The language of cancer communication in Africa

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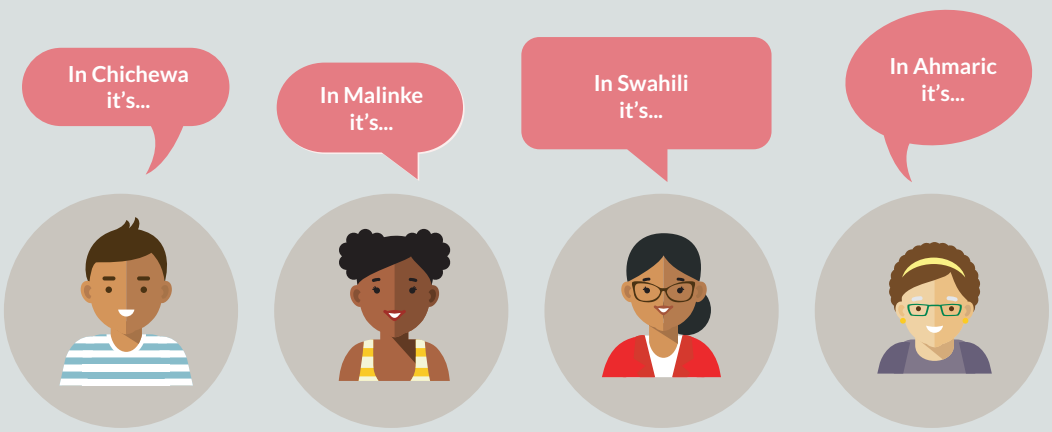
Effective communication plays a crucial role in cancer prevention, early detection and care. Despite its importance it has unfortunately been given insufficient attention, particularly within the African context where it remains an understudied and neglected issue. Barriers in cancer communication can foster stigma and disempowerment among both patients and healthcare professionals. Communication challenges between healthcare professionals and patients are not confined to a specific region – it's a widespread issue across the world, and across cultures and sociodemographic groups within a highly mobile globalized world. Healthcare professionals grapple with difficulties in conveying information to patients due to linguistic differences *(1,2)*. This not only shapes patients' interactions with the health system but also influences their perception of cancer, its preventability and treatability. Language, with its transformative power, can either empower individuals to actively participate in their care or disenfranchise them, hindering their engagement with the healthcare process.

How cancer is spoken about is important, given that language intricately shapes actions, influencing the process from symptom recognition to the proactive pursuit of treatment and care. Often in specific cultural contexts, the linguistic representation of a patient's experience with cancer and cancer care often employs metaphors of warfare and violence *(3)*. Several metaphors commonly employed, including "fighting cancer", "losing the battle" and "cancer warrior" are used within the healthcare setting, in patient narratives and in the community in general *(3)*. Individuals contending with cancer are often characterized as "warriors" or "fighters," while therapeutic interventions are metaphorically framed as "weapons" and part of an "arsenal" *(3)*. Tumours are figuratively depicted as being "blasted" or "exploded" *(3)*. The nuanced impact of these metaphors, specifically their potential to either disempower or empower patients, remains a subject of ongoing debate, criticism, and scholarly discourse.

Language is embedded in culture, and through language, individuals express and articulate their perceptions, emotions, and interpretations of their experiences with illness. The choice of words, narratives, and descriptions used to communicate

Figure 1: **What is cancer in your language?**



these experiences provides insight into the unique ways individuals make sense of and find meaning in their encounters with illness. In essence, language serves as a valuable tool for capturing and expressing the phenomenological dimensions of people's lived experiences of illness *(4)*.

It is crucial to highlight that globally, regardless of the presence of a term for cancer in various cultures, it often carries a significant stigma. For instance, in Western societies, cancer is commonly colloquially labelled as the "C word" *(5)* or "the big C" *(6)*, a designation rooted in its perceived ominous, intimidating and sensitive nature. In specific cultures, such as India, cancer is euphemistically referred to as "a problem". Adding to the complexity, in Dutch, a prevalent insult involves telling someone to "get cancer" *(7)*. Some discussions within the academic sphere have suggested refraining from using the term "cancer" when communicating cases classified as "low risk" to patients. This suggestion aims to alleviate patient anxiety that could influence decisions toward more invasive treatments *(8)*.

The challenges associated with language are not confined to cancer; rather, they extend to other medical conditions, as exemplified by tuberculosis. Tuberculosis, is often referred to as the "disease of poverty," attaching a stigmatizing label to those of low socioeconomic status affected by the condition (9). Within the realm of tuberculosis care and research, certain terms, some of which are also encountered in the context of cancer, perpetuate stigmatization by embodying "metaphors of transgression and punishment." Examples include "treatment defaulter" and "initial defaulter," which imply a judgment akin to loan non-payment, "tuberculosis suspect," insinuating that the patient has committed crime, and "non-compliant," attributing blame while overlooking systemic and structural barriers to treatment interruption *(9)*. Additionally, in the context of cancer, this issue extends to patient labelling and blame in various settings. Terms like "delayed presentation" or "loss to follow-up" may incorrectly imply that patients are at fault, whereas individuals experiencing delays in diagnosis often engage repeatedly with the health system *(10,11)*. This issue may be particularly pronounced in LMICs *(10,11)*. Initiatives such as the Stop TB Partnership's Tuberculosis Terminology Guide have been instrumental in delineating non-stigmatizing alternatives in terminology for tuberculosis care and research *(9)*.

IARC-AORTIC-Aga Khan University undertaking

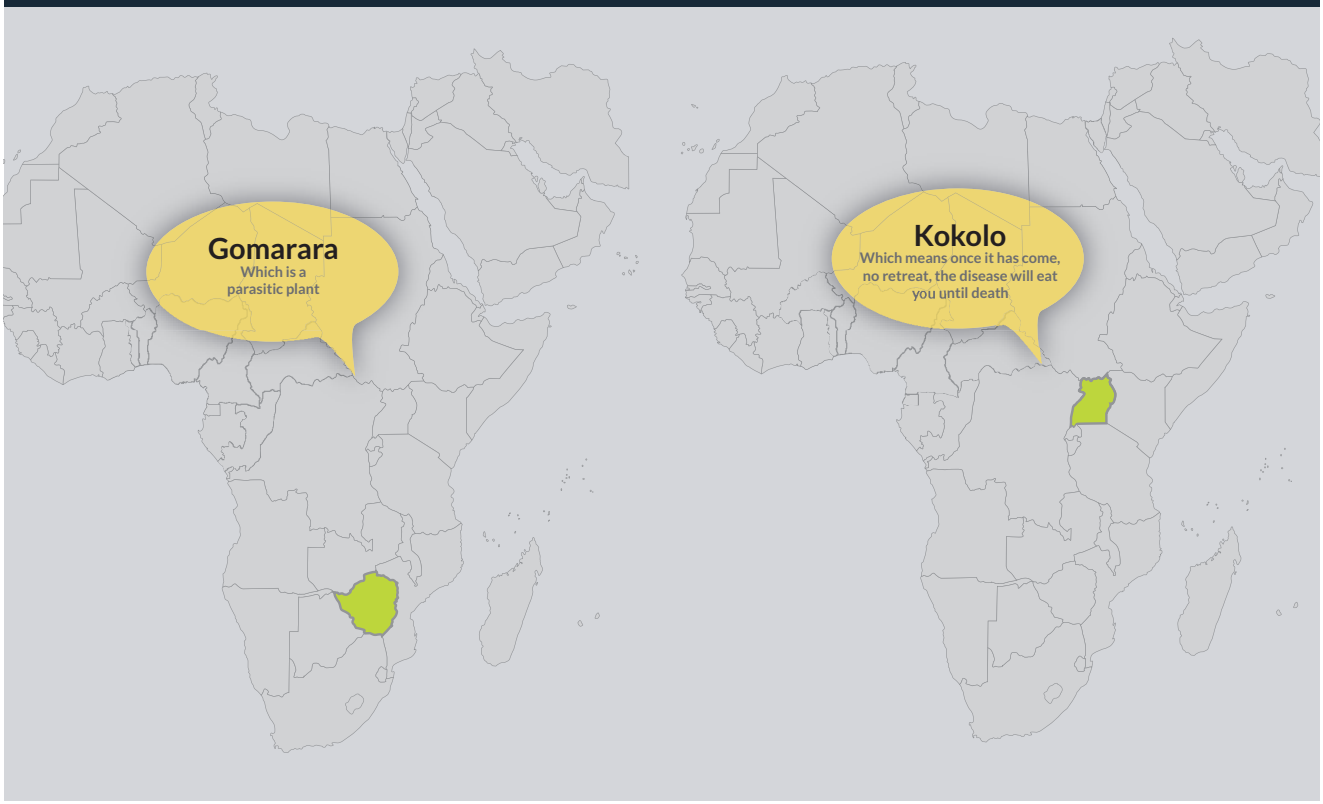
Exploring cancer communication in the African setting is particularly needed for several reasons. Infectious diseases have historically dominated the disease burden in the Continent, and only more recently have lifestyles changed and life expectancy increased to give rise to a substantial cancer burden in the population. The local languages may not necessarily be equipped with a language for this disease and its treatment. Furthermore, late-stage presentations, difficulties in accessing timely diagnosis and treatment, as well as incomplete completion of chemotherapeutic courses are prevalent problems *(12,13)*, possibly pointing to communication challenges amongst a myriad of barriers. Given the vital role of effective communication in providing competent healthcare and fostering active patient participation, in 2023, IARC and AORTIC, in conjunction with the Aga Khan University, Nairobi, commenced an investigation aimed to explore the nature of cancer terminology in African languages. This exploration is also necessary to comprehend how language might contribute to fear, stigma, and communication challenges for healthcare professionals and perpetuate misconceptions and myths about the disease.

Using an online survey, a list of cancer terms used in diagnosis and treatment were provided to participants who were asked to provide each term in their local language (if it exists) followed by a direct translation of the meaning of the term into English (if they know). Terms included cancer, tumour, biopsy, malignant, benign, staging, metastasis, surgery, chemotherapy, radiotherapy, trial, remission, palliative care, survival, recur, and chronic. Participants were invited to participate in the survey through an online survey which was available in English, French, Portuguese and Arabic. Participants invited included health professionals, community health workers, researchers and scientists involved in cancer care and/or research, as well as traditional healers. Thematic analysis was done on the English translated terms in order to identify common themes – topics, ideas and patterns of meaning that come up repeatedly.

Emerging themes

Analysis of the above survey has recently commenced and will be published in peer-reviewed literature in 2024. A flavour of some initial entries are as follows. A participant from Zimbabwe stated that the term "cancer" in Shona was "gomarara" which means a parasitic plant. The participant explained "This is a plant that grows on top of another plant, in a parasitic way, usually killing or disabling the plant". Another participant from Uganda provided the term for cancer in Luganda which is "kokolo" which means "Once it has come, no retreat, the disease will eat you until death". Similar elements of languages that instil fear/tragedy were found in other languages. The weightiness associated with the term "cancer" often extends to its connotation of being overwhelming, unbeatable, and frequently final, contributing to a sense of cancer fatalism. This connotation is evident in our results from the terms used for cancer in Luganda and Shona languages in Uganda and Zimbabwe, respectively, underscoring the gravity

Figure 2: **The word cancer and translation in Shona (Zimbabwe) and Luganda (Uganda)**



and inevitability of fatality. Some languages did not have a term for cancer in the local language. An added complexity in the African setting is that patient-centred communication and shared treatment decision-making may not be directly communicated to the person with cancer themselves, especially for older persons. Rather the diagnosis is first communicated to other family members and cultural norms dictate that further communication and treatment decisions are collective responsibilities.

The full results of our study will shed light on the nature of oncology terminology in African languages and how it may contribute to fear, health disparities, and pose communication difficulties for patients and healthcare professionals. The results reinforce the need for culturally sensitive oncology terminologies for improving cancer awareness and communication, and implications for prevention. It also highlights the need to develop a competent workforce well versed in the nuances and implications of effective and contextual communication in cancer. This work lays the groundwork for future in-depth studies on the topic, considering the diverse languages and cultures across the African continent. ■

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