








# 6 Peer Navigation for HIV-Associated Kaposi Sarcoma in Kenya: The Power of the Survivor's Voice

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## ABSTRACT

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**PURPOSE** Sub-Saharan Africa bears a disproportionate share of the global burden of HIV-associated Kaposi's sarcoma (KS), with high morbidity and mortality rates influenced by stigma, delayed diagnosis, and limited access to care. This study examines Peer Navigation, through both personal and clinical perspectives, as a potential intervention to improve outcomes for those living with KS in western Kenya.

**PATIENTS AND METHODS** This study centers on the lived experience of one KS survivor who became a Peer Navigator in western Kenya. The narrative captures his journey from diagnosis to treatment and the subsequent impact of guiding others through their healthcare journey as a Peer Navigator.

**RESULTS** Between October 2021 and July 2024, the Peer Navigator provided support to 77 patients. These interactions led to improvements in patient knowledge, reduced feelings of social isolation, renewed hope for recovery, and increased confidence in treatment options.

**CONCLUSION** Peer Navigation plays a crucial role in improving outcomes for patients living with HIV-associated KS. By integrating the survivor's voice, this model of care delivery provides invaluable emotional and social support, fostering improved patient-reported outcomes and encouraging treatment adherence, thereby offering a transformative model for care delivery.

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Despite the advent of antiretroviral (ARV) therapy, Kaposi's sarcoma (KS) remains one of the most common HIV-associated cancers, with a disproportionate global burden occurring in sub-Saharan Africa (SSA).<sup>1,2</sup> Physical manifestations of KS range from isolated skin lesions to disseminated visceral disease and disabling lymphedema, resulting in a spectrum of experiences.<sup>2</sup> SSA, our patient's home, bears nearly three quarters of the global burden of KS, and the majority of patients present with advanced-stage disease.<sup>1,3,4</sup> We offer a glimpse into the lived experience of a KS survivor in Kenya who is using the power of his voice to transform his community's perceptions and outcomes.

## Patient Perspective

My experience with HIV-associated KS started with painless left leg swelling. I went to the hospital and was told it was due to prolonged sitting as a driver. The swelling then developed into a chronic weeping wound. I went to a hospital in Mombasa, Kenya, where a biopsy was taken, but I was never given the results. I became so sick that I stopped working and was unable to even use the toilet. I used traditional medicine

with no improvement, which made me believe that the disease must have been from witchcraft. I was sick for years without knowing that I was HIV-positive.

I first learned about my HIV status at a health center near my home. I was given ARVs; however, I threw them away because I was still in denial. The disease progressed for another year until I finally accepted my status and started ARVs.

I was referred to Moi Teaching and Referral Hospital (MTRH) where a biopsy of my leg was performed. By this point, my mobility was significantly compromised; I alternated between crutches and a wheelchair. After the biopsy, I was diagnosed with KS. Starting treatment was challenging because I did not have health insurance. Many friends abandoned me. I was in a lot of pain. Yet, my parents told me not to give up.

One of my remaining friends registered me for the National Health Insurance Fund (NHIF). After my registration matured (The NHIF is a Kenyan government-funded insurance that takes 2–3 months after registration to come into effect



**FIG 1.** Visual representation of power of Peer Navigation. Artwork features handwritten words that encompass the impact of a Peer Navigator in both Swahili and English as contributed by the patient narrator himself, KS survivors engaged in the Peer Navigation program, and the Kenya-based study team. The landscape depicts Mount Kenya, Lake Victoria, and Rift Valley, all prominent Kenyan geographic entities (*Original Artwork by author A.G.S. with contributions by other study authors*). KS, Kaposi's sarcoma.

or mature), I received funding for both chemotherapy and travel because of a study being conducted at MTRH.

The night after starting chemotherapy was the first time I slept peacefully in 6 years. My wounds started to dry, and I no longer needed to use crutches. This was motivation to complete my treatment. After chemotherapy, I felt strong. I could now ride a bike, and I even started a business that could

support my family. Years later, I joined the same study team at MTRH as a Peer Navigator where I encourage patients that cancer does not need to be a death sentence ([Fig 1](#)).

As a Peer Navigator, I meet with patients after their diagnosis. I share my personal experiences with overcoming the challenges of KS. We show educational videos, where I am featured, which helps patients believe I am a survivor. They

begin to look forward to starting chemotherapy and have hope of survival.

I also speak to patients who are noncompliant with ARVs about adherence and share how I overcame disclosing my HIV diagnosis. Unfortunately, some patients still believe that traditional medicine is superior to chemotherapy, believing that the disease is due to witchcraft. When I share that traditional medicine worsened my disease, they often change their views and adhere to chemotherapy.

The Peer Navigation program allows me to save lives; many have completed treatment and regained their normal lives through my encouragement. This gives me a reason to wake up every morning with a smile on my face.

### Clinician's Perspective

The causative factors for KS morbidity and mortality in SSA are multifactorial—health system structure, finances, accessibility, knowledge, and stigma all play a role.<sup>5</sup> The importance of early diagnosis is essential as the burden of treatment can shift from ARVs alone in ACTG To stage to more extensive chemotherapy regimens in advanced T1 disease.<sup>6</sup> Yet, delays in care at multiple levels ranging from the individual patient to health systems often result in severe and advanced disease.<sup>7</sup> As this patient describes in his own journey, a breakdown in diagnosis reporting, influence of traditional medicine views, and stigma leading to ostracization contributed to years of disease progression without treatment. Stigma is prevalent and has been cited as one reason for hesitancy in presentation to and sustained engagement in care.<sup>7</sup> The stigma experience of individuals living with KS is complex as patients live with a highly visible form of cancer linked, in this area of the world, most commonly to a concurrent HIV diagnosis.

The survivor's voice has immense power—one capable of naming shared burdens, breaking stigma influence, promoting adherence to lifesaving therapy, and fostering hope in lives of others. One method of incorporating the survivor's voice into care delivery is through the utilization of Peer Educators or Peer Navigators. Peer Navigators/Educators are broadly defined as members of the community with shared lived experiences and positive adherence practices who serve as a source of educational, social, and emotional support through a patient's health journey.<sup>8</sup> Peer Educators have been integrated into cancer care models in neighboring African countries in multimodal ways, including beyond KS, ranging from narrative videos to in-person support groups and community interventions for the two most predominant

cancers in this region, cervical and breast cancers.<sup>9-11</sup> The utility of Peer Educators is broad and can range from creating awareness of breast cancer and self-examination in adolescents to minimize poor survival outcomes linked to advanced-stage malignancy in Nigeria to promoting cervical cancer screening knowledge, intention, and uptake in Tanzania.<sup>9,10</sup>

Integration of peer support into the cancer care cascade has had positive effects on a range of outcomes including improving cancer screening, quality-of-life indices, and treatment adherence.<sup>12-14</sup> The Peer Navigation program's impact on stigma reduction outcomes in patients with HIV-associated KS has been studied in the broader context of a multicomponent navigation strategy in Kenya, which includes peer support and education.<sup>15</sup> In a qualitative analysis, all participants (27 of 27) reported increased knowledge about their condition and most (21 of 27) described feeling less alone and socially isolated, having newfound hope for recovery, inspired faith in cancer treatment, and being empowered to obtain treatment.<sup>15</sup> It is critical to emphasize the challenge of securing funding for Peer Navigators in low- and middle-income countries, a need that expands well beyond the African Region. In HIV research, Peer Navigators are widely recognized for their value,<sup>16</sup> but this has not yet been incorporated as a standard-of-care cost into cancer programs. Peer Navigation for cancer is a potentially important part of improving cancer standard of care but will be difficult to pursue more broadly if not included in programmatic or Ministry of Health budgets. The impact of peer relationships cannot be overstated; it is through sharing experiences, empathy, and support that patients are encouraged in their road to recovery and long-term, holistic well-being.

This patient's journey has resulted in him joining the same study team that facilitated his care just 2 years after treatment completion. Between October 2021 and July 2024, the Peer Navigator in this particular program navigated 77 patients to encourage them to start or continue KS treatment, with a median of five separate interactions per patient.<sup>17</sup> As a Peer Navigator, his generosity with his words and time has impacted hundreds across western Kenya. His goal is to ensure that those living with KS feel they have consistent support and, most importantly, a friend as they navigate what can often be an isolating experience. Every day, he helps patients find and maintain a sense of purpose and is proof that they too can be the drivers of their own journey. In describing his outlook on this role, he says [of introducing himself to new patients and removing his white coat], "I say I am not your clinician; I am your *brother*. Sit, let's talk."

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