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Kansa talk: mapping cancer terminologies in Bagamoyo, Tanzania towards dignity-based practice

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ABSTRACT

This paper reports and examines the results of qualitative research on the use of local cancer terminology in urban Bagamoyo, Tanzania. Following recent calls to unify evidence and dignity-based practices in global health, this research locates local medical sociolinguistics as a key place of entry into creating epistemologically autonomous public health practices. We used semistructured ethnographic interviews to reveal both the contextual and broader patterns related to use of local cancer terminologies among residents of Dunda Ward in urban Bagamoyo. Our findings suggest that people in Bagamoyo employ diverse terms to describe and make meanings about cancer that do not neatly fit with biomedical paradigms. This research not only opens further investigation about how ordinary people speak and make sense of the emerging cancer epidemic in places like Tanzania, but also is a window into otherwise conceptualisations of 'intervention' onto people in formerly colonised regions to improve a health situation. We argue that adapting biomedical concepts into local sociolinguistic and knowledge structures is an essential task in creating dignity-based, evidence-informed practices in global health.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Oncological care and cancer prevention in Tanzania and across sub-Saharan Africa remains underdeveloped due to decades of resource misdistribution in the global racial capitalist economy and neoliberal structural adjustment programmes in the nation. This structuring has resulted in late-stage diagnosis, poor access to care, poor quality of care and excess mortality. Dignity-based practices offer a way to address these health systems issues through grounding in local knowledge systems, respectful of local autonomy and created in conjunction with affected communities themselves.

WHAT THIS STUDY ADDS

⇒ We provide a rudimentary overview of the sociolinguistic landscape of cancer in Urban Bagamoyo Tanzania, outlining how people talk about, name and describe cancer, its symptoms and associated classifications. Further, we pinpoint the importance of medical linguistics in the development of dignity/evidence synthesised based practices in cancer care, as well as in conceptualising how dignity-based and evidence-based practices can be synthesised.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ We demonstrate the direction that formative research might take with the intention of creating dignity-based practices. The sociolinguistic dynamics surrounding cancer talk and understandings in Coastal Tanzania do not neatly fit with biomedical paradigms, and thus require programmes and interventions that also go beyond the evidence driven solution paradigm. Rather than refashioning people's ways of being and thinking to align with imported models and the biomedical paradigm, we suggest manipulating sound biological knowledge to the sociolinguistic situation at hand.

INTRODUCTION

Over the past few decades, cancer care and research have garnered increased attention in East Africa. Broadly, low-income and middle-income countries have experienced greater increases in cancer incidence and mortality rates, a trend that is predicted to continue over the next decades.[1] Recent forecasts have predicted that there will be about 2.1 million cases and 1.4 million deaths due to cancer by 2040 in Africa alone.[2]

In Tanzania, cancer incidence and mortality rates are rising fast.[3 4] In 2020, the total incidence rate based on known cases was 67.74 per 100 000 people.[5] Women are the most affected population, with cervical and breast cancer being the most common causes of cancer mortality.[5] In a retrospective study of mortality data in Tanzanian hospitals, Lyimo *et al* found that between 2006 and 2015 the age-standardised hospital-based mortality rate due to all cancers was 47.8 per 100 000 populations.[4]

Like most biomedical infrastructure in sub-Saharan Africa, oncological care and resources for preventative activities in Tanzania is

underdeveloped due to decades of exploitation and resource extraction throughout European imperialism and now under globalised neoliberal capitalism—which maintains colonial economic and political relations. As outlined by decolonial revolutionary and theorist Walter Rodney, like other formerly colonised nations, Tanzania was systematically 'underdeveloped' throughout the 19th and 20th centuries by European imperialists to aid the advancement of Europe.[6] Tanzanian healthcare has had a particularly turbulent history in this global political economy. Immediately after independence, first Prime Minister Julius Nyerere established a unique system of scientific socialism called ujamaa (brotherhood) in which all medical care was directly inspired by the Arusha Declaration of 1967, state-run, and focused on primary healthcare.[7 8] Structural adjustment programmes commissioned by the International Monetary Fund began in 1986, and started a still ongoing transition to public–private partnerships, NGOisaton and commodity-based healthcare in the nation.[9–11] Not only did this result in a decline in standard of living throughout the 1990s,[12] but also, as the ethnographic record shows, noticeably more inaccessible healthcare and social suffering.[13–15]

This is the historical process and structural context that has resulted in the underdevelopment of oncological care in Tanzania. The resulting issues are profound. As the National Cancer Control Strategy estimates, only 10% of cases ultimately reach the national cancer referral hospital and 80% of these cases are late stage.[16] Further, Makene *et al* found the median delay between first symptoms and cancer diagnosis was almost 1 year, mostly driven by socioeconomic inequality, self-referral, out-of-pocket expenses, delays in diagnostic testing and delays while raising funds.[17] Both Makene and others researching cancer access in global health[18] and medical anthropology[19 20] across Sub-Saharan Africa find that this is not an issue for all people with cancer diagnoses. Rather, a growing privatised healthcare landscape and opportunity to travel abroad for care excludes wealthy citizens from these trends in Tanzania and across the continent.[19] In addition to low prioritisation by global actors,[19] colonial histories and current capitalist global relations, manifesting in the forms of late stage of diagnosis, poor access to care and poor quality of care, have created the conditions for poor survival rates and excess cancer mortality in Tanzania.

This paper represents a first step in a research programme aimed at developing dignity-based practices to improve early recognition, care seeking, reduction in delays and improved quality of care in Tanzania. As Seye Abimbola asserts, the age of evidence-based practice and research dominance must come to a close, and a new era combining evidence-based practice and dignity-based practices must begin if global health is to truly create health equity.[21] That is, no longer can public health interventions facilitated in formerly colonised localities be created through data collected by Western-scientific methods, imagined through Western knowledge and value systems, for the goal of imposing 'proven' ways of being or thinking in white, wealthy, settler nation-states. Rather, to respect the dignity and autonomy of these communities as they negotiate this new era of global capitalist exploitation, interventions aimed at improving health must be created in conjunction with the communities, grounded in the epistemology of the locality, and respectful of their agency to accept or reject the intervention.

In pursuit of this new status quo for global health, we seek to understand how words, phrases and definitions connected to biomedical knowledge have entered into local lexicons and established knowledge systems in coastal Tanzania. At the basis of any medical system, whether that be biomedical or locally based care practices, are collectively and individually constructed understandings of illness and care that come in the form of words, sentences and heuristics used to communicate suffering and healing.[22 23] One of the first steps in creating interventions that unite typical evidence-based practices and localised dignity-based practices, then, should be to understand the terminologies people use to name, describe and categorise the biological phenomenon. In other words, in order to shift away from the typical global health practices of imposing colonial ways of being, understanding and language onto formerly colonised places to address growing pandemics, the complexity of how globalised biomedical definitions of disease and illness have been synthesised into localities must be understood, respected and built on.

Thus, coinciding with the Tanzanian Ministry of Health's call to 'recognise and respect cultural diversity' to develop the oncological capacity in the nation,[16] we employed qualitative methods in the Dunda Ward of Bagamoyo in Pwani District, Tanzania. This paper pursues three main goals. First, we explore the sociolinguistic landscape of cancer in Bagamoyo and the important medical linguistic phenomena emerging from it. Second, we outline the practical implications of these findings for the development of dignity-based practices in Tanzania. Finally, we discuss the novelty of our approach to knowledge creation.

METHODS

Study setting

This study was conducted in urban Bagamoyo, a fishing and tourist town fifty kilometres north of Dar es Salaam in a ward called Dunda, which is omposed of 4336 households, 17 474 residents and 6 streets. Bagamoyo is a home to many ethnic groups such as the Zaramo, Kwere, Wadoe, Zigua, Sambaa, Pembans and Swahilis. Due to overgrazing in their homelands as well as business and touristic opportunities in Bagamoyo, new ethnic groups such as Barbaig, Masai, Chagga, Sukuma and Hehe have moved into the district. Communities from the larger Indian Ocean littoral have called Bagamoyo a home for centuries including the Baluch, Indians and Arabs.

Fishing and cultivation of food and commercial crops are the major occupations in Bagamoyo. Cash crops grown in the area include coconut, pineapples and sugarcane, which attracts both internal and external labour. Food crops grown are maize, cassava, sweet potatoes and beans. The major religions are Christianity and Islam with their respective denominations and sects. While a variety of languages are spoken in Bagamoyo, Swahili, the national language of Tanzania, is the vernacular tongue.

Study population

Recruitment for this study took place after ethics approval to conduct research was obtained from both the National Institute for Medical Research of Tanzania (NIMR) and the balozi, street-level political leaders, of Dunda Ward. Recruitment was done through purposive snowball sampling, starting with the balozis' households. From the balozis' recommendations of friends, kins and neighbours, the researchers recruited more to the study. To balance the interlocutor population, the researchers went directly to individuals working in business areas such as video libraries, pharmacies, food vendors, charcoal sellers, water peddlers and tailors. The selection criteria for the study were people who were above 18 years old and currently living in Dunda ward.

Patient and public involvement

Patients were not involved in the design or conduct of the study. The impetus for this project was inspired by the personal and professional experiences of members living in and/or from Tanzania (MYR, FB, HT, SM, OK and AL) and the observations of the Alliance for Women, Child and Youth Survivors, Bagamoyo (AWCYS), our local partner organisation. AWYCS, which four members of the team hold roles in (MYR, SM, OK and AL), conceived, designed, and conducted this project with ZE and consultation from both Tanzanian (FB and HT) global partners (BJH, RG and PW). Decision-making power throughout the design and data collection rested with team members affiliated with AWYCS. Further, as stated, balozi in Dunda ward both approved the project and aided with recruitment. While data analysis was done internally and the public was not consulted, results will be disseminated by AWYCS to both community members in public forums and care providers through closed meetings. See online supplemental appendix 1 for this research project's reflexivity statement.

Data collection

We conducted 33 semistructured interviews between May and July 2021. Interviews were administered at home, business and the offices of Alliance for Women, Children, and Youth Survival (AWCYS), a registered Non Governmental Organization (NGO) with offices in Dunda ward. These interviews occurred at various times of the day based on the availability of the participants and lasted 16–25 min. The interviews were conducted by two researchers native to Tanzania (OK and AL), one of whom was the interviewer and the other a note taker. At the time of the interview both researchers were residents of Dunda ward and worked for a community health organisation, whose office is situated in the same ward. During interviews introduced themselves as resident researchers. All interviews and the consent script were conducted in Swahili. Consent for the interview and recording was obtained before the beginning of each

Table 1 Demographic characteristics of interviewees

Sample characteristics*	Demographic distribution (n=33)(%)	
Sex		
Female	24	(73)
Male	9	(27)
Age, years (mean (SD))	31	(10)
Age, years		
20–29	20	(61)
30–39	6	(18)
40–49	5	(15)
50–59	2	(6)
Religion		
Christian	5	(15)
Muslim	28	(85)
Education level		
Primary	9	(27)
Secondary	15	(45)
Certificate	3	(9)
Diploma (A-level)	2	(6)
University	4	(12)
Occupation		
Employee	8	(24)
Self-employed	19	(58)
Student	1	(3)
Unemployed	5	(15)
Street of residence		
Alpha	3	(9)
Caravan	1	(3)
Kilomo	2	(6)
Kingani	1	(3)
Kisutu	2	(6)
Makarani	14	(42)
Mangesani	2	(6)
Mwanakalenge	2	(6)
QX	1	(3)
Uhindini	4	(12)
Ukuni	1	(3)

Based on 2012 census data, this sample oversampled women by a significant margin, but is on par with the distributions and trends in age.[45]
*Variable distributions are reported as n (%) unless otherwise specified.

interview. All interviews were recorded by a tape recorder for later transcription and fidelity of the terms.

In order to organically draw out cancer terminologies, researchers began the interviews by having participants list the most prominent health issues faced by people in Bagamoyo. If cancer was mentioned in this list, participants were then asked to describe the disease, list other names they knew from it, and list the symptoms they thought it caused. In instances, the interviewee did not mention cancer, the researchers asked if they have heard of saratani, the term used in official government literature and promotional materials.

As ethnographic interviews following the tradition of anthropologist Spradley,[24] it is important to note multiple dynamics. Following local customs of meeting and conversation, some of the interviews with one interlocutor morphed into group discussions as other community members joined the discussion. We did not stop this dynamic as it was iterative, reflective of how many in the community converse with each other outside of interviews, and contextually rich. While some of these emergent discussions were on cancer and generated cancer terminologies, many of them digressed into concerns about the dissatisfaction with the state of healthcare systems, costs, access and expertise. These interviews became both a space for Dunda residents to air their grievances and anxieties about their health as well as spaces where understandings of diseases such as cancer are constructed, negotiated and contested. The practice of allowing was ethically approved by NIMR and those who joined the conversation were given the consent script.

Data analysis

MYR reviewed the audio recorded interviews and compiled terms, categorisations and symptoms listed throughout them in a process similar to thematic analysis as outlined by Guest *et al*[25] and Chapman *et al*.[26] In this, interviews were specifically reviewed for the specific words participants used to name cancer, describe it, articulate symptoms and how it relates to other diseases or categorisations. Data were then compiled on an Excel spreadsheet with demographic data of each participant. MYR and ZE translated the words and phrases collected into English iterations. DWK and MYR analysed the dynamics of the disease categorisations and the cancer-associated symptoms on Excel. Following thematic analysis as a subset of grounded theory and the development of cultural models,[26] the words and phrases provided were analysed beyond their frequency. Focusing on 'identifying and describing both implicit and explicit ideas within the data' as Guest *et al* describe,[25] the terminology in Swahili were correlated with other studies examining medical sociolinguistics in the region[27] and across the interviews to reveal patterns in how cancer is being talked about and, thereby, understood within the social world of Bagamoyo.

RESULTS

Demographic distribution

Table 1 shows the demographic distribution of study participants. As seen, most participants were women (73%), Muslim (79%) and under the age of 30 (61%). While this study disproportionately included women compared with the demography of Bagamoyo, the distribution of religious affiliations and the age of the participants reflected the population of the town. Most of the participants resided on Makarani Street, a main residential area of Dunda Ward, but there was representation from all the streets of the ward. Notably, most participants were self-employed (58%), which encompasses any labour that is done outside of salary work such as owning a shop, driving bodabodas (motorcycle taxis) or fishing. Finally, most participants did not have education beyond secondary school.

Magonjwa madogo (small diseases) and magonjwa makubwa (big diseases)

In the introduction of the interview where interlocutors were asked to list and describe the largest health challenges, many participants grouped the different diseases they knew into magonjwa madogo, small diseases and magonjwa makubwa, big diseases. Participants would commonly explain magonjwa madogo as diseases that are 'easily curable', 'normal', 'affordable', 'ordinary', 'known' or 'non-threatening'. Magonjwa makubwa, on the other hand, was described as diseases that are 'not normal', 'no treatment', 'causes fear', 'causes death', 'high cost', 'cannot be cured' or 'high harm'. This binary categorical system was employed by both men and women from all levels of education.

Table 2 shows the top illnesses and diseases participants provided and the number of times those diseases were grouped in the magonjwa madogo or related categorisations and the magonjwa makubwa or related categorisations. As seen, while there is some overlap between the two categories, there is general consistency which diseases are magonjwa makubwa and magonjwa madogo. Cancer was the most commonly mentioned 'big disease' followed by HIV/AIDS, while malaria, despite being a fatal disease, was the most frequent 'little disease' followed by fevers. Almost unanimously, kansa, as well as other terminologies of it such as saratani, or specific cancers such as lung, prostate, or cervical, was referred to as a magonjwa makubwa. In other words, cancer was widely categorised as a disease that is dangerous, untreatable and of great fear.

Description beyond kansa and saratani

In the listing of the most prominent diseases they faced, kansa, the transliteration of the English word, was both the most dominant term used to name cancer when interlocutors categorised the disease as magonjwa makubwa. Further, while listing and categorising diseases that threaten them and the community, a few interlocutors would also include specific cancers named through

Table 2 Number of times diseases were categorised into magonjwa madogo, magonjwa makubwa or both ordered in the number of times the diseases were listed in the category

Disease name given in Swahili	Approximate English translation	No of participants who categorised the disease as magonjwa madogo (small diseases)	No of participants who categorised the disease as magonjwa makubwa (big diseases)
Kansa/saratani	Cancer	1	31
Malaria	Malaria	20	3
Ukimwi, HIV	HIV/AIDS	0	23
UTI	Urinary Tract Infection	12	2
Kisukari, Sukari	Diabetes	1	13
COVID-19	COVID-19	1	8
Homa	Fever	7	0
Tezi dume	Prostate cancer	0	5
Magonjwa ya moyo	Heart disease	0	5
Mafua	Influenza	5	0

UTI, urinary track infection.

expanding on the word kansa. Four different interlocutors specifically listed kansa ya tezi dume (prostate cancer) along with the general term of kansa as magonjwa makubwa. An additional interlocutor, a woman between the ages of 30 and 40, listed the general term kansa as magonjwa makubwa, but also the specific cancers of saratani ya kizazi (cancer of the reproductive organs, most likely referring to cervical cancer), and kansa ya koo (oesophageal cancer). This was the only instance when cervical and throat cancer were specifically named, as well as when the word saratani was used.

However, when interlocutors were asked to list other names for the disease after they organically characterised kansa in magonjwa makubwa, a wealth of additional terminology to name and describe cancer emerged. Some of questions asked initially included have you heard of other terms to describe cancer in your household and community? Thirty-one of the 33 interviewees nominated emic terms in addition to kansa, while two did not provide any terms. The vast majority (81%) gave up to two of these terms, while four gave three or more. Table 3 shows the distribution and diversity of the terminology by interlocutors. These terms are words that the interlocutors used interchangeably with kansa, or words listed as terms in addition to kansa. As seen, there were a plethora of terms that participants associated kansa with, and uvimbe (swelling), being the most dominant additional term provided. Interestingly, Ocean Road, the name of Tanzania's only oncological institution, and kurogwa/kulogwa (sorcery), were also given as emic ways to make sense of the imported concept of cancer. Further, no demographic characteristics of the interlocutors seemed to be predictors of how many terms they would provide in the interviews or how they would classify different diseases. Beyond the dominant usage of the word kansa instead of saratani and the almost-homogeneous categorisation of kansa in the magonjwa makubwa categorisation, there did not seem to be any noticeable trends between different sexes, age groups, education levels or religions in what terms interviewees provided.

Symptoms of kansa

In 26 interviews (78%), participants listed specific dalili za kansa, symptoms of cancer. About half of the symptoms included by participants were references to bodily

Table 3 List of additional words associated with cancer provided and the number of interviews the term was mentioned

Word given in Swahili	Approximate English translation	No of interviews where word was mentioned
Uvimbe	Swelling	17
Ocean Road	Ocean Road	9
Kurogwa/Kulogwa	Sorcery	8
Vidonda vya utumbo	Stomach wounds	5
Homa Kali	High fever	4
Tatizo la Ngozi	Skin problem	3
Kipele	Pimple	2
UTI sugu	Chronic UTI	2
Damu imefunga (ganda) mahali	Condensed blood	1
Upele	Pimple	1
Tatizo kubwa	Big problem	1
Constipation	Constipation	1
Homa kubwa	Big fever	1
Typhoid	Typhoid	1
Mkanda wa jeshi	Army's belt	1
Utumbo umejikunja	Coiled intestines	1
No of unique words provided		16
Total no of words provided		61

Table 4 List of cancer symptoms provided by participants categorised into external and internal groups

Category	Included symptoms in Swahili	Approximate English translations
1. External bodily illnesses	Uvimbe	Swelling
	Uvimbe kwenye chuchu	Swelling on the nipple
	Vidonda	Wounds
	Kuwa na vidonda	Having wounds
	Kidonda kisichopona	Wounds that do not heal
	Kidonda kikubwa	Large wound
	Kidonda kuoza	Rotting wound
	Vidonda vinavyotoa maji	Wounds with fluid
	Nywele kunyonyoka	Hair falling out
2. Internal bodily illnesses	Homa	Fever
	Homa za mara kwa mara	Occasional/intermittent fevers
	Kuvurugika au kunyong'onyea kwa mwili	Disruption or weakening of the body
	Kukosa nguvu	Weakness
	Mwili kudhoofu	Weak body
	Maradhi ya mara kwa mara	Frequent illnesses
	Kukonda/Kupungua mwili	Weight loss
	Kuishiwa nguvu	Loss of energy
	Damu kuganda	Blood clots
	Kutoka kwa damu	Blood comes out
	Damu zisizo na mzunguko maalum	Bleeding without regular cycle
	Kidonda kinasambaa ndani kwa ndani	Wound spreads deep inside

phenomena that we categorised into 'external bodily illnesses' and 'internal bodily illnesses'. Table 4 provides the statements interlocutors provided grouped under these two analytical categorisations. As seen, external bodily phenomena are descriptions of kansa symptoms that are visibly seen on the surface of the body including kidonda (wounds) and uvimbe (swelling). The internal phenomena category featured slightly more symptoms, many centred around damu (blood), homa (fevers) and nguvu (weakness). Although also listed as alternate names for kansa itself, words such as uvimbe, kidonda and homa were also listed by participants as symptoms. The tendency of our informants was while most participants had separate terminology to name kansa and then describe its symptoms, some participants would even list the term as synonym kansa then describe the symptoms of kansa with the term they had just listed. For example, one participant listed uvimbe as an alternate term for kansa, then also listed it as a symptom for kansa.

The other half of symptoms listed by interlocutors was grouped by symptoms affecting a specific region of the body to describe kansa in general. Table 5 depicts this phenomenon. As seen, the symptoms listed concentrated around the genitalia are by far the most prevalent category of symptoms alongside internal bodily ailments listed in table 4. The line between disease terminology and the symptoms of the disease can be blurred, for example, one 56-year-old listed uvimbe as another kansa and then Uvimbe katika sehemu za uzazi as a symptom of cancer itself.

There was no consistent pattern in what dalili za kansa was listed by participants by sex, age or education level. Men listed menstrual disruption as a symptom while women cited coughs and throat pain as symptoms, even though men are disproportionately impacted by throat disease due to higher rates of smoking and alcohol use.[16] While one woman with a university degree was able to list many symptoms for kansa both generally and for specific cancers, other less-educated participants were able to do the same. Further, more often than not, participants listed symptoms that were then classified into the specific body part references seen in table 5 and the broader terms listed in table 4.

Blurring of terminology, symptoms and cancer types

Finally, the line between what is another word for kansa and what is a symptom of kansa is blurred. While interviewers asked Dunda residents for alternate names for cancer, in their response residents provided alternate names for cancer in the form of descriptions of cancer causes and symptoms. This dynamic is most clearly seen in how other names for *kansa* were also listed as symptoms of kansa itself. As seen in table 3, the most popular term to name cancer beyond kansa, uvimbe (swelling), was also used to describe what kansa does to the body. Homa and kidonda were two other terms that were both alternate terms for kansa and words used to describe what kansa does. The general logic shared by a variety of participants that emerged was, in brief, 'uvimbe can be kansa, but kansa is always uvimbe'.

The diversity of the types of cancers was another important often-blurred area. While two participants listed types of cancer such as cervical and throat, most participants used the term kansa generally and listed broad symptoms (fever, headache, swelling). However, a few participants listed specific ailments to a certain part of the body with specific associated terms with kansa. For example, a key trend was women listing symptoms of ovarian cancer along with the

Table 5 List of cancer symptoms provided by participants categorised by the region of the body the symptom was referred to

Category	Included symptoms in Swahili	Approximate English translations
1. Genitalia	Maumivu sehemu za siri	Pain in the genitals
	Kutoka damu hata kama si siku za hedhi	Bleeding even if it is not days of menstruation
	Uvimbe katika sehemu za uzazi	Swelling in the womb
	Kutokwa na damu ukeni	Vaginal bleeding
	Kutopata choo ndogo kiurahisi	Urinal constriction
	Kukosa hedhi	Loss of menstruation
	UTI kali	Severe Urinary
	Kutoka damu sehemu za siri	Bleeding in the genitals
	Damu katika choo kikubwa	Much blood in the faeces
	Kutopata choo	Loss of defecation
	Maumivu makali katika kushiriki tendo la ndoa	Pain during sexual intercourse
	Kukojoa damu	Blood in urine
	Uvimbe kwenye ziwa	Swelling in breasts
	Mzunguko wa hedhi usio wa kawaida	Irregular menstrual cycle
	Harufu ukeni	Vaginal odour
2. Throat	Kakauka kwa mate	Dryness of saliva
	Kidonda kisichopona	Wound that does not heal
	Kukohoa damu	Coughing blood
	Maumivu kooni	Pain in the throat
	Kikohozi	Cough
3. Skin	Mabadiliko ya ngozi/rangi	Skin changes/colour
	Kuwashwa mwili	Itching
	Kubabuka mwili	Body rash
	Vipele	Rashes
	Kubabuka ngozi	Skin peeling
	Ngozi kutoa maji	Skin oozing

UTI, urinary track infection.

association of cancer with 'chronic UTI' or 'bloody UTI'. In short, kansa seemed to be either be a blanket generalised word to describe dangerous swelling or a specific type of cancer that the participant knew.

DISCUSSION

The goal of this study was to document how urban residents of Bagamoyo use alternate and descriptive words for cancer in their daily settings. Our findings revealed that kansa talk is highly diverse, complex and blurred in naming, symptoms and conceptualisations. The meanings of the Swahili word kansa overlap significantly with those of the English term 'cancer', and is grouped into the ethnomedical categorisation of magonjwa makubwa, big diseases. As a magonjwa makubwa, kansa is associated in a group of diseases that cause 'high harm', have 'no treatment' and 'cause fear'. On further exploration into the local terminology the people of Dunda Ward in Bagamoyo employed to name kansa, 16 emic terms used interchangeably to kansa were found. Further, a plethora of symptoms were used to describe the symptoms of *kansa*, some of which were descriptions of diseases within the body and diseases outside the body. The line between what is the name for cancer, how it was described, and what the symptoms of it was highly blurred. The demographics of what terms a person uses or how many terms they use does not seem to be influenced by their sex, education status or age.

In this discussion, we highlight three key sociolinguistic patterns and how they should inform the development of dignity-based practices in Bagamoyo and greater Pwani district.

Formal versus informal taxonomy and categorisation

From the near-unanimous categorisation of kansa as a magonjwa makubwa, it is clear that *kansa* was a serious concern among people in Bagamoyo. Categorised with the likes of ukimwi and kisukari, the Swahili terms for HIV/AIDS and Diabetes, cancer's gravity and 'uncurable' nature are considered similarly severe to these other two diseases and contrasted with magonjwa madogo such as UTIs or homa ya malaria. However, unlike ukimwi or kisukari, the interlocutors usually listed the term kansa, the English adaption of the biomedical name, instead of saratani, the Swahili word for 'cancer', ultimately of Arabic origin. According to the Tanzanian Government, saratani is the primary name for cancer in the Tanzanian medical system. With saratani only having been listed once in discussions of the health issues the people of Bagamoyo face and not provided as an additional term for kansa, the term should be considered a far less-popular denotation for the health problem relative to

kansa. In communication programmes and plans, using the term kansa may be more productive and acceptable to community members.

Moreover, the existence and use of these ethnomedical categorisations has important implications. Because kansa is a magonjwa makubwa and, thereby, a disease that 'causes death' and associated with 'high cost' or 'caused fear' like HIV and diabetes, there is a very real possibility that open discussion of a diagnosis of kansa is also highly taboo and stigmatised in the community. In prior studies of knowledge of different cancers across Tanzania, stigma against cancer patients in communities is contested. In Northern Tanzania, Harris, Shao and Sugarman found that patients with cancer were afraid to speak about a cancer diagnosis openly.[28] Further, Chao *et al* found that women in the northern city of Mwanza and its surrounding area were afraid of a breast cancer diagnosis.[29] However, Morse *et al* revealed that women in Dar es Salaam dominantly do not stigmatise women with breast cancer.[30]

In Bagamoyo, cancer is heuristically linked with other magonjwa makubwa such as ukimwi (HIV/AIDS)[31] and sukari (diabetes)[32 33] that kill and that are often stigmatised. However, fear of a disease and stigma of those who have said disease are not inherently inseparable, and as these prior studies show, cancer may not be stigmatised against at the level HIV is. This ethnomedical categorisation is a ripe arena in which the gravity and danger of cancer can continue to be promoted by the Tanzanian Ministry of Health and other actors. However, it must be pursued with caution in ways that would not result in ostracising of or discrimination against patients with cancer.

A diverse semantic landscape

The 16 additional ways participants used to describe kansa beyond its names begin to reveal how different people thought about and made sense of the disease. Corresponding with Arthur Kleinman's concept of explanatory models, in which the understandings of illness are constructed through the constant exchange of ideas, interpretations and concepts between different people,[34] cancer understandings can be first seen through a emic view—a perspective which places people within the experience, effects and relations that the disease engenders. The most common typology of these terms referenced to how cancer tumours appear on the body. The prevalence of terms such as uvimbe, swelling, kipele/upele, pimple, tatizo la ngozi, skin problem and mkanda wa jeshi, army's belt, all words that refer to manifestation of cancer on the body, suggest that a major way people make sense of kansa is through how it can be visually recognised. Similarly, the terms damu imefunga (ganda) mahali, condensed blood, utumbo umejikunja, coiled stomach and vidonda vya utumbo suggest that many understand cancer through what they believe it does to the body internally. A common strategy employed to help define what kansa is beyond its name is to articulate what the disease seems to do to the body both internally and externally. Given that there seems to be low understanding of the distinct types of cancer, kansa seems to be understood as something that is confined to the type of cancer an individual knows about. As often interviewees listed the same illnesses as descriptions of kansa and symptoms of kansa, this could point towards kansa being a disease that is understood through single type of cancer or the symptoms of one cancer.

Other terms for kansa were related to or directly reference other diseases. In relation to Winch *et al*'s 1996 study on malaria terminology in Bagamoyo,[27] the use of homa kali/kubwa, high/big fever, to describe cancer means that the disease could be understood in relation to a complex ethnomedical system of homa classifications. However, other terms listed by participants were more unusual and demand further investigation. The popular usage of kurogwa/kulogwa, sorcery, suggests that kansa has been synthesised into local ethnomedical knowledge structures explaining how and why illness and disease happen. Interestingly, Ocean Road, the name of the national cancer institute, was also used as a way to understand the disease itself. These ways of understanding through associations to know place known as being a place of cancer care and a common ethnomedical classification system further add to the diversity of how cancer is understood and what it does among the people of Bagamoyo, and point towards potentially important dynamics. As participants who listed homa commonly did not list other symptoms, there could be a lack of recognition of cancer symptoms among people in Bagamoyo. Further, as place-based understanding of disease are not a recorded method of conceptualising diseases and illnesses in Coastal Tanzania, this prevalent way to understand cancer demands more attention.

However, following Kleinman[34] as well as Weiss' articulation of the need for a nuanced account of cultural models of illness explanation and behaviours[35] in this diverse semantic landscape in which many interpretations of what kansa is and what it does to the body exist, emic frameworks alone are not enough. The examples of how people in Dunda Ward make sense of kansa show how understanding cancer go beyond the biomedical paradigm, but are not completely divorced from it. That is, while many individuals' current understandings of cancer not match the biomedical definition of cancer or understanding of what it does to the body, many of these understandings of kansa seem to be derived from or constructed in relation to biomedical constructions of what cancer is. Further, how kansa is healed is also a complicated semantic arena. The location of sorcery by many interviewees suggests that how kansa can become a problem or why it is deadly is understood beyond biological processes in the body, but also the common invocation of Ocean Road indicates that the hospital is another important place where healing of *kansa* happens. In short, understandings of what kansa is in Bagamoyo neither be seen as completely autochthonous—or,

native to the cultural, historical ethnomedical systems of Bagamoyo—nor completely aligned with the globalised biomedical paradigm of cancer. Taking seriously that both ethnomedical models and biomedical understandings of cancer are conceptual places from which residents of Dunda ward can construct understandings of kansa, the semantic landscape of cancer is a dynamic, ever evolving arena in which people draw from different legitimate bodies of knowledge to formulate mismatch, malleable ideas about what this dangerous, increasingly relevant disease is and what it does.

This phenomenon of defining, categorising and distinguishing should not be seen as a mistake or ineptness that must be corrected. Rather, this is the process of knowledge introduction, contestation and synthesis over time. Blurring of lines between causes, symptoms and what to call them is a well-established and studied pattern in both non-Western healing system and when Western biomedicine and knowledge about disease/illness enters these otherwise systems.[36–38] Undoubtedly, though, this also reveals potential issues that need to be worked through to improve recognition of cancer symptoms and impetus to get screened for different diseases. The underdetermined nature of what kansa is and the other terms associated with it suggest that there could be a large gap between the information, diagnoses and treatment medical practitioners provide and how that is received by patients. However, instead of being seen as a situation that must be corrected and simply imposing Western words and definitions, it should be seen as a process of cultural, linguistic and epistemological synthesis that can be guided towards desired results. The semantic underdetermination of what cancer is in Bagamoyo and the number of different ways it is defined and understood in relation to local medical sociolinguistic structures suggests there are a plethora of Swahili words and statements that could be infused with biomedical knowledge.

Developing dignity-based practices in Tanzania and beyond

While the oncological capacity of the nation must be urgently expanded to quell a coming wave of excess cancer morbidity, how kansa is understood and talked about will still be an issue within an expanded system. As alluded to throughout this discussion, the question becomes how can the symptoms and side effects of cancer be translated into Swahili? Instead of being an issue that must be 'fixed' by refashioning people's ways of being and thinking to align with imported knowledges, we ask how can sound biological knowledge be manipulated and refashioned to fit into the situation at hand?

Traditionally, in global public health, 'health literacy' or 'health education' interventions are the answer. As Eugene Richardson highlighted during the West African Ebola outbreak in 2014, these programmes are dominantly premised on two underlying phenomena: coloniality, or the superiority of knowledge derived from European and North American cultures; and evidence as tested through scientifically proven methods such as randomised control trials.[39 40] If the goal of global health is to move towards an alternate horizon of pluralversality[41] or a 'decolonised' global ecosystem with more distributed power, eliminating hierarchies of knowledge must take precedent over the status quo of evidence-based, generalisable study. This is not to say that there should not be evidence-based research or that evidence from prior health literacy or health education studies. It is to say that in the pursuit of dignity-based, epistemically disobedient public health promotion these evidence from other times and other places should be advisory at best.

Dignity-based practices can be developed in Tanzania by recognising that the ambiguity of kansa talk can cause problems, respecting why this situation is the way it is, and, from this recognition, working with the community on ways they feel is best. The goal of this is not to create programmes that are generalisable on global scales. Rather, it is to keep the ethnomedical and linguistic system in-tact while purposely infusing it with sound biomedical understandings. Thus far, we have outlined places where biomedical understandings of cancer could be infused into the current sociolinguistic landscape of Bagamoyo. Here, we briefly offer insights into how knowledges and languages can be synthesised in the spirit of dignity-based global health practice. While the results of this study are designed to inform actions and practices in Tanzania, this thinking can be replicated in other areas where non-Romance languages are the norm. It must be noted, though, that these are not blanket recommendations. In dignity-based research, local context and the dynamics of it take precedent.

1. Know the nature of language: Language is the basis of human society. Words are the currency of that basis and the medium through which all understanding is built. Language is a constantly evolving process as words are created, lost, reformatted, and move between people as they interact with each other. Swahili itself is one of the most unique products of this process in the world. Formulated through over nine centuries of interactions between trading communities and Indian Ocean travellers, Swahili is a trade language combining Arabic with Bantu-descended languages while also featuring words incorporated from Hindu, Portuguese and now English.[42] In this age of global neoliberal capitalism, Swahili will continue to evolved as English maintains dominance but also Chinese becomes increasingly relevant to Tanzania's economy. In regard to medical sociolinguistics and cancer, it should be expected that given the current global economic, political and social ecosystem, medical words from English and Chinese will continue to be adapted into Swahili. The grey area becomes how meaning is attached to those assimilate words to make sense of them within Swahili sociolinguistics. As seen through this project, a variety of different associations—some in alignment with biomedical understandings of cancer, some that are not—are used to make sense of the

adapted word kansa. Over time, these associations and the meaning of the words will continuously change.

2. Respect the will of the people: In contrast to HIV where the Swahili word ukimwi became the dominant name for the disease in Swahili, this research shows that the adapted English word kansa is dominantly used over the 'Swahilised' word saratani. In many cases, interviewees did not know what the word saratani was altogether. The fact that the English-adapted version of the word has taken power over the Swahilised version should not be seen as morally bad. People and their freedom to use, adapt and change words are the driving force of language. What the people of Bagamoyo have collectively decided is the naming for the biological phenomenon of cancer matters and should be respected as such. Rather than shunning the usage of kansa, it should be embraced as the word to focus on to build meaning and definition under.
3. Collaboration is key, but ownership is first: Both these two assertions point towards a fundamental aspect of creating dignity-based programming: collaboration. To create initiatives that build dignity-based, culturally contextual definitions and understandings of kansa should be developed by a team of experts on Swahili sociolinguistics, knowledge holders of traditional Swahili language and medicine, and public health researchers. While a team, the hierarchy inside this group should not be equal. Those most familiar with the intricacies of Swahili and the language surrounding disease and illness on the Swahili coast should hold power in the group. Public health thinking should merely be used to guide how to best implement the knowledge, definitions and associations these local experts create. This has precedent. As anthropologist Stacy Pigg shows in her work on AIDS understandings in Nepal, equitable collaboration between physicians, social scientists, community health workers and the community can reveal the avenues where biomedical terminology and translations can be synthesised into existing medical knowledge and sociolinguistic systems.[43] With participatory community methods, such as those informed by human centred design[44] that can gauge community reception to kansa (note: not 'cancer') education programmes, these programmes can become even more responsive and tailored to the local context of Bagamoyo. Here, dignity of language, epistemology and the ability of people to create medical knowledge and linguistic representations on their own terms is centred.

Limitations

While we present novel findings on cancer sociolinguistics in Bagamoyo, Tanzania and theorise the interface of linguistics, health literacy and the creation dignity-based programming, major limitations to our study must be addressed. First, our sample is not representative of the current known population of Bagamoyo city—particularly regarding gender. Women have disproportionate influence in the sample, which could lead to discrepancies in our data. Voices of men in the community, especially those who work long hours on fishing boats or are migrant workers, are underrepresented. The findings of this phase of the project could be skewed towards the perspectives of this demographic.

Further, translation is an inherently fickle task. While MYR, the primary translator, is a native Swahili speaker and ZE is a proficient, learnt speaker, translation is an imperfect practice. Many of the words featured in this project have no direct English translations just as many of the words surrounding cancer have no direct Swahili translations. Thus, there is a possibility that the translations provided in the results can be interpreted in alternate ways, and thus could impact the overall results themselves.

CONCLUSION

The semantic landscape of cancer in Dunda Ward of Bagamoyo is deep and diverse with little agreement among participants concerning what cancer is associated with and what symptoms it causes. In this article, we argue that the first step in creating interventions that unite typical evidence-based practices and localised dignity-based practices in global health is understanding the terminologies people use to name, describe, and categorise the biological phenomenon. We then demonstrate how this can be done through mapping a rudimentary sociolinguistic landscape of cancer in Bagamoyo, Tanzania. Using data from our qualitative study, we identify areas where dignity-based practices can be created to address areas in which biomedical knowledge can be infused into established ethnomedical knowledge and sociolinguistic systems. Through creation of programmes and improve care-seeking and symptom-recognising behaviours without disrespecting or degrading larger knowledge systems in coastal Tanzania.

In an age of growing calls for the end of epistemic injustice in global health, facilitating 'health literacy' along dominant biomedical paradigms or conducting intervention that transplants dominant biomedical words and concepts into formerly colonised localities is not enough. Rather, deliberate and thoughtful synthesis between biomedical science is both possible and realistic in Bagamoyo and beyond. In this paper, we have sought to provide an example of formative research that seeks to inform the synthesis of dignity-based practices. By drawing attention to how adapting biomedical concepts into sociolinguistic and knowledge structures is an essential task to build localised, autonomous, dignity-based medical systems, we hope that our research focus on the intersections of sociolinguistics and dignity-based global health can inspire parallel projects in other localities around the world. As thinking on how to create dignity-based interventions surrounding local medical linguistics is rudimentary, this research is welcome and needed. Our key assertion here is that words, their histories and

the broader knowledge systems they represent matter. If epistemologically pluralistic health systems are to exist and be built by the field of global health, the coloniality of language and its advancement through status-quo transfers of Western, biomedical knowledge must be overcome.

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REFERENCES

1 Kocarnik JM, Compton K, Dean FE, *et al*. Cancer incidence, mortality, years of life lost, years lived with disability, and disability-adjusted life years for 29 cancer groups from 2010 to 2019: a systematic analysis for the global burden of disease study 2019. *JAMA Oncol* 2022;8:420–44.
2 Sharma R, Nanda M, Fronterre C, *et al*. Mapping cancer in Africa: a comprehensive and comparable characterization of 34 cancer types using estimates from GLOBOCAN 2020. *Front Public Health* 2022;10:839835.
3 Mboera LEG, Rumisha SF, Lyimo EP, *et al*. Cause-specific mortality patterns among hospital deaths in Tanzania, 2006-2015. *PLoS One* 2018;13:e0205833.
4 Lyimo EP, Rumisha SF, Mremi IR, *et al*. Cancer mortality patterns in Tanzania: a retrospective hospital-based study, 2006-2015. *JCO Glob Oncol* 2020;6:224–32.
5 Global Cancer Observatory. Globocan2020: Tanzania factsheet; 2021. Available: https://gco.iarc.fr/today/data/factsheets/populations/834-tanzania-united-republic-of-fact-sheets.pdf [Accessed 15 Mar 2023].
6 Rodney W. *How Europe underdeveloped Africa*. Verso Books, 2018: 433.
7 Nyerere J. *The Arusha declaration: ten years after*. Dar es Salaam: Gov Press, 1977. Available: https://journals.co.za/doi/pdf/10.10520/AJA00020117_202
8 Stöger-Eising V. Ujamaa revisited: indigenous and European influences in Nyerere's social and political thought. *Africa* 2000;70:118–43.
9 Munishi G. *Private health care in Tanzania: private health sector growth following liberalization in Tanzania. Report on work in progress with support from the international health policy programme*. Dar es Salaam: University of Dar es Salaam, 1997.
10 Mwabu G, Ugaz C, White G. *Social provision in low-income countries: new patterns and emerging trends*. Oxford University Press, 2001. Available: https://econpapers.repec.org/bookchap/oxpobooks/9780199242191.htm
11 Tripp AM. *Changing the rules: the politics of liberalization and the Urban informal economy in Tanzania*. University of California Press, 1997: 292.
12 Policy implications of adult morbidity and mortality: end of phase I report. Dar es Salaam, Tanzania Ministry of Health: United Republic of Tanzania; 1997.
13 Benson JS. The impact of privatization on access in Tanzania. *Soc Sci Med* 2001;52:1903–15.
14 Caplan P. Between socialism & neo-liberalism: mafia Island, Tanzania, 1965-2004. *Rev Afr Polit Econ* 2007;34:679–94.
15 Kamat V. This is not our culture! discourse of nostalgia and narratives of health concerns in post-socialist Tanzania. *Africa* 2008;78:359–83.
16 Tanzania national cancer control strategy. Dar es Salaam, Tanzania Ministry of Health: United Republic of Tanzania; 2013. Available: https://www.iccp-portal.org/system/files/plans/NCSS%20Book.pdf [Accessed 16 Mar 2023].
17 Makene FS, Ngilangwa R, Santos C, *et al*. Patients' pathways to cancer care in Tanzania: documenting and addressing social inequalities in reaching a cancer diagnosis. *BMC Health Serv Res* 2022;22:189.
18 Foerster M, Anderson BO, McKenzie F, *et al*. Inequities in breast cancer treatment in sub-Saharan Africa: findings from a prospective multi-country observational study. *Breast Cancer Res* 2019;21:93.

19 Livingston J. *Improvising medicine: an African oncology ward in an emerging cancer epidemic*. Duke University Press, 2012.
20 Mika M. *Africanizing oncology: creativity, crisis, and cancer in Uganda*. Ohio University Press, 2022: 311.
21 Abimbola S. When dignity meets evidence. *Lancet* 2023;401:340–1.
22 Good MJD, Brodwin P, Good B, *et al*. *Pain as human experience: an anthropological perspective*. University of California Press, 1994: 223.
23 Briggs CL. Communicability, racial discourse, and disease. *Annu Rev Anthropol* 2005;34:269–91.
24 Spradley JP. *The ethnographic interview*. Waveland Press, 2016: 255.
25 Guest G, MacQueen K, Namey E. *Applied thematic analysis*. 2455 Teller Road, Thousand Oaks California 91320 United States: SAGE Publications, Inc, 2012.
26 Chapman AL, Hadfield M, Chapman CJ. Qualitative research in healthcare: an introduction to grounded theory using thematic analysis. *J R Coll Physicians Edinb* 2015;45:201–5.
27 Winch PJ, Makemba AM, Kamazima SR, *et al*. Local terminology for febrile illnesses in Bagamoyo district, Tanzania and its impact on the design of a community-based malaria control programme. *Soc Sci Med* 1996;42:1057–67.
28 Harris JJ, Shao J, Sugarman J. Disclosure of cancer diagnosis and prognosis in northern Tanzania. *Soc Sci Med* 2003;56:905–13.
29 Chao CA, Huang L, Visvanathan K, *et al*. Understanding women's perspectives on breast cancer is essential for cancer control: knowledge, risk awareness, and care-seeking in Mwanza, Tanzania. *BMC Public Health* 2020;20:930.
30 Morse EP, Maegga B, Joseph G, *et al*. Breast cancer knowledge, beliefs, and screening practices among women seeking care at district hospitals in Dar es Salaam, Tanzania. *Breast Cancer (Auckl)* 2014;8:73–9.
31 Roura M, Urassa M, Busza J, *et al*. Scaling up stigma? The effects of antiretroviral roll-out on stigma and HIV testing. *Sex Transm Infect* 2009;85:308–12.
32 Mtuya C, Cleland CR, Philippin H, *et al*. Reasons for poor follow-up of diabetic retinopathy patients after screening in Tanzania: a cross-sectional study. *BMC Ophthalmol* 2016;16:115.
33 Metta E. "A disease that God has given me" patients and Caregivers' perspectives on diabetes in southeastern Tanzania. *BMC Public Health* 2023;23:213.
34 Kleinman A. *The illness narratives: suffering, healing, and the human condition*. Basic Books, 2020: 308.
35 Weiss MG. Cultural epidemiology: an introduction and overview. *Anthropol Med* 2001;8:5–29.
36 Kleinman A. Concepts and a model for the comparison of medical systems as cultural systems. *Soc Sci Med* 1978;12:85–93.
37 Stoner BP. Understanding medical systems: traditional, modern, and Syncretic health care alternatives in medically pluralistic societies. *Med Anthropol Q* 1986;17:44–8.
38 Young A. The relevance of traditional medical cultures to modern primary health care. *Soc Sci Med* 1983;17:1205–11.
39 Richardson ET. On the coloniality of global public health. *Med Anthropol Theory* 2019;6.
40 Richardson ET. *Epidemic Illusions: on the coloniality of global public health*. Cambridge, MA, USA: MIT Press, 2020: 224.
41 Affun-Adegbulu C, Adegbulu O. Decolonising global (public) health: from Western Universalism to global Pluriversalities. *BMJ Glob Health* 2020;5:e002947.
42 Nurse D, Hinnebusch TJ, Philipson G. *Swahili and sabaki: a linguistic history*. Univ of California Press, 1993: 813.
43 Pigg SL. On sitting and doing: ethnography as action in global health. *Soc Sci Med* 2013;99:127–34.
44 Holeman I, Kane D. Human-centered design for global health equity. *Inf Technol Dev* 2019;26:477–505.
45 Tanzania national census 2012. Dar es Salaam, Tanzania Bureau of Statistics; 2013. Available: https://www.nbs.go.tz/nbs/takwimu/references/Tanzania_in_figures2012.pdf [Accessed 15 May 2023].