stockouts, and inconsistent access to immunohistochemistry and molecular testing. Screening programs remain underdeveloped due to inadequate resources for follow-up diagnostics. At MRRH, chemotherapy and surgery are available but constrained by equipment shortages, long wait times, and limited workforce despite rising patient volumes. Palliative care remains a strength, supported by national morphine availability and the efforts of Hospice Africa Uganda, though integration within oncology clinics remains incomplete. Improvement to CRC care will require expanding diagnostic infrastructure, digitizing health records, workforce development, and strengthening supply-chain management. Addressing chemotherapy and medication stockouts represents a tangible, near-term step toward improving quality of care. Experience from MRRH demonstrates both the challenges and opportunities to scaling cancer care in resource-limited settings and provides an illustrative example, albeit limited as a single-institution review, for addressing CRC systems across Uganda.

PAPER CONTEXT

Main findings: Colorectal cancer care in Uganda remains limited by inadequate diagnostic capacity, medication stockouts, and workforce shortages, although palliative care integration and national policy support represent key strengths.

Added knowledge: This narrative review synthesizes Uganda's colorectal cancer evidence through a health-systems lens, combining published literature from Uganda and an institutional health needs assessment to identify feasible, context-specific interventions.

Global health impact for policy and action: Expanding endoscopic and pathology capacity, digitizing health records, and strengthening supply-chain management are actionable strategies to improve equity and quality of cancer care in low-resource settings.

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Background

Colorectal cancer (CRC) is the third-most common cancer worldwide accounting for approximately 10% of cancer-related mortality. In 2022, GLOBOCAN recorded 1.9 million new cases of CRC and over 900,000 deaths [1]. Incidence and mortality vary significantly by geography: rates are stable or falling in many high-income countries (HICs), whereas limited

registry data suggest rates are rising with high mortality in low- and middle-income countries (LMICs). This disparity reflects differences in screening, earlier detection, and access to adjuvant therapies seen in HICs [2,3]. Lessons from HICs provide a template for LMICs, but direct replication is unrealistic. Instead, understanding system specific gaps is paramount to adapting proven strategies to the local context.

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Over the past two decades in Uganda, CRC has demonstrated a rising incidence as seen in several systematic reviews and meta-analyses largely collated from retrospective hospital-based studies [4–6]. Likely drivers include greater diagnostic awareness, longer life span, dietary changes, and improved access to diagnostics [5]. To date, there are few evaluations of Uganda’s cancer care delivery system, and even fewer as it relates to CRC. More recently, given limitations of the population-based cancer registries (PBCRs) in Uganda, creative studies using geographic estimates of cancer incidence have been published [7]. However, gaps in CRC-specific knowledge remain. This gap limits the ability of funders, implementors, and clinicians to target key weaknesses and design synergistic cancer programs. This review examines CRC in Uganda using the WHO pillars of cancer care (prevention, early detection, diagnosis/treatment, and palliative care), presents gaps using the WHO health-systems strengthening framework (Figure 1), and includes a case study from Mbarara Regional Referral Hospital (MRRH).

Methods

Study design and literature search strategy

We conducted a narrative review of published literature describing CRC epidemiology and care in Uganda, supplemented by an institutional HNA from Mbarara Regional Referral Hospital (MRRH). Evidence was organized along the CRC continuum (i.e. prevention, screening and early detection, diagnosis and staging, treatment, and palliative care) and interpreted using a health systems lens. A medical librarian supported development of a search strategy using the MeSH term ‘Colorectal Neoplasms’ combined with the term ‘Uganda’ using the Boolean

operator ‘AND’. We searched PubMed/MEDLINE from database inception through December 2025 and reviewed reference lists of included articles.

Eligibility criteria and study selection

We included peer-reviewed studies published in English that provided data from Uganda or directly described Ugandan policies, programs, or capacity relevant to CRC burden, prevention, screening, diagnosis/staging, treatment, or palliative care. Articles that did not provide insight into these subjects or were duplicates were excluded. One author conducted the search and reviewed all available titles for relevancy based on the inclusion criteria. Abstracts and papers were then reviewed by the author above and one additional author. Descriptions were synthesized based on their independent reviews. We reviewed select regional studies if they also included information pertaining to CRC in Uganda within our domains of interest. When Uganda-specific evidence was limited, we attempted to bring in information from transferable contexts, but only for our discussion and synthesis. Those papers were not included in our overall results.

Data extraction and synthesis

For each included source, we extracted year, setting, design, relevant CRC continuum domain(s), and key findings related to care delivery and system capacity. Findings were synthesized narratively by domain. We noted major limitations (e.g. single-center designs and incomplete staging or follow-up) when interpreting the evidence.

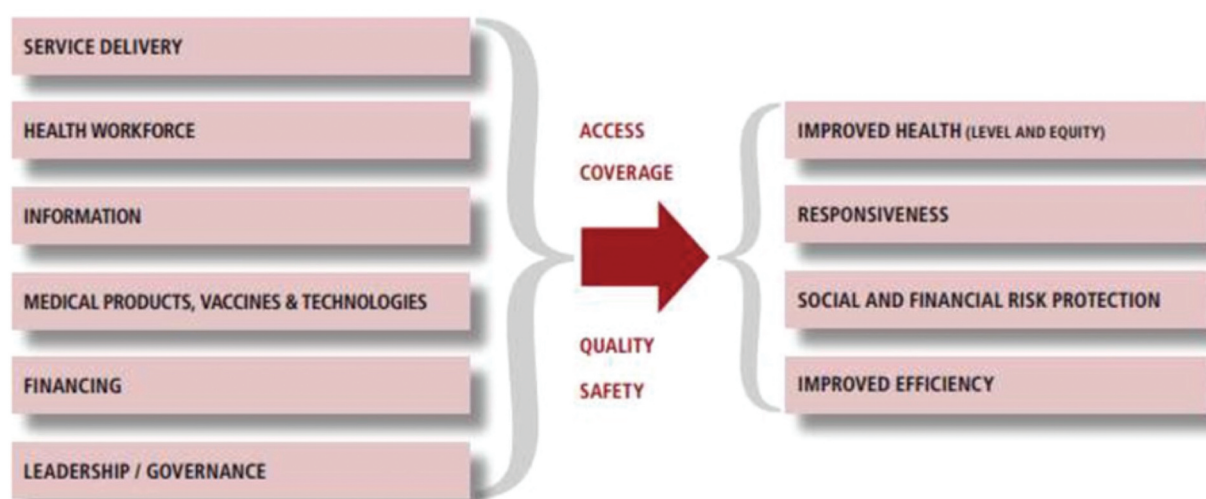


Figure 1. The WHO health systems framework (reproduced with permission) [8].

MRRH health needs assessment

We performed an unstructured HNA based on the availability of CRC-related services at MRRH in January 2025. It is important to note that cancer care services are provided through the Uganda Cancer Institute (UCI) and within the Mbarara Cancer Center. For the purposes of this HNA, this was considered a singular entity as the services provided by the cancer center are housed within MRRH and available to the same patient population.

This HNA was produced in coordination with senior CRC specialists at our US partner institution, where key components of providing CRC care were identified. After identification of those key components, the author-team used clinical and operational observations along with informal discussions with six department heads from laboratory, pharmacy, radiological, oncological, surgical, and pathological departments to review areas of need and help determine areas of workflow constraints. These conversations were not recorded and informal notes were

taken. Institutional documents such as availability of specific lab tests, immunohistochemistry, drugs, and radiology tests were reviewed with their respective stakeholders, and are available upon request. Administrative clearance consisted of an agreement between the US partner institution and MRRH's oncology department, available upon request. IRB approval was not required due to lack of human subjects research or patient data.

Results

Literature search

The Uganda-focused evidence base comprised studies spanning the CRC continuum, including epidemiology and outcomes, prevention and risk factors, screening and early detection, diagnostic and staging capacity, treatment and outcomes, radiotherapy capacity, and palliative care. Our search identified 143 papers (Figure 2). Of these, nine were included in our narrative review and four additional articles were

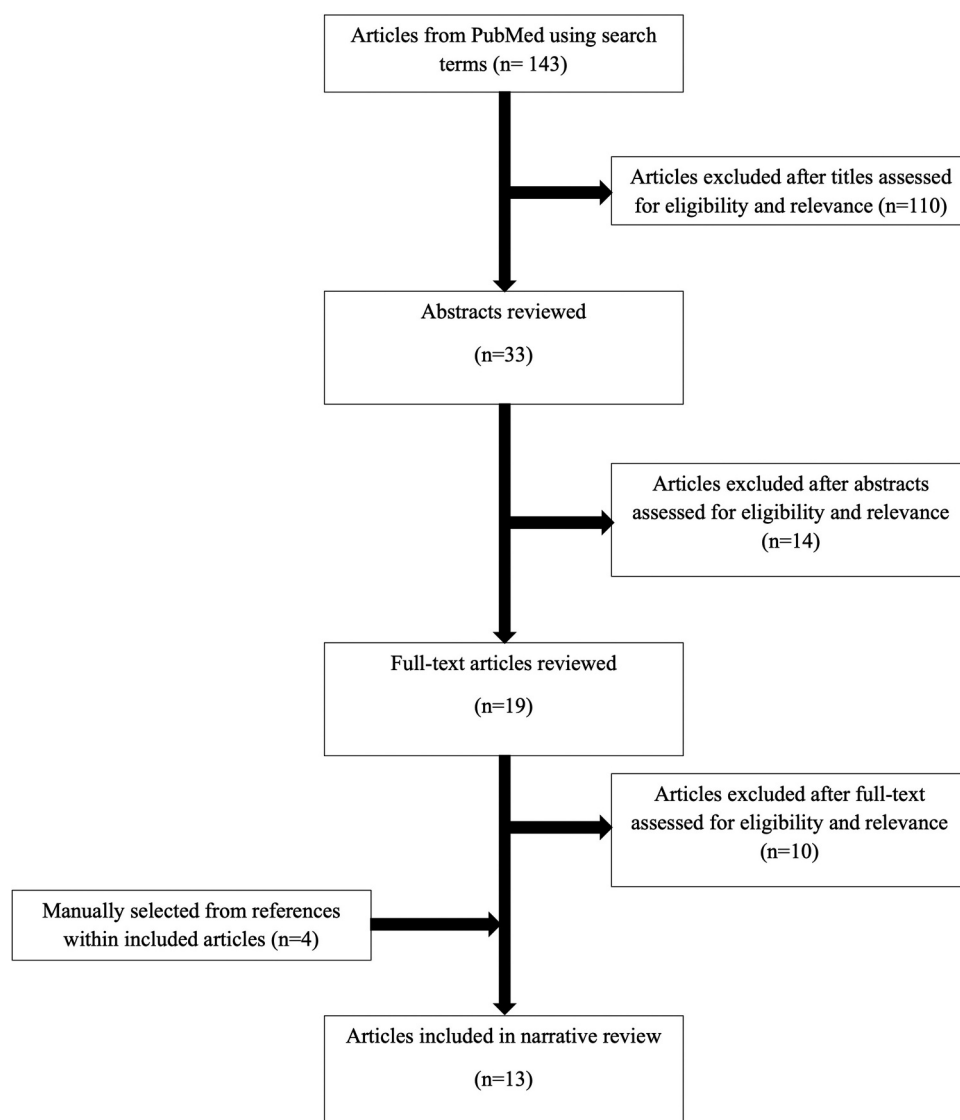


Figure 2. Article selection flow diagram.

selected from the citations based on relevance to the different aspects of the care-continuum. Table 1 summarizes the Uganda-specific sources used in the narrative synthesis and the primary contribution of each source, alongside remaining evidence gaps.

Among the different domains, there was limited data in multiple areas. Of the articles found in our review, there was no primary outcomes or interventional data regarding screening in Uganda. There was also very limited data regarding treatment and outcomes, with only two papers discussing those findings. Prospective data is also limited in the literature with most evidence being retrospective. Epidemiologic studies that were noted were also largely case-control studies and conducted retrospectively from chart reviews. Evidence from the palliative care domain demonstrated active implementation and outcomes related to those changes, however, information directly related to CRC was still limited.

Health needs assessment

The results from our HNA are characterized in Table 2. These results refer explicitly to what is available at MRRH, unless otherwise specified. The areas that demonstrate lower amounts of resources are particularly in the screening and diagnostics categories, which are both limited by lack of endoscopy resources. Objectively, many of the necessary items needed for the delivery of cancer care are present, however, the numbers required for delivering care to the catchment area of southwestern Uganda, roughly 6–8 million people, are limited.

Discussion

Prevention

In terms of primary prevention, an individual's lifetime risk of CRC is affected primarily by unmodifiable (e.g. age, genetic mutations) and modifiable (e.g. dietary and lifestyle habits) risk factors. The importance of modifiable risk factors is illustrated by one large study from 2012 in Sweden, where migrant CRC incidence rose toward host-country levels [9]. Obesity, low levels of physical activity, smoking, alcohol intake and certain diets (low fiber/grain and processed meat) have all been independently linked to higher CRC risk [2]. Furthermore, these lifestyle factors also influence overall cancer burden. Government health agencies have recognized this, supporting primary prevention by limiting carcinogenic behaviors through policies such as smoking bans and soda taxes [2,10].

In Uganda, preliminary studies have identified associations between CRC and urbanization, smoking

history, consumption of boiled meat, and family history of CRC. Similarly, high-fiber diets may be protective [11,12]. However, limited epidemiologic data restrict the ability to develop targeted prevention programs.

Importance of governance

Addressing these risk factors requires engagement of the health system. Unlike cervical cancer, which has a distinct prevention method (i.e. HPV vaccination), no comparable intervention exists for CRC. Based on known modifiable risk factors, CRC prevention depends on both health education and government policies to curb harmful behaviors. Recently, Uganda has made progress, most notably with the 2015 Tobacco Control Act, which limited both the sale and consumption of tobacco in public places and almost halved the documented prevalence of smoking [13]. While this act was not aimed at lowering the burden of CRC, smoking is a known modifiable risk factor and highlights how healthy lifestyle modifications can also help reduce CRC incidence. Such investments could simultaneously reduce CRC and other non-communicable diseases (NCDs), providing an opportunity to improve population health overall.

Governance here has the capability to strongly influence the prevention of CRC and other NCDs. Given Uganda's underfunded health system relative to HICs, policy changes are particularly powerful because they require minimal coordination between the different parts of the health system yet can still yield broad benefits. However, the scope of governance is limited to evidence-based interventions, highlighting the need for stronger epidemiologic data on CRC risk factors, especially in the Ugandan context. Currently, centralized data collection is hampered by limited PBCR coverage, but this drawback is being creatively addressed by using retrospective 'catchment population' approaches to help estimate cancer incidence [7,14]. However, these analyses can only help estimate incidence, because data, including exposures and risk factors, within the medical record is regularly unavailable. While a gold-standard national registry should be the goal for Uganda, using this retrospective catchment population approach may be a reasonable alternative, but it is important to note the epidemiologic limitations that this evidence cannot provide data for specific risk factors that could be used for future policy interventions.

Early detection

As of 2015, 32 countries had implemented national CRC screening programs, predominantly in HICs with higher reported incidences [10]. In LMICs, screening is limited due to cost, infrastructure

Table 1. Uganda-focused evidence map for CRC across the care continuum.

Ref #; Yr	Domain	Study design	Main Uganda evidence contributed	Major gap/Implication
[4]; 2005	Epidemiology & outcomes	Kampala registry survival analysis ($n = 104$)	Kampala-based registry analysis describing cancer survival for multiple malignancies, including colon cancer, used to characterize Uganda outcomes context.	Limited CRC survival data outside Kampala; expands need for broader registry coverage and follow-up.
[11]; 2024	Prevention/ risk factors	Multicenter retrospective case – control study ($n = 128$)	Uganda specific evidence linking dietary patterns to CRC risk, multi-hospital study.	Associations require confirmation in larger and more diverse Ugandan samples
[15]; 2025	Early detection	Qualitative interview ($n = 11$) stakeholders from multiple aspects of care delivery	Uganda stakeholder/barrier assessment outlining feasibility constraints and opportunities for CRC screening. Implementation is dependent on diagnostic capacity, which is still limited.	Unifocal representation of professionals without patient or community member inclusion.
[16]; 2020	Diagnosis/ staging	National cross-sectional audit	Uganda national audit mapping imaging availability and distribution relevant to CRC staging capacity.	Limited to review of those reported to the Atomic Energy Council (AEC)
[17]; 2021	Diagnosis	Single site (UCI) capacity-building evaluation	Uganda evaluation of pathology capacity-building describing gains in diagnostic throughput and quality	Sustaining gains requires continued training, QA systems, and reliable supplies/maintenance.
[18]; 2025	Diagnosis/ tumor biology	Retro- and prospective multicenter cross-sectional study ($n = 127$)	Multicenter molecular/pathologic evidence relevant to tumor biology and biomarker testing needs (e.g. MSI/MMR).	Limited availability of MSI/MMR testing constrains risk stratification and targeted therapy decisions.
[19]; 2025	Treatment systems	Retrospective multicountry cohort registry study (Uganda $n = 67$)	Registry evidence including Ugandan sites describing gaps in guideline-concordant care and retention.	Loss to follow-up and inconsistent documentation limit assessment of guideline-concordant care in Uganda sites.
[20]; 2022	Treatment & outcomes	Retrospective multicenter and registry-based cohort ($n = 247$)	Uganda multicenter retrospective cohort describing treatment patterns and outcomes, highlighting late presentation challenges.	Incomplete staging and longitudinal outcomes reporting limit causal inference and benchmarking.
[21]; 2025	Radiotherapy capacity	Qualitative scoping and observational review with expert commentary	Uganda based review of radiotherapy capacity; describing availability and expansion relevant to cancer treatment planning.	National referral pathways and equitable access to radiotherapy require further evaluation and patient-level data. Review and synthesis, no primary data generated.
[22]; 2018	Palliative care	Cross sectional single institute (HAU) survey of patients/family, health care workers ($n = 122$)	Uganda palliative care program description outlining service model and important care preferences among patients.	There are significant discordances between the different parties at end of life, and palliative care integration into oncology services remains uneven across sites and levels of care.
[23]; 2022	Palliative care	Multisite ($n = 226$) cross-sectional survey of health facilities	Uganda multicenter descriptive assessment of indicators on palliative care and morphine availability.	Opioid access can be disrupted by stockouts and supply-chain constraints; facility-level variability persists.
[24]; 2018	Palliative care	Mixed methods single center review ($n = 595$)	UCI single center survey/IDI evidence on end-of-life discussions supporting communication training needs.	End-of-life communication practices are under-studied; intervention and evaluation studies are needed.
[25]; 2021	Palliative care/QoL	Single center (UCI) cross-sectional study ($n = 51$)	Uganda single center cross-sectional study on stoma-related quality of life and stigma informing supportive care.	Psychosocial and stigma-related barriers are under-addressed; implementation studies of supportive care are needed.

Table 2. Mbarara Regional Referral Hospital CRC services HNA as of January 2025.

Domain	Service	Availability	Additional Details
Screening	Fecal Testing	No*	Only available as diagnostic test
	Colon or sigmoidoscopy	No	No availability either as screening or diagnostic
Diagnosis	CT Scan	Yes	Cost between 30–50 USD, 2 machines
	MRI	Yes	Only 1 machine, repairs needed frequently. Cost 300–1000 USD
	Radiologist	Yes	On site, typically formal read costs extra beyond just the scan
	Pathologist	Yes	1 full-time pathologist as well as pathology residents
	Immunohistochemistry	Yes	Have a variety of stains, including HER2 and standard carcinoma stains. May cost extra for patient.
	Next Generation Sequencing	No	May be available locally, but not at MRRH.
Treatment	Blood tests	Yes	Many types of serum testing including standard monitoring and tumor markers
	Medical Oncologist	Yes	1 full-time oncologist along with 2–3 medical officers and additional residents
	Surgical Oncologist	Yes	4 surgeons capable of CRC resection
	Chemotherapy	Yes	All standard chemotherapy for CRC available
	Monoclonal antibodies	Yes	More frequent stockouts and less available
	Radiotherapy	No	Only available in Kampala at Mulago National Hospital
	Nurses	Yes	4 Oncology specific nurses who can administer chemotherapy and care for patients on the ward.
	Pharmacists	Yes	2 pharmacists along with techs and students assisting with mixing drugs
Palliative Care	Morphine	Yes	Available in multiple different dosages, primarily liquid. Usually in stock
	Palliative care physicians	No	Most physicians in the clinic have received some palliative care training
	Social worker	No	Pediatric oncology has one
	Medications for symptom management	Yes	Doses with chemotherapy free, but additional may cost money based on availability

*Fecal testing is available diagnostically when reagents are available, but availability is not robust enough for screening.

constraints, other competing public health priorities, and a lower perceived incidence of CRC compared to HICs [2,5,6]. Screening modalities fall into two broad classes: direct visualization (e.g. Colonoscopy, CT colonography, colon capsule, or flexible sigmoidoscopy) and stool/blood-based methods (e.g. fecal immunochemical testing [FIT], fecal occult blood test [FOBT], multi-target stool DNA [MT-sDNA], or fecal stool DNA testing [FIT-DNA]) [26].

Modalities that involve direct visualization are often cost-prohibitive in LMICs due to healthcare expenditure and pre-existing infrastructure requirements [15]. Stool-based diagnostics such as FOBT, FIT, or FIT-DNA are more feasible given lower cost and infrastructure demands. FIT-DNA has been shown to have high sensitivity and specificity for CRC in high-resource settings but performs poorly for pre-cancerous lesions, and data on effectiveness in LMICs remain limited. However, despite this, FIT has been piloted successfully in parts of Sub-Saharan Africa (SSA) [27]. Challenges remain because diagnostic capacity must exist to confirm disease after a positive screening test.

In Uganda, no national CRC screening program exists, and evidence on implementation or effectiveness is minimal [15]. Our review found no studies describing CRC screening interventions in Uganda, making it difficult to assess optimal strategies or test performance. Observed barriers to implementation in Uganda likely mirror those seen elsewhere in SSA: poor follow-up, limited endoscopic capacity, and patient reluctance to test when asymptomatic [28,29]. Thus, while FIT offers potential for early detection, diagnostic capacity remains a limiting factor.

Scaling up screening

Although Uganda may lack some of the infrastructure to expand screening, understanding the key barriers – limited workforce, inadequate medical products/technology, and constrained financing – is still vital.

To characterize these areas for improvement, it is necessary to define how these building blocks are used in CRC screening. Implementing effective screening requires a trained health workforce. For CRC, this means increasing the number of providers who can perform colonoscopy or sigmoidoscopy. Uganda has fewer than five formally trained gastroenterologists nationwide, and consequently, a shortage of providers who can perform colonoscopy [30]. Addressing this shortage is essential, as colonoscopy is critical for both screening and diagnosis. In other African countries with similar limitations, task shifting to non-physician providers has been effective, though not yet as common as the utilization of nurse endoscopists in Europe [31,32]. Identifying safe, creative strategies to expand endoscopy capacity will be vital to any screening program and should be prioritized as incidence of CRC and other GI malignancies continue to rise.

‘Tiered screening’ strategies are also an important consideration when attempting to implement in a system with limited capacity. ‘Tiered screening’ refers to using a low-cost test to identify patients who may need more invasive follow-up. In Nigeria, FIT has been identified as a feasible first-line option and may be relevant in Uganda [33]. Implementation would require investment in test kits and reading devices; with costs in Ghana and Nigeria ranging from 1 to 3 USD per kit [27,34]. However, FIT

cannot be used in isolation as further testing with colonoscopy is necessary and still limited in East Africa.

For most Ugandans, health care expenditure is a major barrier to care [35]. The most successful screening program in Uganda has been cervical cancer screening, largely because screening is provided free of charge through support from the UCI [36–38]. Consideration of the health financing costs caused by increased screening will be important to population level success. Costs of colonoscopies in SSA vary; in Nigeria, this procedure costs approximately half of the median monthly income, which can be cost-prohibitive [27,34]. Thus, identifying sustainable funding for both medical products (e.g. FIT, endoscopes) and patient-related costs will be crucial before CRC screening can be safely introduced at scale in Uganda.

Diagnosis and treatment

The gold standard diagnostic test for CRC is colonoscopy, usually accompanied by biopsy and histologic confirmation. In most HICs, pathology is supplemented by immunohistochemistry (IHC), polymerase chain reaction (PCR), and, in later-stage patients, next-generation sequencing (NGS). These provide prognostic and therapeutic guidance, particularly mismatch repair (MMR)/microsatellite (MSI) testing. Beyond pathology, staging is critical and usually involves CT of the chest, abdomen, and pelvis along with pelvic magnetic resonance imaging (MRI) in rectal cancer to assess for lymph node involvement.

As with all treatment for cancers, CRC treatment is guided by stage, likelihood of cure, patient ability to tolerate treatment, and other factors. The three main modalities of treatment are surgery, chemotherapy (either cytotoxic therapy for both early and late-stage disease, immunotherapy for MSI-high early and late-stage disease, and targeted therapies/monoclonals for specific molecular features in late-stage disease), and radiotherapy for select rectal cancer patients. For resectable colon cancer, surgery is the primary treatment, followed by adjuvant chemotherapy based on staging. Rectal cancer patients often require chemotherapy and radiation prior to surgery [39,40]. First-line cytotoxic chemotherapies for CRC include 5-Fluorouracil (5-FU)/capecitabine, irinotecan, and oxaliplatin. Later-line regimens incorporate targeted agents or monoclonal antibodies for select patients, while immunotherapy has shown remarkable efficacy in MSI-High disease across stages. In the U.S., 5-year survival for colon cancer is around 91%, 73%, and 13% for localized, regional, and distant disease, respectively; rectal cancer survival is 90%, 74%, and 18% for the same stages [41].

Evidence from Uganda

There exists limited evidence regarding CRC diagnostics and therapeutics within Uganda. Of the 13 reviewed papers, only two addressed these topics. As mentioned above, colonoscopy is essential for diagnosing CRC, and in Uganda, the availability remains scarce. One 2024 paper describes that there are less than 5 gastroenterologists in the country and a significant shortage of endoscopes [30]. Some articles suggest that access to colonoscopy is restricted to Kampala, although anecdotally, private availability exists in other large cities as well. Data on staging practices were also not included, though CT is relatively available nationwide (about 25 machines), costing 30–75 USD per scan [16].

Access to pathology services is often limited to facilities with colonoscopy or surgical capacity [17]. Pathologic diagnosis of CRC is predominantly adenocarcinoma, the most common histology worldwide. Proportionally, patients in Uganda are younger than those in HIC cohorts, and there are a higher proportion of left-sided tumors which may reflect limited colonoscopy access and reliance on sigmoidoscopy [42,43]. Supplemental diagnostics such as MSI and IHC testing are currently limited, but increasing this capacity will be helpful for identifying targeted therapies [17,18]. New data demonstrate that, in Uganda, there is an incidence of around 40% of MSI-High patients with CRC, which is significantly higher than those in western populations [18]. Continuing to test for these mutations is important for understanding the biologic underpinning of CRC in Uganda and East Africa.

In 2020, the National Comprehensive Cancer Network (NCCN) and African Cancer Coalition (ACC) released sets of harmonized guidelines for common cancers in SSA, with the intention of tailoring recommendations to regional resource constraints [44]. Despite this, there are still substantial deviations from the guidelines among SSA countries, which speculatively may be due to shortages of trained oncologists, limited radiotherapy capacity, chemotherapy stockouts, and patient-specific factors. A multi-country registry review of CRC found most nations deviated from the Harmonized NCCN guidelines. In Uganda ($n = 67$), most patients were untraceable and many did not receive cancer-directed therapy [19,45].

Ugandan-specific treatment-modality and outcomes data remain limited and mostly focused on surgical data. In a Kampala cohort ($n = 247$), Wismayer et al. demonstrated a 3-year survival of 33.3%, with predominantly late-stage presentation [20]. Notably, when patients received surgery and chemotherapy, their outcomes were more favorable than those who just received single-modality therapy. Regimens in this review were not specified; however,

NCCN harmonized guidelines recommend combination folinic acid, 5-FU, and oxaliplatin (FOLFOX) or capecitabine and oxaliplatin (CAPOX), both of which are available in Uganda [44,46]. Standard radiotherapy is more accessible, according to Kavuma et al., however CRC-specific outcomes in Uganda are lacking [21].

Steps for improvement

Examining the Ugandan health system with respect to diagnosis and treatment demonstrates strengths but also limitations in their service delivery, health workforce, and information. Similarly to SSA, patient retention is a major hurdle across Uganda and is compounded by the fact that more than 70% of the population lives in rural areas [47]. The inability of patients to continue follow-up care is often multifactorial, but commonly financial, given the reliance on subsistence farming for their income [47]. Importantly, chemotherapy is government-financed and free for patients if it is in stock. However, patients must pay for the rest of the comprehensive care – pathology, labs, staging scans, and supportive medications – plus travel costs and accounting for lost wages [35,48]. Programs targeting these barriers, such as patient hostels near the hospital and transport reimbursements have been effective in reducing patient attrition [49,50]. Decentralizing care from referral hospitals could help, but resources in those settings are already constrained by workforce shortages. Simultaneous capacity building and iterative education for providers in rural hospitals about the symptoms of CRC have been shown to improve referral rates and treatment in other LMICs [51]. Focus on these interventions should take priority as the health workforce is maturing and service delivery is still limited.

Separate from cancer care delivery is tracking cancer-related outcomes. Cancer registries are vital for trend analysis and evaluating population-level interventions. Uganda and many SSA countries lack robust registry data and consequently have difficulty describing the impact of diseases on a population level. Data pertaining to diagnostics, pathology testing, tumor types, treatment plans, survival and other epidemiologic information will provide the guidance for context-specific screening, diagnosis, and treatment strategies. Expanding beyond the limited PBCRs to a national system is paramount to improving outcomes for CRC in Uganda.

Palliative care

In HICs, early palliative care referral is becoming a priority for patients with metastatic cancer and is associated with improved quality of life, mood, and survival [52]. For patients with advanced CRC,

palliative care is essential given the risk of bowel obstruction, cachexia, and complex pain [53]. Integration of palliative services into oncology clinics has been shown to be one of the most effective interventions in improving patient satisfaction, well-being, and symptom control in patients with advanced cancer [54]. Beyond symptom control, palliative care facilitates end-of-life discussions and goal-concordant treatment planning. This is especially important in advanced CRC where multiple complications can occur and could involve extensive surgical intervention. Early engagement ensures patient participation and reinforces palliative care as an integral part of comprehensive oncology.

Palliative care in CRC often becomes urgent due to disease-associated complications such as nerve invasion/compression, bowel obstruction, bleeding, pain, and failure to thrive [53]. In these instances, palliative care ensures patient needs are heard while optimizing management of complex symptoms. Palliative care providers are well versed in pain management and can help safely titrate pain medications while employing multimodal strategies to prevent tolerance [55]. Furthermore, they also advocate for patients by guiding discussions on next steps in care and symptom management. Palliative care is also helpful in transitioning from cancer-directed to comfort-focused care, which is key to maintaining patient autonomy.

Bright spots in care delivery

In Uganda, palliative care has been one of the country's greatest achievements in cancer services over the past 30 years. Uganda continues to be a regional leader and innovator in palliative care across SSA, including in CRC management. While palliative care is well established, data on care outcomes, priorities, and performance in CRC remains limited. Nonetheless, there is substantial literature describing palliative care infrastructure and patient experiences in Uganda.

One of the most impactful palliative care interventions was increasing the availability of morphine. Morphine was introduced in 1993 through a collaboration between the Ministry of Health (MoH) and Hospice Africa Uganda (HAU). HAU – a charity founded by Dr Anne Merriman and Nurse Mbaraka Fazal – aimed to provide low-cost, high-quality palliative care nationwide. Together, the MoH and HAU developed national morphine distribution networks and subsidized its cost to ensure affordability. Access expanded further when the government issued a Statutory Instrument in 2004 that allowed nurses and clinical officers with specialized training to prescribe oral morphine. This in combination with organizations such as HAU significantly strengthened Uganda's palliative care system [22]. Strong governance exemplified by both this

Statutory Instrument and the MoH's creation of a national palliative care strategy emphasized workforce capacity building, task-shifting, and sustained morphine supply as the cornerstones for improved access and outcomes [56].

Recent metrics demonstrate that more than 80% of Ugandans live in districts with at least one facility offering palliative care. Morphine is largely available at each of these facilities for at least two-thirds of most months according to a report by Kagarmanova et al. [23]. While these stockouts remain a challenge, morphine availability represents continued progress in expanding access to essential medicines, particularly in remote regions of the country. Community engagement has been critical to integrating palliative care into comprehensive cancer care for patients. Acceptance of palliative care has been influenced by community health workers who work to reduce stigma surrounding death, dying, and palliation [22]. This, in coordination with HAU, has been essential to patients receiving quality end-of-life care at home and respecting their wishes of a death at home. The interaction of medical product availability expanded health workforce through dedicated HAU efforts, reduced patient financing for palliative care, and concerted government policies have worked in unison to create resiliency within this part of the Ugandan health system. This success offers a model for strengthening other aspects of their cancer care delivery system.

Mbarara Regional Referral Hospital: health needs assessment

This section integrates the continuum of care framework analyzed above with a comprehensive HNA of Mbarara Regional Referral Hospital (MRRH). The goal of this HNA is to identify priority areas for improvement and small-scale interventions that could enhance the outcomes for patients with CRC.

MRRH is a 600-bed teaching hospital affiliated with Mbarara University of Science and Technology (MUST). It serves southwestern Uganda with a catchment area of 6–8 million people, offering both medical and surgical subspecialty services. Medical services are provided free of charge, although frequent stockouts of medications and sundries require individuals to pay for much of their care out of pocket since there is no universal health insurance. The facility treats more than 1,000 new cancer patients per year, including an estimated 60–70 new CRC cases each year [57]. UCI supports the cancer facility with chemotherapeutics and salary for nurses and doctors, while additional support comes from the Ugandan government and private donations.

Early detection

At MRRH, early detection interventions for CRC are not routinely available. Patients are typically referred only after a confirmed diagnosis, following presentation at lower-level centers with symptoms and subsequent transfer to urban sites for colonoscopy and pathologic examination. At MRRH, no organized CRC screening program exists. FOBT is occasionally available depending on reagent supply but is used diagnostically rather than for screening. Program development is limited both by the lack of high-sensitivity screening tests (e.g. FIT) and by inconsistent access to confirmatory procedures such as colonoscopy or sigmoidoscopy. As noted, endoscopic capacity across East Africa remains limited; even at MRRH, a regional referral hospital with a cancer center, colonoscopy is unavailable. Expanding diagnostic capacity for colonoscopy and sigmoidoscopy should therefore be a top priority, because stool-based screening should be scaled alongside a defined pathway for confirmatory endoscopy, pathology, referral, and follow-up.

Diagnosis and treatment

At MRRH, diagnostics and treatment services are present but remain limited compared to higher-resource hospitals. Available diagnostics include basic laboratory tests, serum tumor markers, abdominal ultrasound, CT scanning, on-site radiology, and pathology. As described, endoscopic capacity remains extremely limited. Advanced pathology diagnostics are constrained as access to IHC is inconsistent and molecular tumor profiling with PCR and NGS is unavailable. Staging relies primarily on CT and abdominal ultrasound; MRI is available but limited, and PET scanning is not available. Although MRI is standard for rectal cancer staging, PET is not routinely required for CRC diagnosis or staging [39,40].

Improving pathology and endoscopy access are the most pressing needs for CRC diagnosis at MRRH. Better pathology-related diagnostics would provide more detailed tumor characterization and open additional treatment options. UCI's formulary includes monoclonal antibodies such as cetuximab (anti-EGFR) and trastuzumab (anti-HER2), which are typically reserved for late-stage disease in HICs but potentially valuable at MRRH given the high rate of late presentation. Incorporating these agents alongside standard chemotherapy could improve progression-free survival in advanced CRC and other malignancies.

Scaling up pathology resources in Uganda has been shown to improve patient outcomes. Niyonzima et al. used a multi-modal approach combining capacity building, upgraded equipment, and consistent assay availability to demonstrate increased pathology throughput and greater use of IHC and

targeted therapies [17,58]. Although resource- and time-intensive, this model demonstrates that strengthening diagnostics is a critical first step towards expanding oncologic capacity in facilities like MRRH.

Therapeutically, MRRH provides surgery, chemotherapy, and supportive care medications. At the time of writing, staffing includes one medical oncologist, oncology nurses, medical officers, two oncology pharmacists, a dedicated oncology ward, and four surgeons capable of colorectal surgery (CRS). Despite this staffing, long wait times and overcrowding hinder care delivery. Surgical referrals for CRS are also often delayed due to general surgery volume and limited operating room capacity. Continued development of the ancillary infrastructure is vital for sustainable oncologic care. However, despite these bright spots, several gaps persist. Currently, there is no radiotherapy at MRRH, chemotherapy and supportive drugs for pain, nausea, and infection experience frequent stockouts, and records remain paper-based. Addressing these deficiencies requires major capital investment as radiotherapy and electronic medical records (EMRs) demand substantial financial and time commitments. Reducing medication and chemotherapy stockouts would markedly improve treatment consistency and quality. Forecasting and inventory management are essential, and improving communication of epidemiologic data to the central pharmacy at UCI may help predict needs more accurately.

Palliative care

Like the rest of Uganda, palliative care remains a relative strength at MRRH. Pain control with morphine is consistently available and less affected by stockouts than other medications. Anti-diarrheal and anti-emetic drugs are free until stockout occurs, then they must be purchased. Furthermore, several providers have received palliative care training and incorporate its principles in clinical practice, though dedicated visits or structured discussions on palliative topics remain uncommon. Formalizing these interactions could improve patient satisfaction and overall quality of care. At UCI, a study of medical officers revealed limited discussion of end-of-life care, despite its importance to patients [24]. Similarly, a study in Kenya found that integrating palliative and oncology care increased discussion and management of symptoms and quality-of-life concerns [59]. Expanding structured palliative care conversations at MRRH could therefore improve quality of life for patients and overall cancer outcomes.

Palliative chemotherapy and procedures are integral to palliative care. At MRRH, palliative radiotherapy and colonic self-expanding metal stents (SEMS) are unavailable, and palliative surgery is constrained

by cost, workforce shortages, and social stigma surrounding visible stomas [25]. Expanding endoscopic and surgical capacity could also help broaden palliative options for patients. Interventions should also address psychosocial barriers – particularly stigma around stomas – through dedicated social workers or palliative care providers within the oncology ward and clinic.

Limitations

The limitations of this study are apparent and related to the type of evidence reviewed, the quantity of literature specific to Uganda, and the nature of our HNA. With respect to the type of evidence used, this article relies on the conclusions drawn from retrospective or case-based reviews. There are a few examples of prospective data collection, however these are limited. Furthermore, the strength of assertions from this review are only as valid as the strength of sources used, and consequently the generalizability and accuracy of our conclusions are limited.

Literature specific to Uganda was sparse as well. In this review, only 13 articles from peer-reviewed sources were able to be identified. The dearth of publications specific to CRC in Uganda unfortunately limits our ability to make strong conclusions about the state of CRC care in Uganda. However, it should also be noted that the lack of this evidence points towards a clear need for additional work in the field.

Lastly, our HNA also has several limitations. Our assessment was created by a group of senior specialists in the field but was not validated nor conducted in a systematic manner. Furthermore, the informal nature of the data collection limits reproducibility. It is also only a single-center assessment and not broadly generalizable to the rest of the Ugandan context.

Conclusions

CRC care in Uganda has advanced over recent decades, with growing understanding of CRC epidemiology and cancer characteristics, yet major gaps remain across all elements of comprehensive care. These gaps are illustrated by our case-based review and HNA of MRRH, however not nationally representative. Screening is essential to shift disease diagnosis to earlier stages and therefore improve treatment outcomes, but must be implemented in parallel with the expansion of gold-standard diagnostics such as colonoscopy to accommodate for those who screen positive. Expanding colonoscopy capacity requires workforce training and capital expense into endoscopic equipment. Simultaneously, strengthening cancer registries is critical for disease tracking and system feedback. Continued progress in diagnostics must be paired with reliable access to multimodal

treatment and molecular testing, which can inform targeted and immunotherapy use and improve understanding of cancer biology in the Ugandan context. Addressing medication stockouts should be an immediate priority, as this is a tangible and practical way for improving outcomes. Finally, palliative care – one of Uganda’s major oncology strengths – should be more deeply integrated into oncology clinics such as UCI and MRRH.

In Mbarara, these challenges are also evident, and dedicated efforts are needed to strengthen cancer care across the continuum (i.e. prevention, screening, diagnosis, treatment, and palliation). As a next step, practical interventions such as digitizing records, expanding colonoscopy access, and reducing chemotherapy stockouts appear most feasible. Identifying sustainable strategies to implement these changes will be paramount to advancing oncologic care in Mbarara.

In conclusion, while there remain gaps in both the literature and the health care infrastructure in Uganda, there are clear bright spots to build on and feasible interventions that can be pursued to help improve local outcomes for CRC.

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Samee Hameed conceived the study concept, designed the review framework, and led the overall development of the manuscript.

Tim Niyogusaba served as co-lead author, contributing substantially to literature review, manuscript writing, and synthesis of research findings.

Jacinta Ambaru Ojia helped design the review, drafted initial sections, contributed to literature research, and assisted in the Mbarara Regional Referral Hospital health needs assessment.

Sara Al-Zubi contributed to literature review, drafting multiple sections, and manuscript revisions.

Caroline Nyakato assisted in conducting the Mbarara health needs assessment and contributed to drafting the Uganda-specific sections.

Peter Olds provided project guidance, supported the Mbarara health needs assessment, and contributed to critical manuscript revisions.

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All authors meet the requirements for authorship based on the ICMJE criteria for authorship. The authors contributed to drafting and revising the manuscript critically for important

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Data availability statement

Given the two separate parts of this paper, there are subsequently two separate domains of data. Data from the literature review portion is provided in the paper and these articles are available on the web for review. Separately, our health needs assessment data is available for review on request, and stakeholders remain available to answer specific questions should questions arise.

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