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Impacts of Stigmatization on Cancer Care in Uganda: A Narrative Review

Masika Anna Mahinda

Department of Pharmacy Kampala International University Uganda
Email: mahindamasika@studwc.kiu.ac.ug

ABSTRACT

Cancer outcomes in Uganda are shaped not only by biomedical factors but also by social meanings attached to cancer. Stigmatization, manifesting as blame, fear of contagion, moral judgement, and social exclusion—affects help-seeking, disclosure, continuity of care, and psychosocial wellbeing. In Uganda, where cancer awareness is variable, diagnostic delays are common, specialist services are centralized, and out-of-pocket costs remain substantial, stigma can intensify barriers across the care pathway. This narrative review synthesizes evidence and contextual insights on how cancer-related stigma influences prevention, screening, diagnosis, treatment adherence, palliative care, survivorship, and health system performance in Uganda. We propose a pathway-based conceptual model and summarize stigma-reduction and patient-centered interventions suitable for Ugandan settings, including community dialogue approaches, integration of psychosocial oncology, training for respectful communication, survivorship advocacy, and structural interventions that reduce financial toxicity. Addressing stigma should be treated as a core quality-of-care strategy to improve timely presentation, treatment completion, and patient dignity.
Keywords: cancer stigma, Uganda, cancer care continuum, disclosure, adherence, psychosocial oncology, palliative care, health-seeking behavior.

INTRODUCTION

Uganda is experiencing a steadily rising cancer burden, reflecting broader demographic, epidemiologic, and health-system transitions. Population growth and longer life expectancy have increased the number of people living long enough to develop malignancies, while persistent exposure to infection-related cancer risks continues to drive incidence [1]. Infections strongly linked to cancer, including human papillomavirus (HPV) for cervical and other anogenital cancers, hepatitis B virus for hepatocellular carcinoma, and other oncogenic pathogens, remain prevalent in many communities. At the same time, lifestyle transitions such as urbanization, dietary change, reduced physical activity, alcohol use, and tobacco exposure are contributing to the growing burden of non-communicable diseases, including cancer [2]. These combined forces mean that cancer is no longer a rare condition affecting only a small fraction of Ugandans; rather, it is increasingly visible at household and community level, with substantial implications for morbidity, mortality, and economic wellbeing. In response, Uganda has taken steps to expand oncology services, including improvements in diagnostic capacity, availability of chemotherapy, radiotherapy services, and the growth of specialist care in selected referral settings. However, major gaps persist across the cancer care pathway from early symptom recognition and timely diagnosis to treatment initiation, adherence, follow-up, and survivorship support [3]. Many patients still present with advanced disease, when treatment is more complex, outcomes are poorer, and costs are higher. Interruptions in care are common, driven by transport challenges, out-of-pocket costs, drug stock-outs, limited specialist capacity, weak referral systems, and competing household priorities. These constraints are widely documented and remain critical determinants of cancer outcomes [4]. Yet, beyond these "visible" structural barriers lies another powerful, often less systematically addressed driver of delayed and disrupted cancer care: stigmatization. Cancer stigma shapes how individuals interpret symptoms, whether they disclose illness, when and where they seek care, and how they sustain engagement with treatment. Stigma may

operate silently—through fear, shame, secrecy, blame, or social withdrawal that ultimately affects both clinical outcomes and patient wellbeing. In settings where community narratives and beliefs about cancer include fatalism ("cancer means death"), contagion myths, moral judgments, or spiritual interpretations (e.g., cancer as punishment or witchcraft), stigma can become a major barrier even when services are physically available [5]. Cancer stigma refers to negative beliefs, attitudes, and behaviors toward people affected by cancer. It can be expressed in several forms. External or enacted stigma involves discrimination, social exclusion, blame, or harsh treatment from family, community members, employers, or even health workers. Internalized stigma occurs when a patient absorbs negative societal beliefs and experiences self-blame, shame, reduced self-worth, or hopelessness. Anticipated stigma refers to the expectation of being judged, rejected, or treated differently, which may lead to secrecy, delayed disclosure, or avoidance of services [6]. Structural stigma is embedded within institutions, policies, or routine practices that systematically disadvantage cancer patients, such as poor privacy in clinics, dismissive care, lack of patient-centered communication, or workplace policies that punish repeated clinic attendance.

In Uganda, cancer stigma rarely occurs in isolation. It often intersects with other stigmatized conditions and social identities. For example, cancers linked to HPV, especially cervical cancer, may be entangled with stigma related to sexuality, reproductive health, and gender norms. Because HPV is sexually transmitted, cervical cancer can be wrongly interpreted as proof of promiscuity or "immorality," placing women at risk of blame, abandonment, or partner conflict. Similarly, cancers that share clinical features with HIV-related illness (weight loss, chronic fatigue, skin changes) may trigger HIV stigma by association [7]. Disfigurement and functional impairment, such as mastectomy-related body image changes, head-and-neck cancers affecting speech or eating, or stoma formation, may lead to social avoidance, self-isolation, and reduced economic participation. Poverty and disability may compound stigma, particularly when illness disrupts income generation and increases dependency. The result is a complex stigma environment that can shape cancer outcomes in ways that are both direct (discrimination) and indirect (fear-driven avoidance and reduced adherence) [8]. Given these realities, understanding how stigma operates along the Ugandan cancer care pathway is essential. A clear mapping of stigma mechanisms from symptom appraisal to diagnosis, treatment initiation, adherence, follow-up, and survivorship can identify where patients are most vulnerable to disengagement and what interventions may be feasible in low-resource settings. This review therefore focuses on the forms, drivers, and consequences of cancer-related stigma in Uganda and highlights practical, context-relevant interventions to reduce stigma and improve patient outcomes [9].

Uganda's oncology capacity is growing, yet many patients still present late and experience broken care. Beyond distance, costs, referral delays, and limited specialists, cancer stigma is under-recognized, poorly measured, and rarely embedded in control strategies. Stigma from families, communities, workplaces, and even clinics drives concealment, delayed health-seeking, missed visits, nonadherence, distress, and poorer quality of life. It intersects with HIV stigma, HPV/sexual-reproductive stigma, gender norms, disfigurement, poverty, disability, and caregiving burdens [10]. Evidence on how stigma disrupts each step of the care pathway is fragmented, so mapping drivers and testing scalable, context-fit interventions is urgent to sustain timely, continuous cancer care. This study aims to map and synthesize evidence on how cancer-related stigma operates across the entire cancer care pathway in Uganda, detailing its forms, key drivers, and real-life consequences, while also identifying practical, context-feasible interventions that can reduce stigma and improve timely care-seeking, treatment continuity, and quality of life for people affected by cancer. The review is significant because stigma is a modifiable barrier that can undermine outcomes at multiple points of care. By clarifying how stigma shapes symptom interpretation, disclosure, and help-seeking, the review can inform strategies that promote earlier presentation and reduce diagnostic delays—critical for survival. It will also strengthen continuity of care by explaining how anticipated and internalized stigma contribute to missed appointments, disengagement, and non-adherence, guiding supportive responses such as counseling, peer support, and patient navigation. Evidence on stigma within healthcare settings can advance patient-centered oncology services through improvements in respectful communication, privacy, confidentiality, and psychosocial support. Further, mapping structural stigma can guide policy and program design by highlighting institutional gaps (e.g., weak confidentiality safeguards, limited psychosocial services, lack of workplace protections) relevant to national cancer control planning. Finally, by addressing equity and intersectionality linkages with HIV/HPV stigma, gender norms, disability, and poverty, the review supports equitable interventions and identifies evidence gaps for future research.

Methods and Scope

This article uses a narrative review design to synthesize evidence on cancer stigmatization in Uganda and its implications across the cancer care continuum. Specifically, it (i) defines what cancer stigma looks like in Ugandan communities, including labeling, blame, secrecy, and discrimination shaped by prevailing beliefs about causation, contagion, and morality; (ii) examines how stigma influences each stage of care—risk perception, symptom appraisal, disclosure, help-seeking, screening, diagnostic follow-up, treatment initiation and adherence, palliative care uptake, and survivorship; (iii) maps downstream consequences for patients, families, and the health system, such as delayed presentation, interrupted treatment, psychological distress, social isolation, financial strain, caregiver burden, and

reduced service utilization that undermines efficiency and outcomes; and (iv) proposes feasible, locally grounded mitigation strategies, including community dialogue, survivor-led messaging, culturally sensitive counselling, confidentiality safeguards, stigma-responsive training for health workers, and linkage to social protection and peer support. A narrative approach is intentionally selected because stigma in Uganda is not a uniform, single construct: measurement tools vary widely, and experiences of stigma are often intertwined with social norms, gender relations, spirituality, and economic vulnerability. Integrating both qualitative and quantitative findings therefore enables a more nuanced interpretation and supports practical implementation options.

Conceptualizing Cancer Stigma in Uganda

Conceptualizing cancer stigma in Uganda requires recognizing how multiple stigma forms operate simultaneously across interpersonal, intrapersonal, and health-system levels. Enacted stigma is seen in overt exclusion, gossip, withdrawal of social support, marital conflict, and even neglect, leaving patients socially and economically vulnerable. Anticipated stigma—fear of rejection, being "talked about," or blamed for the illness often drives concealment and delays in disclosure or care-seeking [11]. Internalized stigma deepens harm through shame, reduced self-worth, secrecy, and withdrawal, which can undermine treatment adherence and psychosocial wellbeing. Courtesy stigma extends these burdens to caregivers and relatives who may be judged or avoided due to association. Structural stigma is embedded in service designs that unintentionally shame patients, including limited privacy, harsh communication, diagnostic queues that expose a patient's condition, scarce psychosocial support, and costly, multi-step pathways that effectively "punish" poverty [12]. Common narratives reported across East African contexts like cancer as a death sentence, a curse or punishment, contagious, linked to sexual wrongdoing (notably cervical cancer), or interpreted as evidence of HIV, shape community reactions and strongly influence how patients interpret symptoms, disclose illness, and navigate care pathways.

Impacts Across the Cancer Care Continuum in Uganda

Across Uganda's cancer care continuum, stigma acts as a hidden driver of low prevention uptake, delayed diagnosis, treatment interruption, and poorer survivorship. At the prevention stage, moral judgement and misinformation, especially the sexualized framing of HPV vaccination, can make parents fear that vaccination signals early sexual activity, while stigma around infection-related cancers discourages hepatitis B testing and cervical screening, increasing incidence and late-stage disease [13]. Once symptoms emerge, many patients conceal problems (particularly involving the breast, cervix, anus, or prostate) and adopt "watchful waiting," self-medication, prayer, or traditional healing to avoid gossip, clinic visibility, blame (e.g., cervical cancer linked to "sexual misbehavior"), and marital instability. Even when screening is available, embarrassment, partner distrust, and fears of mastectomy, disfigurement, or reduced marriageability weaken attendance and follow-up, fragmenting screening-to-treatment pathways [14]. After diagnosis, non-disclosure may protect patients socially but can limit financial and emotional support, delay treatment initiation, and restrict caregiver involvement, effects worsened by insensitive health-worker communication. During treatment, stigma amplifies the burden of travel and cost, and visible side effects (hair loss, weight loss, malodor, ostomies) can trigger rejection, leading to late initiation, interruptions, and incomplete therapy. Stigma also fuels anxiety, depression, isolation, and poor palliative care use, while survivors face persistent labeling, workplace discrimination, and avoidance of follow-up [15].

Stigma at Multiple Levels: Patient, Community, and Health System

In Uganda, cancer-related stigma operates across interconnected levels, shaping how people interpret illness, seek care, and sustain treatment. At the patient level, many individuals internalize shame and fear, anticipate ridicule, or view cancer as inevitable death, leading to secrecy, fatalism, and reduced self-efficacy to navigate diagnosis and therapy [16]. At the interpersonal/family level, stigma is reinforced through blame, abandonment, and unequal gender power dynamics—often intensifying caregiver fatigue and straining household decision-making around disclosure, finances, and adherence. At the community level, myths and moral framing (e.g., cancer as punishment, contagion, or "curse") combine with misinformation to fuel discrimination, social exclusion, and delayed care-seeking. Within the health system, structural conditions can unintentionally reproduce stigma: poor privacy, overcrowded clinics, rushed communication, limited counselling, and shortages that normalize harsh interactions [17]. Weak integration of mental health services and social support further leaves patients to cope alone with anxiety, depression, and practical burdens. Stigma's harms are not evenly distributed; they disproportionately affect women with cervical or breast cancer (sexual/moral stigma, body image, partner dynamics), men with prostate cancer (masculinity norms, sexual dysfunction stigma, delayed help-seeking), adolescents and young adults (peer stigma, fertility concerns, identity disruption), people living with HIV (layered stigma), and rural/low-income patients (high community visibility, limited privacy, and transport barriers) [18].

Intervention Options for Uganda

Uganda's cancer-stigma reduction response should combine community demand creation, health-facility practice change, and wider structural supports. At the community and population level, cancer literacy campaigns should actively correct myths and normalize early evaluation through radio talk shows, community dialogues, CHWs/VHTs, and partnerships with faith leaders [19]. Testimonial-based messaging using survivor narratives

can reduce fatalism and the "death sentence" framing, while deliberate men's engagement (partner-inclusive education for cervical and breast cancer) can limit blame, abandonment, and delayed care. School- and youth-focused programs can reduce intergenerational stigma and strengthen acceptance of HPV vaccination. Within health facilities, respectful communication training is essential, covering disclosure skills, empathy, confidentiality, and culturally competent counselling, paired with "privacy-by-design" improvements in triage, consultation space, and discreet patient flow [20]. Integrating psychosocial oncology (counselling, peer support groups, brief mental health screening, and clear referral pathways) can reduce distress and improve adherence, especially when reinforced by peer navigators/patient champions who guide patients through diagnosis and treatment. Structurally, reducing financial toxicity via transport vouchers, decentralization of follow-up services, and social protection linkages can prevent shame-driven dropout; decentralizing elements of care (regional follow-up clinics, outreach, tele-oncology consults) also minimizes travel exposure and community labeling. Policy and workplace protections that deter discrimination further support retention in care and employment [21].

CONCLUSION

Uganda's cancer-stigma reduction strategy should be multi-level, linking community demand creation, facility practice change, and structural supports that keep patients engaged in care. At the population level, sustained cancer-literacy campaigns should correct myths, reduce fear, and normalize early evaluation through radio talk shows, CHWs/VHTs, community dialogues, and faith-leader partnerships. Survivor testimonials can counter fatalism and "death sentence" narratives, while targeted men's engagement can reduce blame, abandonment, and treatment delay for cervical and breast cancers. School- and youth-based programming is equally critical for long-term attitude change and HPV vaccine acceptance. Within facilities, stigma-sensitive, respectful communication training, emphasizing disclosure, empathy, confidentiality, and culturally competent counselling, should be matched with privacy-by-design improvements in patient flow and consultation spaces. Integrating psychosocial oncology, peer support, and patient navigators can reduce distress and improve adherence. Finally, decentralization, transport support, and anti-discrimination protections can reduce financial toxicity, protect livelihoods, and prevent stigma-driven dropout.

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