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Sustainability of Cancer Registration in the Kilimanjaro Region of Tanzania – A Qualitative Assessment

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Abstract

The projected cancer burden in Africa demands a comprehensive surveillance strategy. Kilimanjaro Christian Medical Centre (KCMC) is developing a population-based cancer registry,

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and understanding stakeholders' perceptions of factors impacting cancer registration sustainability is critical to its long-term success. We conducted 11 semi-structured qualitative interviews with clinicians and administrators. Interviews were double-coded and evaluated for predetermined and emerging themes.

Nearly half (45%) of participants discussed change commitment, stating that the cancer registry would benefit KCMC and that they were committed to it. However, change efficacy was low – participants were not confident in their shared ability to sustain the registry. Most participants (73%) discussed the importance of resource availability and administration support. Several themes emerged across interviews: (i) lack of cancer registry awareness, (ii) ambiguity about its purpose, (iii) the importance of training, (iv) the importance of outcome data, and (v) the importance of international partners. These findings may facilitate cancer registry development and sustainability in similar settings.

Introduction

Cancer Registration in Africa

In 2008 cancer registries in Africa represented only 11% of a population bearing over 571,000 new cancer cases (Ferlay et al. 2010; Parkin 2006). Institutions seeking to establish or sustain cancer surveillance systems on the continent have faced challenges (Rastogi et al. 2004; Zullig et al. 2013), yet many of these programs move forward without assessing organizational needs. Formal evaluation is critical to laying groundwork for sustainability. Understanding local perceptions of barriers and readiness to surmount them is an important foundation for developing a cancer registry that can effectively serve its population.

We had previously conducted a quantitative needs assessment examining organizational readiness to implement a cancer registry at a tertiary medical centre in the Kilimanjaro region of Tanzania (Zullig et al. 2013). Respondents were generally confident and committed to registry development. However, approximately one-third of respondents reported that there were no funds to maintain the registry. In light of this initial disconnect between high organizational confidence and commitment versus limited financial resources, we posit that understanding additional contextual factors impacting long-term sustainability of cancer registration activities is of critical importance.

The objective of the current study was to develop a comprehensive understanding of perceived factors associated with sustainability of cancer registration activities through key stakeholder interviews. To our knowledge, this is the first effort to engage administrative and clinical stakeholders in a low- or middle-income country (LMIC) in a formal, qualitative assessment of sustainability of cancer registration activities.

Methods

Weiner's Theory of Organizational Readiness to Change

Weiner's theory of organizational readiness to change provided the conceptual model (Weiner 2009). The key tenet is that organizational readiness is a multi-level, multi-faceted construct comprised of both organizational members' shared resolve to implement a change and their belief in the collective capacity to make a change. The former construct is termed *change commitment* and the latter is *change efficacy* (Weiner 2009; Weiner et al. 2008). We apply principles of the theory in the context of sustainability.

Participant Recruitment and Questionnaire Design

Recruitment and interviews were conducted in March 2013. To identify participants, we acquired a list of administrative department heads and clinical stakeholders. As a secondary recruitment method, we attended a clinical conference to identify possible participants. We selected stakeholders based on their anticipated interaction with the cancer registry and to achieve a diverse sample with regard to professional roles (e.g., clinical, administrative) and physician specialty. We estimated a target of ten interviews, based on feasibility due to time and budget constraints, while balancing the need to achieve saturation.

We prepared an interview guide that consisted of ten open-ended questions. Questions were designed to delve further into our previous findings from the quantitative needs assessment based on Weiner's theory of organizational readiness to change (Weiner 2009; Zullig et al. 2013). The semi-structured interview guide was designed with findings from our previous work guiding our hypotheses but with attentiveness to ensure that participants were able to express their own opinions and perceptions. We began with general questions and progressed to more explicit, context-specific ones. Questions were designed to address the perceived need for the cancer registry, resource availability, sustainability of cancer registry implementation and perceived professional roles associated with the registry.

In accordance with the participant's preference, interviews were conducted either in person or via voice over Internet protocol (VOIP). The location of the in-person interviews was left to the participant's discretion but was typically his or her office. Participants were given the option of completing the interview in either Swahili or English; all chose English. Verbal informed consent was obtained at the time of interview. Duke University Health System's Institutional Review Board reviewed and exempted this study. Ethical clearance was obtained from the Research Ethics Committee at the Kilimanjaro Christian Medical Centre (KCMC) and Kilimanjaro Christian Medical University College. All interviews were digitally audio-recorded, transcribed in smooth verbatim style and crosschecked for accuracy.

Data Analysis

Interview texts were analyzed in accordance with standard social science qualitative methodology (Rubin and Rubin 2005). A list of five initial codes was created based on our theoretical framework (Weiner 2009) and previous experience (Zullig et al. 2013). These initial codes included change commitment, change efficacy, resource availability, communication and leadership support. Additional codes emerged as the interviewers reviewed transcripts. Two interviewers (LLZ and SV) coded the interview transcripts separately and subsequently jointly reviewed the texts. After consensus was achieved, a larger group of the research team (LLZ, SV, SYZ, CM) reviewed the study material to ensure data analysis integrity and that codes had been interpreted within the cultural context. The research team then organized codes under thematic headings and identified key representative quotes (Rubin and Rubin 2005; Ryan and Bernard 2003). Our primary aim was to understand stakeholders' perceptions of factors impacting sustainability of cancer registry activities at the KCMC and how these views might inform ongoing registry development and training.

Results

Participant Characteristics

Each of the clinical and administrative stakeholders we approached agreed to be interviewed, suggesting a high level of organizational motivation and interest in sustaining the cancer registry. We interviewed 11 participants, with an approximately even balance of administrators and clinical-only staff (55% administrators; 45% clinical-only). Participants were diverse in specialty and gender, and the majority were trained as physicians (82%; Table 1). Eighty-two percent of interviews were conducted in person.

Codes based on the theoretical framework are discussed in detail below. Key quotes describing each code are highlighted in Table 2. Emerging themes and iconic quotes are presented in Table 3.

Change Commitment

Five participants (45%) provided discussion of the hospital's commitment to changing practice to implement sustainable registry practices. Participants stressed the importance of each department committing its respective expertise to support change (e.g., the pathology department providing clear confirmation of cancer diagnosis, medical records supporting record keeping). There was a common sentiment that implementing and sustaining the registry would serve to benefit the organization in the long run. One participant summarized the organization's holistic commitment to change in this way:

> KCMC should be responsible for the cancer registry and should take [ownership] and see … that the registry is sustained in various ways, and make sure that there are some benefits to the hospital [that] come out of its existence.

Another participant indicated that there were many members in the organization who support the cancer registry and that there is a need to systematically “identify those people properly [with regard to] who can go an extra mile” with the goal of sustaining registration.

Change Efficacy

Weiner defines change efficacy as “shared belief in their collective capability” to make a change (Weiner 2009). Five participants (45%) assessed institutional or national capacity for cancer registration, all voicing doubt with the following examples: inaccurate or lost patient files, lack of a national patient identification, and scarce interest in oncology among physician trainees. Individual concerns went beyond a shortage of trained personnel or materials to express that “the culture of creating … and maintaining records is very loose.” This “culture” also suffers from a stark distinction between research and clinical care, where research efforts are often seen as extraneous to the purpose of medical record keeping.

Resource Availability

The majority of participants (*n* = 8, 73%) discussed resource availability. This discussion generally revolved around the availability of funds, staffing and information technology infrastructure. With regard to financial resource availability, several participants indicated that funds were unavailable, but that they were committed to the registry despite this: "We are quite poor, and we aren't able to do that, but if there is anything that a cancer registry is planning to do … [for] cancer patients, then the door is open and we are ready to help." Several participants provided possible solutions for overcoming this implementation barrier. Two suggested partnering with the Tanzanian government or non-governmental organizations as a strategy to bolster resource availability. Another noted that while initially a cancer registry requires a small outpouring of funds it could eventually create revenue: "It doesn't need a lot of money, and what they eventually learn from the cancer registry, the cancer registry itself can be an income-generating tool."

Availability of staffing was another common theme. Participants generally felt that there were too few staff, that staff were overburdened with existing work commitments, and that they were inadequately trained for cancer registration. According to one participant, "We need the staff. We need people that are trained. We need the infrastructure to do it too. We need … committed doctors in the specific units…."

Technology infrastructure was also mentioned frequently. One participant summarized technological needs by saying the organization "need[s] computers and even software, like a database." While there is a technological foundation at KCMC, participants generally viewed their organization's technological infrastructure as in its infancy. Hospital medical records are currently paper-based. Participants expressed frustration with current record-keeping practices and suggested that the cancer registry operate independently: "You should bypass a system which is not working because working with [new] systems because trying to make [this] work, it doesn't work." Several participants indicated that they desired a transition toward electronic medical records and thought the cancer registry would both benefit from electronic records and, perhaps, promote adoption of an electronic record system.

Communication

Communication was discussed in a myriad of ways: with administration, between clinical departments and with patients. Ten out of 11 participants mentioned an aspect of communication. Participants indicated that they desired communication with and from administration: "open discussion and a lot will come out from there." Moreover, they indicated that communication was critical to foster inter-departmental collaboration: "very two-way-traffic kinds of relationships with the departments." One participant indicated that organization-wide communication is important between "… essentially everyone, and especially because cancer patients are distributed to everybody at KCMC, … there's no way we can underestimate or undermine any department, any unit."

Leadership Support

Eight participants (73%) discussed the importance of support from hospital administration and key leaders in sustaining the cancer registry. Several participants indicated that a signal from organizational leadership was the primary factor influencing registry sustainability. One participant said:

> The first thing to me is administration. I'll say this again and again, because the system that we have at KCMC is hierarchical, all the way through [to] the bottom. And once you have the head of the hospital, the head of departments and all other people at KCMC committed and interested in the cancer registry, there is so much chance that the cancer registry will [succeed].
>
> But at the end of it all, the buck stops at the office of the executive director.

Additional quotations highlighting the importance of leadership support are listed in Table 2.

Emerging Themes

Emerging themes included: (i) a general lack of awareness about the cancer registry, (ii) ambiguity about the purpose of the cancer registry, (iii) the critical nature of training staff (both to increase awareness and ensure best practices for registration), (iv) the importance of including patient outcome data, and (v) connecting with international partners. Lack of awareness about the registry was evident across all interviews, both with regard to what participants did and did not say. Nearly 82% indicated they had no personal experience with a registry. Speaking of gaining organizational commitment, one participant said, “Maybe they [do not know] exactly what importance … the cancer registry [will] bring to KCMC and Tanzania, [such] as pride.”

There was confusion about the purpose of the registry. Some participants viewed it as a short-term research project potentially fuelling long-term instability, while others viewed it as a joint clinical–research venture, and still others were completely uncertain of its purpose. One participant summarized this issue as follows:

> [The] cancer registry is definitely both a clinical and research tool. And the reason that people think it's more [of] a research tool is because, of course, it has only existed for a very brief time, and probably by that time the community here was not really told what the importance of [the] cancer registry [was].

Several participants indicated that they perceived the registry as having a potentially positive impact on improving patient care. There was a strong emphasis on using registry data for clinical purposes such as internal reporting and disease tracking:

> I want to see [the] cancer registry coming up with kinds of deliverables, deliverables that everyone else will be able to see and say “this is something very important.” I mean, this is something unique to support, because in a way it's also supporting us.

Distinct from the theory-driven theme of staffing resource availability was the emerging theme of the importance of providing training to staff in various aspects of the registry.

Nearly all (*n* = 10, 91%) participants discussed this during their interview. Participants offered staff training as a solution to overcome lack of awareness:

> I think the first thing, if you want to make it sustainable, is that … you need to train; training is very important …. And after training, then you probably need to appoint people who will work on that permanently.

Collecting patient outcome data is not standard practice for many cancer registries. However, participants identified this as a high priority. They recognized several barriers to longitudinal patient tracking, including lack of a unique personal identification number, lack of a system for defining residential addresses, and patients having insufficient personal financial and/or transportation resources to present at the hospital for care, which makes including them in the registry challenging. Most participants reported that patient outcome data was a critical component of the registry to inform clinical care. Because of the aforementioned barriers, at least three participants suggested that it would be important to have registry staff collect data in the community. One participant described this as follows:

> That patient may not have enough money to come to KCMC, so that patient will tell the doctor, only give me medication, to give me medicine, and they're going home…. We will go to the field, go to the health centre and identify also cancer patient[s].

Creating international partnerships was previously identified as a mechanism to overcome lack of financial resources. A related theme emerged regarding the perceived interconnectedness of the organization within a broader context of international cancer care. For example, when discussing the role of the pathology department, one participant said it was important to, “make sure that we have a diagnosis that is standard, you know, because that will help to harmonize even with … other countries.” This eye toward bridging along international lines also resonated in the following quote:

> The very last thing would be, I think, international cooperation is really important, the way we have seen it from everywhere, and we know that in today's world nothing can just exist on an un-united basis. Probably you need to connect with people; you connect with others that are doing the same thing.

Discussion

Interviews with key clinical and administrative stakeholders were consistent with findings from a previous, quantitative study (Zullig et al. 2013). In general, participants were committed to supporting the cancer registry but identified a lack of resource availability, particularly with regard to financial resources, staffing and information technology. Similarly, several participants expressed negative change efficacy. These are elements of readiness to change – a key component of sustainability. Anticipated sustainability may affect people's readiness to change and, ultimately, their willingness to initiate change, the amount of effort that they are willing to expend and their persistence when confronted with obstacles. Negative change efficacy may reflect that participants collectively did not perceive their organization had the ability to sustain the cancer registry. However, participants presented thoughtful suggestions for overcoming these limitations, recommending a tangible and authentic commitment to change. These possible solutions may be translatable to the development of cancer registries in other LMICs:

- Involve key leaders during the initial planning stage and secure buy-in early.
- Train staff early and provide continuing education opportunities to demonstrate organizational commitment, facilitate communication and ensure a well-qualified team.
- Assign a visible leadership role to a single person who can take responsibility for the registry while holding other team members accountable.
- The registry must be designed and promoted to inform research questions and support patient care.
- Collaborative partnerships are critical both within the organization (e.g., between clinical departments) and externally (e.g., with international partners and other institutions) in order to safeguard daily operations and for benchmarking, shared learning and support.

In summary, KCMC and institutions like it in other LMICs face many challenges to implementing and sustaining cancer registration programs. However, when organization members share a vision for their institution, that vision may strengthen their collective ability to overcome resource limitations. One participant shared his vision for the cancer registry at KCMC. We assert that this vision and commitment to excellence is critical to the success of cancer registration in LMICs:

> …[I view] KCMC as an icon [of] education, so other people from other hospitals could come and see what KCMC is doing, and such a registry can … be established somewhere else. KCMC [could] be a centre of excellence maybe – that's what I could maybe suggest as a dream to me, as a dream to see where KCMC [is] headed… the experience which would be gained from the cancer registry [can help] develop the management of the cancer patient [at] KCMC.

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References

Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. Estimates of Worldwide Burden of Cancer in 2008: GLOBOCAN 2008. International Journal of Cancer. 2010; 127(12):2893–917.

Parkin DM. The Evolution of the Population-Based Cancer Registry. Nature Reviews Cancer. 2006; 6(8):603–12.

Rastogi T, Hildesheim A, Sinha R. Opportunities for Cancer Epidemiology in Developing Countries. Nature Reviews Cancer. 2004; 4(11):909–17.

Rubin, HJ.; Rubin, IS. The Art of Hearing Data. Second. Thousand Oaks, CA: Sage Publications, Inc.; 2005.

Ryan GW, Bernard HR. Techniques to Identify Themes. Field Methods. 2003; 15(1):85–109.

Weiner BJ. A Theory of Organizational Readiness for Change. Implementation Science. 2009; 19(4):67. [PubMed: 19840381]

Weiner BJ, Amick H, Lee SY. Conceptualization and Measurement of Organizational Readiness for Change: A Review of the Literature in Health Services Research and Other Fields. Medical Care Research and Review. 2008; 65(4):379–436. [PubMed: 18511812]

Zullig LL, Muiruri C, Abernethy A, Weiner BJ, Bartlett JA, Oneko O, Zafar SY. Cancer Registration Needs Assessment at a Tertiary Medical Center in Kilimanjaro, Tanzania. World Health & Population. 2013; 14(2):12–23. [PubMed: 23713208]

Table 1

Semi-structured interview respondent characteristics ($N = 11$)

Characteristics	*N* (%)
Sex	
Male	7 (63.6)
Female	4 (36.4)
Highest degree earned	
MD	9 (81.8)
PhD	1 (9.1)
Secondary school	1 (9.1)
Physician specialty or department	
Community medicine	2 (18.2)
Internal medicine	2 (18.2)
Medical records	1 (9.1)
Obstetrics and gynecology	1 (9.1)
Parasitology	1 (9.1)
Pathology	2 (18.2)
Pediatrics	1 (9.1)
Surgery	1 (9.1)
Professional role	
Department head	5 (45.4)
Interim department head	1 (9.1)
Clinician only/faculty	5 (45.4)
Interview setting	
In person	9 (81.8)
Via VOIP	2 (18.2)
	Mean (SD)
Interview length (minutes)	25.2 (12.5)

VOIP = voice over Internet protocol.

Table 2

Predetermined, theoretically driven themes

Theme	Example quote
Change commitment	• I think it's the responsibility of everybody to understand what the cancer registry is. Also, at the end of the day when you say everybody is responsible, that means working … and not coming up where people say, “It's not me, it's not me, it's not me.” • KCMC should be responsible for the cancer registry and should take [ownership] and see … that the registry is sustained in various ways, and make sure that there are some benefits to the hospital [that] come out of its existence.
Change efficacy	• The culture of creating … and maintaining records is very loose. • People don't think that they can gain much by training in oncology, because first of all the medicines are very expensive, [and] the technology … is also very expensive, and they think they cannot make any money from it rather than diagnosing it.
Resource availability	• I cannot just say that we have funds in a certain way that we can support. We are quite poor, and we aren't able to do that, but if there is anything that a cancer registry is planning to do … [for] cancer patients, then the door is open and we are ready to help. • It doesn't need a lot of money, and what they eventually learn from the cancer registry, the cancer registry itself can be an income-generating tool.
Communication	• … very two-way traffic kinds of relationships with the departments … • So essentially everyone, and especially because cancer patients are distributed to everybody at KCMC, … there's no way we can underestimate or undermine any department, any unit.
Leadership support	• Implementation sometimes could be slow because the management has not stated anything openly regarding the cancer registry. • … if we have these people committed, the leadership is committed [to] the cancer registry, this is actually going to be [the] number one investment we probably have to do. • … the keys to improve a place is first to make the key people, meaning the people who are the leaders of that particular place, … know and understand better about that particular aspect of [the] issue which you are planning to implement. If you can't make them understand it better, they are the first people to make that particular aspect of [the] issue stagnant.

KCMC = Kilimanjaro Christian Medical Centre.

Table 3

Emerging themes

Theme	Example quote
Current lack of awareness	• I don't know what's the competence of the cancer registry, what information is in the cancer registry, what is needed to be collected from the patients. I have not been involved with any registry. But I am keen about this situation because we as a nation, if you don't have a cancer register, how do you talk about cancer in this country? We'll just be like blind.
Purpose of registry	• [The] cancer registry is definitely both a clinical and research tool. And the reason that people think it's more [of] a research tool is because, of course, it has only existed for a very brief time, and probably by that time the community here was not really told what the importance of [the] cancer registry [was]. • [To share] the common causes [of cancer] that we are coming across…and to have our figures updated as we go along in managing the patients… It will also help us … knowing [not only] the [cancer] type, but [also] the magnitude …of patients that we are treating in our individual departments. Looking at the challenges we are facing in treating the patients and also unifying the information that we'd like to extract from these patients. …At the moment each department works on its own.
Staff training	• I think the first thing, if you want to make it sustainable, is that … you need to train; training is very important… And after training, then you probably need to appoint people who will work on that permanently. • There must be specific people who are informed and knowledge, be those nurses or whatever, who are responsible and accountable to that registry. And their responsibilities must be well defined.
Patient outcomes	• Of course a number of patients who report to our department with cancer, they present in advanced states…. Sometimes they don't come back because they're coming from far [away], but we don't have the means of knowing what has happened [to them]. Maybe through a cancer registry we might get the contact [with] where these patients are and if there is anything that would let us know the[ir] progress. • What we are collecting has to be linked with outcomes, and we really have to know the outcomes, [including] mortality outcomes.