

Insights from Conducting Community- and Health Facility-Based Cancer Research in Sub-Saharan Africa

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Abstract

This article reflects on the process of conducting community- and health facility-based research on cancer awareness and early diagnosis in selected countries in sub-Saharan Africa, namely, South Africa, Uganda and Zimbabwe. We draw from two research projects: the African Women Awareness of CANcer project and the African aWAREness of CANcer and Early Diagnosis programme. Drawing on reflections from the project management team, field notes and minutes from team meetings, we describe key challenges and lessons learnt. Our results constellate around six core features of community-based and health facility-based research, namely, entry and access, sampling, geographical and infrastructural challenges, safety and security, overburdened and under-resourced health facilities, and contextual nuances. Conducting community- and facility-based health research in sub-Saharan Africa has context-specific challenges and opportunities which have an impact on the planning and conducting of such research. Doing rigorous research in sub-Saharan Africa requires locally relevant, collaborative, timely and creative solutions, and mutually beneficial community partnerships.

Keywords: community-based research; health facility-based research; cancer; sub-Saharan Africa

Introduction

Low- and middle-income countries (LMICs) face a disproportionate burden of cancer mortality, and by 2030 are predicted to account for three quarters of cancer-related deaths (Sung et al., 2021). Increasing cancer incidence and poorer prognosis can be attributed to ageing societies, health disparities related to quality and accessibility, and high prevalence of risk factors (*The Lancet*, 2018). The stage at presentation is an important predictor of prognosis, with advanced stage presentation (stage III or IV) associated with a poorer prognosis. Early-stage presentation can lead to curative treatment and better health outcomes and is imperative for comprehensive cancer control (World Health Organization, 2020). An important component of shifting to earlier stage diagnosis is thorough research on the individual, community, health system and structural factors which result in later stage diagnosis in LMICs. Indeed, understanding and addressing health needs in under-resourced contexts is imperative to creating reliable, quality and equitable health solutions (Casale et al., 2013). However, conducting health research in these contexts has a particular set of challenges and opportunities which has an impact on planning and conducting research (Andrews et al., 2019; Casale et al., 2013; Kue et al., 2015; Nel et al., 2017). There is a lack of research on the challenges and opportunities particular to planning and conducting cancer research in health facilities and community settings in LMICs.

Public health issues, in both urban and rural areas in LMICs, are complicated by high rates of urbanisation, inequality, poverty, development backlogs, insufficient resources, inadequate social and public health systems, challenging geographic and bureaucratic landscapes, and poor environmental management (Mathee et al., 2010). Considering this, health research in both the community and facility settings must be conscious of the social, economic and structural context in which it is conducted (Andrews et al., 2019). Even when building in relevant safeguards, doing fieldwork in LMICs is often fraught with challenges related to gaining (and retaining) entry into research sites, safety concerns, incomplete interviews and high non-response rates (Mathee et al., 2010; Mulumba, 2007; Nel et al., 2017; Sharp & Kremer, 2006).

Despite the inherent complexity related to conducting health research in community and facility settings, limited knowledge remains in scientific communities on these challenges associated with conducting research in LMICs (Casale et al., 2013). Casale et al. (2013, p. 9) argues that “no matter the extent of scientific rigour, consultation and planning, unexpected obstacles will inevitably emerge during field research, and these will require adaptive strategies to be overcome”. Documenting the nuances of fieldwork challenges and preparing public health researchers for conducting research in LMICs is imperative not only for meeting targets and for collecting good quality data, but also for producing research that is contextually and culturally sensitive, adaptive and rigorous (Casale et al., 2013; Mulumba, 2007; Munro et al., 2009).

Research that employs community-based approaches, such as community-based participatory research, offers a closer analysis of the nuanced and contextually fraught process of doing health research, from conceptualisation to dissemination (Andrews et al., 2019; Maar et al., 2011; Mulumba, 2007; Nel et al., 2017). Scholarship has begun to develop a refined picture of the process of health research, such as the impact of inherent power imbalances between participants and researchers (Maar et al., 2011), the importance (and limitations) of community and local stakeholder partnerships (Andrews et al., 2019; Kue et al., 2015; Mathee et al., 2010), challenges of North–South research collaborations (Casale et al., 2011), structural challenges and resource constraints (Casale et al., 2013), the imposition of broader public health agendas on local community needs (Simon et al., 2007) and the ethical implications of conducting health research on vulnerable populations (Maar et al., 2011; Simon et al., 2007).

The aim of this article is to reflect on the process of conducting health research on awareness of cancer and early diagnosis in sub-Saharan Africa (SSA), in community- and facility-based settings, and to identify lessons, challenges and strategies that may be useful for future research in similar contexts.

Methods

Drawing on retrospective reflections of the project management team, regularly recorded notes by fieldworkers, field site coordinators and researchers, and notes and

minutes from team meetings, we describe key challenges and lessons learnt during data collection for two projects (described below).

We draw on the following two research projects:

- The African Women Awareness of CANcer (AWACAN) project developed a valid and reliable tool to measure breast and cervical cancer awareness among women in SSA to support the development and evaluation of interventions aimed at promoting timely diagnosis of cancer. AWACAN was a multi-method research project conducted between 2016 and 2020. It had four objectives, namely, (1) developing and validating a survey instrument to measure community breast and cervical cancer symptom awareness, knowledge and beliefs in Africa (Moodley et al., 2019); (2) describing and comparing breast and cervical cancer symptom beliefs, knowledge and awareness in rural and urban settings in Uganda and South Africa (SA) via a cross-sectional survey (Moodley, Constant, et al., 2021); (3) assessing the degree to which symptom overlap between breast and cervical cancer and common infectious diseases influences symptom assessment and help-seeking behaviour via in-depth interviews with women with potential breast or cervical cancer symptoms (Harries et al., 2020; Mwaka et al., 2021); and (4) exploring primary care level provider interpretation and management of breast and cervical cancer signs and symptoms via vignettes and interviews with healthcare workers (Moodley, Harries, et al., 2021).
- We extended our AWACAN project into the African aWareness of CANcer and Early Diagnosis (AWACAN-ED) programme, which focuses on advancing early diagnosis of cancer in southern Africa. AWACAN-ED is made up of three workstreams, namely, (1) assessing the time intervals from noticing breast, cervical and colorectal cancer awareness to referral and diagnosis and the factors—such as demographic, financial, health history, perceptions and affective responses to symptoms and socio-economic factors—influencing these intervals; (2) developing tools that promote more timely presentation and referral for breast, cervical and colorectal cancer; and (3) evaluating the tools across local settings to ensure that they are operationally and economically feasible and equitable, socio-culturally acceptable and support timely referral. This article focuses on the fieldwork conducted for workstream one between 2022 and 2023.

Setting

The AWACAN study was conducted in SA and Uganda. Uganda has a population of 45.85 million people and is a low-income country (United Nations Population Fund, 2023). The urban and rural study sites, namely Gulu Municipal (now Gulu City) and Nwoya district, were selected in Northern Uganda, the poorest region in the country (Owari, 2020). SA, with a population of 59.39 million people, is a middle-income country. The urban study site, Khayelitsha, is in the Western Cape, which is one of the wealthier provinces but one of the nine provinces with the most income inequality. The

rural site, Lusikisiki, is in the Eastern Cape, which has low levels of wealth (National Department of Health [NDoH] et al., 2019; Statistics South Africa, 2019).

The AWACAN-ED study is being conducted in health facilities in SA and Zimbabwe. In SA, the research was conducted in two of the nine provinces, namely the Western Cape and the Eastern Cape, differentiated from each other by access to resources and health status (NDoH et al., 2019). The SA public health system has three tiers: primary, secondary and tertiary. Patients with symptoms generally self-present to primary healthcare clinics and may then be referred to secondary level regional/district hospitals (and occasionally directly to tertiary outpatient departments) for further investigations. Resource dependent, patients may be diagnosed and treated at secondary level or referred to a tertiary level facility for further diagnostic investigation and management. Zimbabwe is divided into 10 administrative provinces, and the public health system has three tiers: primary, secondary and tertiary. Like SA, patients self-present to primary level facilities for possible cancer symptoms. In provinces where secondary level hospitals are available, patients are referred for a diagnostic biopsy procedure. Once the cancer diagnosis has been confirmed, most of the patients are then referred to the tertiary hospitals for expert management depending on their geographical location.

Documentation of Key Challenges, Lessons and Adaptations

The AWACAN and AWACAN-ED project teams had weekly field team meetings in each country. During these meetings, fieldwork progress, concerns and strategies were shared. The meetings were also used as spaces for the field team to work through challenges as they arose. In addition, bi-monthly management meetings were held with the broader teams across countries. The field teams were in close contact both in person and via WhatsApp to address challenges and questions as they arose in the field. The research team and field site coordinators documented challenges faced by the teams and the emergent strategies developed to address them. Monthly investigator meetings attended by the entire research team were held throughout the project.

Ethics

Ethics approval for AWACAN was obtained from the Faculty of Health Sciences Human Research Ethics Committee (HREC 544/2016) at the University of Cape Town, the Lacor Hospital Institutional Research Ethics Committee (LHIREC 027/11/2016) and the Ugandan National Council of Science and Technology (HS60ES). Ethics approval for AWACAN-ED was obtained from the Faculty of Health Sciences Human Research Ethics Committee (HREC 664/2021) at the University of Cape Town, the joint research Ethics Committee of Parirenyatwa Hospital and the University of Zimbabwe Faculty of Medicine and Health Sciences (JREC 363/21), the Medical Research Council of Zimbabwe (MRCZ/A/2831), and the Research Council of Zimbabwe (MRCZ/A/2831). For both studies, written informed consent was obtained from all participants.

Findings

The findings have been structured around six main themes: (1) entry and access; (2) sampling; (3) geographical and infrastructural challenges; (4) safety and security; (5) overburdened and under-resourced health facilities; and (vi) contextual nuances.

Entry and Access

Gaining entry and access to community and health facility spaces for our research was imbued with contextual sensitivities, practical limitations and bureaucratic processes. Entry and access to community and health facility spaces in both projects were facilitated through (1) leveraging existing community and stakeholder networks, (2) building relationships where existing connections did not extend, (3) establishing project advisory committees (PACs), (4) sharing agency through collaborative processes, and (5) navigating through numerous levels of ethical approvals and institutional permissions.

Leveraging Existing Networks and Relationship-Building

A central component to our research process was consulting with community and local stakeholders, which was not only necessary for ethical, relevant and contextually sensitive research practice but also practically made the process of conducting both research projects easier. Drawing on pre-existing relationships with stakeholders who are embedded in the research sites eased access, fostered trust and created clear expectations. However, this takes time. Allocating dedicated time and budget in the initial project conceptualisation would have been helpful. The development of these relationships required meeting relevant stakeholders in their own spaces. Community and health facility walkabouts were conducted to build relationships with relevant community and healthcare facility stakeholders, assess tangible characteristics and geographies of the communities and healthcare facilities, and obtain an understanding of possible challenges and generate broad and flexible solutions.

In community settings, our research teams spent considerable time with community members talking about the number of households in each selected village, access paths and roads available in the villages, security concerns including illicit drug use sites, rivers and forests that may obstruct travels in the villages, community functions and commitments (including market days) that may draw away potential participants, and availability of the local leaders to provide guidance to the fieldworkers during sampling and data collection.

Establishing PACs and Collaborative Agency-Sharing

In AWACAN, through linking the team with the community, collaborators assisted in the establishment of PACs. The PACs were instrumental in advising on pragmatic considerations for our study and negotiating for community priorities to be met during the project. That is, PACs were instrumental in creating collaborative approaches to

research practice. One such example is the PACs advocating for the recruitment of local community members, instead of university students, to serve as the field team for the period of the study. We employed several unemployed young adult school leavers. In this process, the PACs advocated a fairer exchange between community and the researchers in the research process. In addition, master's and doctoral students in SA and Uganda gained first-hand exposure to community-engaged research. At pre-agreed time points we reported back to the PACs on the study progress. Upon completion of the study, the entire AWACAN team provided feedback and elicited feedback from community members.

The main role of the AWACAN PACs was to provide strategic direction and support to the research team in their progress towards implementation of project objectives. The Ugandan team had one PAC, serving both research sites, which comprised a wide range of stakeholders including district health officers, ministry of health officials, district councillors, and representatives from local and national cancer registries. Given the distance between the SA study sites in the Western Cape (Khayelitsha) and the Eastern Cape (Lusikisiki), two PACs were convened. The PACs comprised a mix of project staff and local representatives. Collaborators were instrumental in setting up meetings and communication between the project team and relevant stakeholders, local governance structures, community leaders and community members.

Collaborators and PACs instilled the rules of engagement in community-based research. The primary lesson was that we needed to move away from regarding ourselves as elite experts from the academy, to become researchers who were willing and privileged to learn from the community experts. The second was to learn to “go with the flow”. For instance, accommodating unexpected changes such as last-minute rescheduling of meetings and occasionally starting meetings up to two hours later than planned. A flexible approach to community-engaged research allowed us to engage with communities while respecting their processes and countering our own urgency to complete the work on our own schedule.

Navigating Ethical Approvals and Institutional Permissions

Conducting research in both community and health facility settings for AWACAN and AWACAN-ED required numerous levels of ethical approvals and permissions, including at institutional, provincial, city and hospital levels. Both projects experienced delays in data collection owing to delays in receiving permissions which pushed out project timelines. Adaptive lessons from this process are to start these applications early and allocate additional time, be persistent and follow up regularly, and anticipate extra time to obtain additional levels of permission. We also needed to gain community buy-in and informal levels of approval. Site visits before data collection, after securing all relevant ethical and institutional approvals, are necessary to build good relationships with relevant stakeholders at research sites and obtain unofficial approvals in these spaces.

Sampling

In the AWACAN project, sampling necessitated creative straddling between theoretical knowledge about random sampling techniques and the practical realities on the ground. At a theoretical level, the selection of study sites included a blend of rural and urban sites in each country (Uganda and SA) and availability of socio-demographic data on education levels, types of housing (formal versus informal), average household sizes and access to basic amenities such as running water and electricity. The research team compiled a comprehensive sampling strategy which detailed sampling procedures at four levels, namely, provincial level, district/municipality level, ward/village level and household level. Random starting points were established at household level followed by systematic sampling based on the pre-determined sampling interval for each site. However, we soon found that local realities were often dislocated from theory, and we had to make several adaptations to our sampling strategies to account for unforeseen challenges.

We found that the selection of random sampling points was further complicated by community factors. In rural areas in particular, several community members were suspicious about why we chose a specific home and not another as a starting point. We resorted to negotiating with community opinion leaders to endorse our strategy to community members and to give the researchers opportunities to explain how sampling works to community members before starting the data collection. Available data were often not up to date owing to shifts in geographical boundaries over time, particularly in rural areas, and proliferation of informal households in some urban areas. For example, informal settlements would be established over a weekend in Khayelitsha whereas rural geographical boundaries in the Eastern Cape shifted in line with authorised changes in municipal boundary demarcations.

In the absence of reliable data, we relied on our local collaborators to provide what they deemed the best estimates and adapted our sampling strategies accordingly. Some of the greatest lessons learnt in this process were to budget additional time and resources for unanticipated challenges, to be flexible with adaptation of our plans and to be transparent and explicit about our processes and procedures, even when these did not fit “conventional” criteria for sampling.

Geographical and Infrastructural Challenges

The data collection for both projects was complicated by infrastructural and geographical challenges. These challenges included (1) weather and environmental challenges, and (2) access to electricity and connectivity.

Weather and Environmental Challenges

In AWACAN, access to rural and peri-urban communities in SA and Uganda was affected by unnamed dirt roads, the lack of house numbers, supplementary dwellings on the same property as the main house, and discrepancies between maps and actual

dwelling. In SA, access to the rural research site was challenging because of the hilly terrain coupled with long distances between households. Each morning, fieldworkers were picked up at the local hospital, driven to a central point in the village such as a school, church or health facility, and then returned at the end of the day. For most of the day, fieldworkers walked through villages conducting household surveys. Precarious weather conditions would require the field teams to cancel data collection at short notice, which delayed data collection timelines.

In Uganda, data collection was conducted during the rainy season and fieldworkers struggled to navigate through sudden downpours and impassable roads. Some villages were overly congested with no safe pathways between buildings. Safe access was further hindered by unprotected drainage channels. Gated households were difficult to access as the owners were concerned about their security. In rural Nwoya, forests and rivers without safe bridges were the main geographical barriers to the movement of the fieldworkers. About a third of Nwoya district are located in the national game park and fieldworkers feared wild animals, although no such encounters were recorded. In one of the villages, which is heavily forested, several fieldworkers suffered allergic reactions from a local plant and ended up in the emergency department of the local hospital where they were treated and discharged. We cancelled the fieldwork the following day to ensure that everyone had fully recovered before proceeding with the fieldwork.

Each fieldworker was provided with protective clothing and other essentials to protect them and data collection materials from inclement weather. In addition, when the weather made roads impassable, motorcycles were necessary to access certain sites. While these strategies were helpful in mitigating some of these challenges, it is important to note that geographical challenges are time-consuming and have additional unseen costs. Realistically, it is not possible to ascertain the level and nature of all challenges before fieldwork. We could have put together a timeline and budget that better buffers for unforeseen challenges.

Electricity and Connectivity

Scheduled power interruptions in SA, known as loadshedding, affected the research projects. Our teams at rural sites were often unable to join team meetings or communicate with staff in different locations. The lack of telephone network coverage in rural sites affected communication between the urban and rural teams, so rural sites were not only disconnected geographically but also at a communication infrastructural level. To mitigate the effects of sporadic and unstable network coverage, we provided the teams with numerous network providers, with the costs of airtime and data exceeding budgeted costs. When planning research in rural areas, it is important to budget for likely additional costs associated with communication needs.

In Uganda, the fieldworkers' iPads and power banks often ran out of battery charge, with electricity challenges most frequently experienced in the rural site. The team adapted by providing at least two power banks to each pair of research fieldworkers. Syncing data after field data collection before leaving the field sites were challenging as telephone networks to provide internet were occasionally not available in the rural site. The field coordinator often looked for and met fieldworkers to upload data from high level grounds where internet availability would be adequate. Occasionally, the team would stop fieldwork earlier and travel back to the field office in Gulu Municipality where internet was always available before they uploaded the data. In SA, at the rural site for AWACAN-ED, the field team had to return to the office every day to upload the data that were collected owing to a lack of internet connectivity at the field site.

Safety and Security

During the AWACAN project, security in our peri-urban sites in SA and Gulu Municipality, particularly in the informal settlements, was a primary concern. We therefore focused on how to ensure not only the safety of our field team, who were all young women, but also to safeguard electronic research equipment such as data collection iPads and fieldworker phones. In SA, our initial idea was to provide police escorts during data collection, but our local governance structures cautioned that this would cause unnecessary attention which may potentially yield unintended consequences, including suspicion and resentment of the field team, who were local residents. On the recommendation of the local governance structures, we opted to engage the services of unemployed young men who were vetted by the local governance structures to accompany the field team daily. In one instance, the young men warned the field team of a security concern in a specific section of one neighbourhood. The field team therefore withdrew from this area for about two weeks and returned after the security issue was resolved. The AWACAN team was provided with rigorous training on safety, worked in pairs, provided emergency contacts to the team, and had regular checks on the team's whereabouts by the supervision team. This entailed conducting several walking tours to identify potential safety and assembly points such as nearby schools, health facilities and local supermarkets, in the event of unexpected safety-related challenges.

In Uganda, the local council leaders provided effective and affordable services for both security and guidance during sampling and data collection. In Gulu Municipality, the fieldworkers were concerned with violence from illicit drug users in three particular wards. The field coordinator, therefore, had to arrange with local council leaders for additional security guides (young men) to lead the fieldworkers during data collection. No violent incidences were recorded, as the guides proved useful in providing confidence and safety to the fieldworkers in these sites.

In both Gulu Municipality and Nwoya, a common concern in the local communities were illegal land buyers and instances of fake land sales with subsequent claims of larger acreage than bought. The field teams were mistaken for illegal buyers. Fieldworkers faced instances whereby household heads—who were men—would suddenly appear home, alerted by neighbours, wanting to know who the fieldworkers were. The men would interfere with the interviews, act in threatening ways, and demand explanations regarding the presence of the fieldworkers in their homes. The team adapted by providing advance information through the local council leaders about the presence of the fieldworkers for research purposes and not land transactions. The field coordinator often travelled through the villages where data collection took place to inform and also to intervene in cases of such interferences and safety concerns.

On several occasions, research activities in SA were disrupted by political rallies and industrial action, for instance, health workers' strikes and taxi strikes. This resulted in the postponement of fieldwork activities until calm resumed which, in turn, delayed completion of field-related research activities. Perceived safety influenced mundane decision-making as demonstrated in the contrasting scenarios between our peri-urban South African and Ugandan sites. The field team in peri-urban SA made extra effort to remain inconspicuous by not wearing any branded clothing that might reveal their identity, which was deemed a potential security threat. In contrast, in Uganda where safety was not a major concern, the field team preferred to wear branded clothing so that community members would recognise them as research team members.

Overburdened and Under-Resourced Health Facilities

In an already overburdened public health system, accommodating research is a challenge. Providing health services is always a priority over conducting research. In health facilities there were issues about resources and spaces, in addition to reluctance to support researchers and enable access to medical records. Across both projects, the space in healthcare facilities was limited and space to conduct research needed to be negotiated. Despite limited resources, the facility managers, sister in charge and clinicians facilitated access to designated spaces in health facilities for the teams to collect data. However, allocation of these spaces did not always result in uninterrupted access to these rooms. Clinicians, nurses and other hospital staff entered the room as they needed to collect records, medication and other items stored in the room. In addition, in both projects there were short time windows allocated for research use as the rooms were required for clinical service provision and this also limited the number of participants that the field staff could recruit on the day. Competing research activities in facilities and drug stock checks also affected recruitment, which resulted in multiple rescheduling of interviews and many cancellations.

Continuous relationship-building with healthcare workers was an important strategy for accessing space to conduct the research, accessing potential participants, collecting patients' medical records and conducting data collection with healthcare workers. Frequent visits and contact with relevant healthcare workers by the principal

investigator, senior research officer and field site coordinator allowed for building rapport and easing access in the clinics. In addition, the research activities were affected by the overburdened health facilities and the limited space, with healthcare workers taking on additional tasks. Strategies to overcome this reluctance included making appointments to conduct the research in person, being flexible to allow face-to-face or online data collection, providing the survey tool beforehand, keeping good humour and making sure the process took as short as possible.

Accessing patient medical records in AWACAN-ED was complicated by the reliance on paper-based medical records in health facilities. In some cases, paper-based files for patients were lost. In Zimbabwe, patients from some facilities keep their medical records with them which affected the team's ability to collect cancer staging information. Electronic record-keeping, when available, was occasionally outdated and did not have relevant staging information for recent patients. In addition, clinical notes in some clinics are inadequate for collecting comprehensive patient medical data. The availability of final staging data was affected by patients not returning to the health facilities for various reasons, including pursuing alternative medicine pathways, not having sufficient funds for further medical care, transferring to an alternative health facility, and passing away. Sitting with clinicians to go over the medical records for patients' whose staging data were not readily available in their files was one adaptive strategy to access the data.

Contextual Nuances

During the AWACAN project, we encountered context-specific challenges related to (1) methods, (2) content, and (3) the research capacity and field staff experiences.

Methodological Challenges

The methodological challenges were related to our choice of methods, sampling and data collection tools. In the AWACAN study, we used a "think aloud" cognitive interviewing technique in our tool-validation process. The notion of "thinking aloud" proved problematic in cultural contexts where thinking aloud in the sense of speaking to oneself is often associated with psychological illness. One of our instructions to the participants was to imagine that they were speaking to themselves and explain what they were thinking as they interacted with the survey questions. Often, this instruction elicited responses such as surprise and amusement with many women noting that they do not speak to themselves, that is, they are not mentally ill. This necessitated additional time for clarification on the meaning of think aloud and the purpose of using this method for the tool-validation process, including demonstrating how to "think aloud".

Content-Related Challenges

Content-related challenges included language and images related to cancer, community perceptions of cancer, the gender of the interviewers and a possible vicarious impact of the study on the interviewers. Translating English words that described probable cancer

symptoms was difficult in the absence of equivalent terms in African languages, and specifically isiXhosa and Acholi for AWACAN. Following feedback from the tool-validation process and in consultation with local language experts, one of our adaptive strategies was to settle for brief descriptive sentences to describe concepts such as menopause, and close-to-equivalent terms where appropriate. For instance, cervical cancer in isiXhosa was translated as cancer of the mouth of the womb. In addition, we used visual images to illustrate more complex breast cancer-related concepts such as *peau d'orange* to describe the orange peel appearance of the breast. However, we were unable to locate breast symptom images with dark skin and decided to contract an artist to paint images of these symptoms on dark skin for contextual relevance (see awacan.online for the images).

The content of the AWACAN study, awareness of breast and cervical cancer symptoms, touched on sexual and reproductive matters. This required sensitivity in determining who was the most appropriate to conduct the research surveys and qualitative interviews, bearing in mind the nature of questions asked. We unanimously decided to ensure that all the interviewers were women, based on our knowledge that it would be culturally inappropriate to have men asking women questions pertaining to their sexual and reproductive health. Our interviewers were drawn from the various communities in our study sites to attend to contextual and content sensitivities.

Research Capacity and Field Staff Experiences

In AWACAN-ED, the lack of research capacity at the rural site presented a challenge for hiring staff with the relevant skills needed to carry out the fieldwork. Because of urbanisation, many graduates who have relevant research skills live in the large cities around the country. In this regard, we have a limited pool of candidates for rural sites and had to reach out to our pre-existing networks to put forward recommendations for candidates.

We were keenly aware of the possibility of researchers being vicariously affected as they interviewed women in the community, some of whom presented with concerning symptoms, and conducted a cross-sectional survey with people who were newly diagnosed with cancer, some of whom were very sick and others who passed away after the data collection. The researchers reported that they were emotionally affected in the process of doing the research, especially in the early stages of the fieldwork. To mitigate these effects, we included regular debriefing sessions where field teams had a safe space to reflect on their daily experiences during the data collection. However, additional intentional preparation, training and debriefing sessions would have better prepared the field teams for managing difficult emotions in the field.

The participants were provided with money or vouchers as reimbursement for their participation. Community members were suspicious of the intentions of the fieldworkers which resulted in delayed participation or refusal to participate. This was especially prevalent in the urban site where a perception of transfer of misfortune by

exchange of money was thought by some to be a trending demonic practice. Some prospective participants did not want to receive money because it was thought to be a medium of passing on bad spirits. The team adapted to these challenges by providing extensive explanations to the local council leaders beforehand and then also to the prospective participants. The team also developed a badge with the logos of the four participating universities which was signed by the Ugandan lead investigator.

Discussion

Conducting cancer-related research in both community and health-facility settings requires the research and field team to respond to fieldwork challenges as they emerge with practical, contextually appropriate, and scientifically rigorous adaptive strategies. In the subsequent discussion, we illustrate how these six core features of community- and health facility-based research have contributed to ongoing research seeking to refine the picture of health research processes.

The summary of the main solutions to the challenges of conducting community- and health facility-based cancer research is as follows:

- leverage existing community and stakeholder networks and build relationships where existing connections did not extend;
- establish PACs and share agency through collaborative processes;
- leverage community and stakeholder networks and PACs to gain access to communities and health facilities and to get community buy-in;
- ensure that knowledge translation is packaged so that is linguistically and contextually appropriate, and easily understood by community members;
- select research methods that have already been validated for the context and/or adapt methods that are not contextually validated;
- desist from considering ourselves as elite experts from the academy, to become researchers who were willing and privileged to learn from the community experts;
- ensure that community-based sampling necessitates creative straddling between theoretical knowledge about random sampling techniques and the practical realities on the ground;
- prioritise developing local research capacity and recruit people who are from the community in which the research is being conducted;
- ensure appropriate budget and time management; and
- develop a safety and security plan that is sensitive to the contextual realities of the research site.

Table 1 presents the key areas where additional budget and time allocation is needed.

Table 1: Key areas for additional budget and time allocation

Aspects that require additional budget	Aspects that require additional time when planning research
Accessing sites and addressing security, geographical and weather-related challenges	Developing and maintaining community and stakeholder networks
Conducting random sampling in community settings in LMICs	Engaging with community and local stakeholders
Providing energy solutions, such as power banks, to keep tablets charged	Negotiating access and entry into communities and health facilities
Providing communication needs, such as data and airtime, to mitigate unreliable networks	Planning random sampling in community settings in LMICs
	Acquiring ethical approvals and institutional permissions
	Developing local research capacity through ongoing training

Regarding entry and access, our findings demonstrate that consulting with community and local stakeholders is not only necessary for ethical, relevant, and contextually sensitive research practice but also practically makes the process of conducting the research easier (Andrews et al., 2019; Casale et al., 2013; Mathee et al., 2010). The process of community and stakeholder engagement allows for alignment of researcher, stakeholder and community needs and questions (Andrews et al., 2019). Conducting meaningful cancer-related research in LMICs requires community and stakeholder engagement that is locally specific (Kue et al., 2015; Mathee et al., 2010). However, there are limitations to community and local stakeholder engagements (Munro et al., 2009). Scholarship has noted that the lack of integration and consideration of community perspectives and knowledges, challenges related to confidentiality, lack of trust between researchers and communities, ownership and use of information remain challenges in community-based research (Campano et al., 2015; Kennedy et al., 2009; Stoecker, 2008).

Negotiating access and entry into communities and health facilities is an imperative part of conducting cancer research in SSA. While our adaptive strategies worked well, access and entry into these sites takes time and is an ongoing, interpersonal process that spans not only the duration of the project but also requires continued engagement before, during and after the project. Planning entry into communities and health facilities involves a clear but flexible approach, understanding the proposed research sites beforehand, and a realistic assessment of resources available. An overarching theme of entry and access into research sites involves continual (in)formal engagement with relevant community and healthcare facility stakeholders to assure alignment of research

with community needs. Relationship-building is a central process in project development, implementation, and evaluation.

Although community and stakeholder engagement is necessary to involve the voices of relevant stakeholders in the research process (Andrews et al., 2019), early engagement does not necessarily lead to equal partnership or project ownership by local stakeholders who have competing engagements and interests (Mathee et al., 2010). However, the process of engaging communities and local stakeholders can be important for the development of culturally appropriate questions, study design and methods (Kue et al., 2015). Instead of viewing the process of community and stakeholder engagement as a redemptive practice, we must view it as an iterative process that requires continued engagements to address tension points, distrust and inadequate initial engagement (bearing in mind, no engagement is completely sufficient) (Casale et al., 2013; Mathee et al., 2010). Entry and access for cancer-related research are facilitated through building local partnerships before research study funding, gaining the support of the community before conducting research, putting together a community advisory board, and leveraging established community spaces. It is imperative to note that, although the relationship between researchers, participants and local stakeholders is embedded in an unequal power dynamic, stakeholder engagement may potentially serve to reduce power imbalances, increase community buy-in and, consequently, facilitate community agency in research practice.

A related component of stakeholder engagement is local capacity building. Research fieldwork often requires the recruitment of skilled fieldworkers to ensure data quality (Casale et al., 2013). However, in rural areas in SA, skilled fieldworkers are scarce. There are limited opportunities in rural areas and many skilled fieldworkers move to urban centres. In addition, limited research skill-building opportunities exist in underserved communities. Conversely, it is important to use local staff who have knowledge of culture and context. As a question of social justice, it is important to enhance the research skills of the researchers in the under-resourced communities in which we are collecting data (Andrews et al., 2019). It is important that the research team is made up of people from the local context who share a cultural and linguistic background with the participants (Kue et al., 2015). Staffing in areas with a shortage of skilled fieldworkers requires creative solutions to build research capacity in rural communities and it is imperative to put together comprehensive and ongoing training.

Our findings pertaining to physical access to research sites and attendant challenges reiterate previous studies which document that access to rural and peri-urban communities is affected by unnamed dirt roads, the lack of house numbers, supplementary dwellings on the same stand, and discrepancies between maps and actual dwellings (Mathee et al., 2010; Mulumba, 2007). Access to sites that are rural are further complicated by limited services and distrust of outsiders (Casale et al., 2013). Challenges related to physical access require flexibility, planning and putting in a buffer budget for money and time.

Random sampling in peri-urban spaces in SSA presents a unique challenge owing to the lack of availability of maps or maps outdated rapidly because of area changes, the lack of house numbers and multiple dwellings on a single stand (Mathee et al., 2010). Current random sampling strategies in high income countries demonstrate gaps in understanding contextual specificities that shape the way in which randomisation can (and cannot) be done in peri-urban areas in SSA. To address this, research teams must emphasise flexibility and allocate additional time and resources to unexpected challenges. While there is a role for planning, there needs to be enough room for changes in plans and plans not working out. In addition, in AWACAN-ED, population estimates provided by health facilities for the number of cancer patients seen were not reflective of the number of new patients arriving at clinics nor did they account for clinic and ward closures. This challenge is indicative of broader challenges of cancer population estimates in SSA (Ferlay et al., 2021; Graham et al., 2012).

Safety was a primary concern for the field staff and participants in areas with high crime and violence rates (Munro et al., 2009; Nel et al., 2017). Social identities, such as race, gender, sexuality and disability status, shape the risk of the type of violence and harassment that field teams may experience during fieldwork. Social identities shape what kinds of space researchers and field teams can enter, how and when they enter the space, who and how they interact with the research participants (Sharp & Kremer, 2006). In this regard, there is no one-size-fits-all approach to ensuring safety and security for field teams. Instead, we need to think about being safe in unsafe spaces. The implication is the need to be aware of and sensitive to context-specific structural challenges and possible power imbalances that may arise when conducting research among vulnerable populations. These factors need to be carefully thought about when planning and conducting cancer-related research in LMICs.

Conducting cancer-related research in overburdened health facilities requires researchers to work within these limitations and make the most of what is available. Working within these limitations requires flexibility, continuous relationship-building, and sensitivity to the material realities of healthcare workers. That is, while doing cancer-related research, we must be aware of what the research presence adds to healthcare workers' already heavy workload.

When conducting cancer-related research in LMICs, we must be conscious of issues of contextual relevance. That means that we may need to select methods that have already been validated for the context and/or adapt methods that have not been contextually validated. In addition, we must be cognisant of the socio-economic environment that requires participants to rush to other places—such as appointments, home and for transport. The clarification of the research project at both a community leadership and potential participant level is the onus of the research team. Through leveraging community and stakeholder networks to spread the word about the research study, we can use an oral style of getting community buy-in. The implication is that knowledge translation is a critical, though often overlooked, component of community-based

research which requires packaging of all research-related information in linguistically and contextually appropriate messaging that is easily understood by local community members.

Conclusion

Conducting community- and facility-based health research in SSA has particular challenges and opportunities which have an impact on planning and conducting research. Doing rigorous research in SSA requires locally relevant, collaborative, timely and creative solutions, and mutually beneficial community partnerships. Flexibility and adaptability are central practices for conducting cancer-related research in SSA in both community and health facility settings. Ensuring additional time and resource budget to account for unforeseen challenges allows for adequate and scientifically rigorous adaptive solutions to be implemented.

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