Cancer Registration Needs Assessment at a Tertiary Medical Centre in Kilimanjaro, Tanzania

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Abstract

Cancer burden is increasing in Africa more than in any other continent, but population-based tracking of cancer incidence is incomplete. Cancer registries can improve understanding of cancer incidence.

To assess organizational readiness to sustain registry development, we conducted a survey assessing change efficacy, resource availability and change commitment at the Kilimanjaro Christian Medical Centre (KCMC), an academic hospital in Moshi, Tanzania. Fifty-two surveys were returned (80% response rate). There was strong reliability among change efficacy and commitment survey items, with Cronbach's alphas of 0.93 and 0.77, respectively.

Clinicians, nurses and administrators conveyed similar responses regarding change efficacy. Clinicians had similar responses for change commitment. Echoing opinion in many low- and middle-income countries, approximately one-third of respondents indicated there were no funds to maintain the registry, and funds were not obtainable. For most resources, respondents felt that

resources were sufficient or attainable. Respondents were generally confident and committed to registry implementation. Lessons learned at KCMC may be more broadly relevant.

Introduction

Cancer and Cancer Registration in Africa

The burden of cancer in sub-Saharan Africa is growing. Over the next ten years, the burden of cancer and chronic disease will increase in Africa more than in than any other continent (de-Graft Aikins et al. 2010). By best estimates, the cumulative incidence of cancer (excluding Kaposi's sarcoma and non-melanoma skin cancer) in Zimbabwe, for example, is only about 30% less than that of France, but cancer mortality is almost double (Parkin et al. 2008). These data suggest that in Africa both the incidence of cancer and mortality due to cancer are severely underestimated. An important first step in improving these estimates involves the establishment of reliable, population-based cancer registries. Unfortunately, in most of Africa the population-based tracking of cancer incidence has been incomplete; resources are limited, knowledge of cancer trends in this area is inadequate, and trends are based mostly on case series (Orem and Wabinga 2009; Parkin et al. 2008).

Models of capacity-building to support cancer registry development are a chief issue for low- and middle-income countries. In fact, the International Agency for Research on Cancer (IARC) has a Global Initiative for Cancer Registry Development in low- and middle- income countries that aims to create capacity to produce reliable and high-quality information on the burden of cancer to inform effective cancer control policies. The US-based National Cancer Institute (NCI) recently issued a report seeking to facilitate lessons learned from IARC and other groups to provide technical assistance and training to foster development of cancer registries in low- and middle-income countries (National Cancer Institute 2012). Our approach for the assessment of organizational readiness to change in preparation for cancer registry development supports this aim.

Assessing the perceptions of key stakeholders presents a critical foundation for establishing a sustainable, population-based cancer registry. In fact, experts in organizational change have found that readiness to change is an important predictor of successful implementation (Kotter 1996; Weiner et al. 2008). Without a clear understanding of organizational perceptions and readiness to change, the development of a cancer registry might not be aligned with the organization's values and needs. Organizational readiness to change is a multifaceted issue comprising two chief constructs – organization members' change commitment and change efficacy to implement organizational change. Change comprises intertwining levels, including both individual and organizational levels. When an individual believes that he or she can successfully make a change and that change is personally beneficial, the individual may be more likely to support an organizational change (Holt et al. 2010). Moreover, assessing individuals' readiness to change and perceived needs is critical for a sustainable foundation for population-based cancer registry development. Our objective was to assess shared beliefs among stakeholders in the organizational ability to initiate and maintain cancer registration activities at a tertiary referral medical centre in Moshi, Tanzania. In doing so, we present a model for ensuring sustainable cancer registry development in low- and middle-income countries (LMICs).

Methods

Kilimanjaro Christian Medical Centre

Located in northeastern Tanzania, the Kilimanjaro Christian Medical Centre (KCMC) was founded in 1971 by the Good Samaritan Foundation and has operated continuously for over four decades. KCMC has approximately 560 beds and serves a patient population of over 11 million people living in the Kilimanjaro region (Kilimanjaro Christian Medical Centre 2012). In addition to providing patient care, in 1996 KCMC was expanded to include medical training, with the establishment of Tumaini University Kilimanjaro Christian Medical College (Kilimanjaro Christian Medical Centre 2012).

KCMC has a history of cancer registration, although data collection has not been systematic and the quality and completeness of registry data have not been documented. At the time of manuscript preparation, KCMC cancer registration activities were inactive. However, because of the increasing cancer burden in eastern Africa and the need for high-quality, comprehensive data to inform resource planning, there has been renewed interest in expanding KCMC cancer registration activities.

Survey Design

We conducted a self-administered needs assessment survey at KCMC over a two-week period in June 2012. The survey contained 41 items assessing change commitment, change efficacy (Gist and Mitchell 1992; Weiner 2009) and determinants of change efficacy such as resource availability. Survey items assessing change commitment included, "How committed is your facility to implementing this change?" and "How willing is your facility to work hard to implement this change?" among others. Response options included "not at all," "a little," "fairly," "very" and "don't know."

The survey also assessed change efficacy. Change efficacy refers to organization members' shared organizational confidence in the communal ability to implement a change effectively – in this case further development of a cancer registration program. Examples of change efficacy items are, "Can the organization assign the right tasks to the right people in implementing this change?" and "Can the organization effectively use the resources that are currently available to implement the program?" Change efficacy items used in the survey were rated on a five-point Likert scale: "not at all confident," "a little confident," "fairly confident," "very confident" and "don't know."

The survey addressed two determinants of change efficacy – resource availability and situational factors (Weiner 2009). Resource availability refers to organizational members' perceptions about the availability and obtainability of resources. This includes an assessment of material, financial and human resources needed to advance the cancer registry. Respondents were asked about resources including pathologists, clinical staff to collect patient data, computers and software, among others. Response options for resource availability items included, "have none and resource is not available," "have insufficient, but resource is attainable," "already have sufficient resource," "not necessary" and "don't know." In addition to these discrete items, respondents were given the opportunity to answer open-ended questions with free responses. Regarding situational factors, respondents were asked whether hospital staff have sufficient time and political support to make needed changes.

Sampling and Recruitment

Because our goal was to obtain a comprehensive, organizational perspective, we conducted non-probability, purposive sampling (Trochim and Donnelly 2006). To maximize organization leaders' support, we initially met with the hospital's executive director and subsequently contacted the department chairs of obstetrics and gynecology, pediatrics, urology, surgery, internal medicine, medical records and nursing. Department chairs provided additional contacts and facilitated obtaining responses from their unit. We attended clinical meetings such as morning report to increase survey awareness and participation. In accordance with respondents' preference, surveys were administered on paper as well as electronically via e-mail.

Statistical Analysis

Frequencies were tabulated and, where appropriate, inconsistencies were checked against the original surveys for manual correction if required. Missing variables and incomplete questions were coded "missing." Missing values were examined for patterns in reporting and correlations with professional roles. Data were first analyzed for descriptive outcomes, including proportions, means, medians and ranges. Chronbach's alphas were examined as a measure of reliability among the change efficacy and change commitment survey items. Bivariate associations among clinical role, resource availability and change efficacy survey items were reported using chi-squared and

Fisher's exact tests as appropriate.

After we had examined raw change efficacy survey responses, survey responses were collapsed (e.g., "not at all confident" and "a little confident" were merged) and re-examined descriptively. Survey items were then classified into two categories – organizational management versus motivation. Within each category, survey items were ordered from highest percentage of confidence to lowest.

All analyses were conducted using Stata (StataCorp. 2011. Stata Statistical Software: Release 12. College Station, TX: StataCorp LP). Duke University Health System's Institutional Review Board reviewed and exempted this study. The Research Ethics Committee at Kilimanjaro Christian Medical Centre and Tumaini University Kilimanjaro Christian Medical College approved this study.

Results

Response Rate and Respondent Characteristics

A total of 64 surveys were administered (57 paper-based surveys delivered to possible participants; 7 electronic surveys e-mailed). Fifty-two surveys were returned, for a response rate of approximately 80%. Respondent characteristics are presented in Table 1.

Table 1. Respondent characteristics (*n* = 52)

	Percent/mean	SD	Minimum, maximum
Male	61.5%	–	–
Age	38.3	9.9	24, 66
Professional Role			
Physician	57.7%	–	–
Nurse	17.3%	–	–
Resident	9.6%	–	–
Administrator	7.7%	–	–
Medical student	7.7%	–	–
Medical Department			
Internal medicine	32.7	–	–
Surgery	13.5	–	–
Pediatrics	11.5	–	–
Urology	7.7	–	–
Medical records	7.7	–	–
Gynecology	5.8	–	–
Dermatology	3.9	–	–
Pathology	1.9	–	–
Not reported[a]	15.4	–	–

[a] Many respondents interpreted the medical department/specialty question as though it applied to physicians only. Therefore, the medical department was not reported by many nurse-respondents.

Missing Values

Data were examined for systematic patterns of missing values. No patterns were detected. No association was found between professional role and missing value. We examined associations between year of birth, a proxy measure for years of professional experience and missing values; no association was found.

Change Commitment

In addition to examining individuals' confidence in the organization's readiness to change, respondents were asked about the organization's commitment, motivation and willingness to work hard to implement the cancer registration program (Table 2). Cronbach's alpha for the change commitment items was 0.77, indicating acceptable reliability. Regarding both commitment to the cancer registry and willingness to work hard to implement the registry, approximately half of respondents reported that the organization was very committed/willing. However, only 37% (n = 19) reported that the organization was very motivated to implement the cancer registry.

Table 2. Change commitment (*n* = 52)

	Not at all committed % (n)	**A little committed % (n)**	**Fairly committed % (n)**	**Very committed % (n)**	**Don't know % (n)**	**Missing % (n)**
How committed is your facility to implementing this change?	3.9% (2)	5.8% (3)	28.9% (15)	51.9% (27)	9.6% (5)	0% (0)
	Not at all motivated % (n)	**A little motivated % (n)**	**Fairly motivated % (n)**	**Very motivated % (n)**	**Don't know % (n)**	**Missing % (n)**
How motivated is your facility to implementing this change?	1.9% (1)	9.6% (5)	44.2% (23)	36.5% (19)	7.7% (4)	0% (0)
	Not at all willing % (n)	**A little willing % (n)**	**Fairly willing % (n)**	**Very willing % (n)**	**Don't know % (n)**	**Missing % (n)**
How willing is your facility to work hard to implement this change?	0.0% (0)	5.8% (3)	36.5% (19)	50.0% (26)	7.7% (4)	0% (0)
	Not at all % (n)	**A little % (n)**	**Somewhat % (n)**	**Very much % (n)**	**Don't know % (n)**	**Missing % (n)**
How much does your facility want to implement this change?	1.9% (1)	3.9% (2)	30.8% (16)	55.8% (29)	7.7% (4)	0% (0)

Notes:
1. Respondents were instructed that when an organization makes a change, like expanding the cancer registry program, there is a core group of people who implement the change and use the program. This group probably includes administrators, managers, physicians, nurses or other staff. Respondents were advised that the survey items assessed their perception and opinion, not factual knowledge. They were then asked to indicate which response best reflected their understanding and confidence in their facility and its leadership regarding expanding the cancer registry.
2. Cronbach's alpha for the change commitment items was 0.77.

Change Efficacy

Cronbach's alpha for the change efficacy items was 0.93, indicating strong reliability. A comprehensive list of the survey items assessing change efficacy are described in Table 3. Forty percent (n = 21) of respondents indicated they were very confident that their organization could effectively use the resources currently available in order to implement the cancer registry. Over half of respondents (56%, n = 29) indicated they were very confident that clinicians could be encouraged to use the cancer registry. Similarly, 34.6% (n = 18) reported that they were very confident their organization could effectively coordinate the efforts of those involved in implementing the cancer registry. Respondents were divided regarding their perceptions of the organization's ability to communicate clearly regarding implementation of a cancer registry. Slightly less than one-third (29%, n = 15) believed very confidently that the organization could maintain the momentum going in order to implement the cancer registry. Approximately one-third of respondents were very confident and fairly confident (35%, n = 18; 37%, n = 19, respectively) that the organization could keep track of progress in implementing the registry.

Table 3. Change efficacy (*n* = 52)

	Not at all confident % (n)	A Little confident % (n)	Fairly confident % (n)	Very confident % (n)	Don't know % (n)	Missing % (n)
Effectively use the resources that are currently available to implement the program?	9.6% (5)	7.7% (4)	36.5% (19)	40.4% (21)	5.8% (3)	0% (0)
Encourage clinicians to try using this program (e.g., refer patients)?	0% (0)	9.6% (5)	32.7% (17)	55.9% (29)	1.9% (1)	0% (0)
Effectively coordinate the efforts of those involved in implementing this program?	5.8% (3)	13.5% (7)	42.3% (22)	34.6% (18)	3.9% (2)	0% (0)
Support clinicians as they adjust their clinical practice in response to this program?	1.9% (1)	11.5% (6)	36.5% (19)	44.2% (23)	3.9% (2)	1.9% (1)
Effectively solve problems that might arise in implementing this program?	7.7% (4)	17.3% (9)	42.3% (22)	26.9% (14)	3.9% (2)	1.9% (1)
Communicate clearly why the facility is implementing this change?	1.9% (1)	15.4% (8)	38.5% (20)	38.5% (20)	5.8% (3)	0% (0)
Keep the momentum going in implementing this change?	1.9% (1)	21.2% (11)	44.2% (23)	28.9% (15)	1.9% (1)	1.9% (1)
Keep track of how things are going in implementing this change?	1.9% (1)	19.2% (10)	36.5% (19)	34.6% (18)	3.9% (2)	3.9% (2)
Assign the right tasks to the right people in implementing this change?	5.8% (3)	15.4% (8)	32.7% (17)	44.2% (23)	1.9% (1)	0% (0)
Coordinate tasks so that implementation goes smoothly?	3.9% (2)	21.2% (11)	28.9% (15)	44.2% (23)	1.9% (1)	0% (0)
Support people as they adjust to this change?	1.9% (1)	17.3% (9)	50.0% (26)	23.1% (12)	5.8% (3)	1.9% (1)
Get people involved and interested in implementing this change?	9.6% (5)	9.6% (5)	42.3% (22)	34.6% (18)	1.9% (1)	1.9% (1)
Manage the politics of implementing this change?	7.7% (4)	17.3% (9)	32.7% (17)	30.8% (16)	7.7% (4)	3.9% (2)

Notes:

1. Respondents were instructed that when an organization makes a change, like expanding the cancer registry program, there is a core group of people who implement the change and use the program. This group probably includes administrators, managers, physicians, nurses, or other staff. Respondents were advised that the survey items assessed their perception and opinion, not factual knowledge. They were then asked to indicate which response best reflected their understanding and confidence in their facility and its leadership regarding expanding the cancer registry.
2. Cronbach's alpha for the change efficacy items was 0.93.

Perceptions of Organizational Motivation versus Management

The change efficacy survey items were collapsed and categorized (e.g., "fairly confident" and "very confident" were merged; survey items were classified into motivation versus management domains). There was a clear threshold of confidence and agreement between the organizational motivation versus management domains (Table 4). For example, being fairly or very confident within the management domain survey items ranged from 64% to 77%. The mean percentage response of fairly or very confident across these survey items was 73%. In contrast, respondents reported being fairly or very confident (or similar) for between 81% and 89% of motivational survey items.

Table 4. Collapsed change efficacy and change commitment responses (n = 52)[a]

	Not at all or a little confident % (n)	Fairly or very confident % (n)	Don't know or missing % (n)
Management tasks			
Communicate clearly why the facility is implementing this change?	17.3% (9)	76.9% (40)	5.8% (3)
Effectively use the resources that are currently available to implement the program?	17.3% (9)	76.9% (40)	5.8% (3)
Effectively coordinate the efforts of those involved in implementing this program?	19.3% (10)	76.9% (40)	3.9% (2)
Get people involved and interested in implementing this change?	19.3% (10)	76.9% (40)	3.9% (2)
Assign the right tasks to the right people in implementing this change?	21.2% (11)	76.9% (40)	1.9% (1)
Support people as they adjust to this change?	19.2% (10)	73.1% (38)	7.7% (4)
Keep the momentum going in implementing this change?	22.2% (12)	73.1% (38)	3.8% (2)
Coordinate tasks so that implementation goes smoothly?	25.1% (13)	73.1% (38)	1.9% (1)
Keep track of how things are going in implementing this change?	21.1% (11)	71.1% (37)	7.8% (4)
Effectively solve problems that might arise in implementing this program?	25% (13)	69.2% (36)	3.9% (2)
Manage the politics of implementing this change?	25.0% (13)	63.5% (33)	11.6% (6)
Organizational Motivation			
Encourage clinicians to try using this program (e.g., refer patients)?	9.6% (5)	88.6% (46)	1.9% (1)
Support clinicians as they adjust their clinical practice in response to this program?	13.4% (7)	80.7% (42)	5.8% (3)
	Not at all or a little % (n)	**Somewhat or very much % (n)**	**Don't know or missing % (n)**
How much does your facility want to implement this change?	5.8% (3)	86.6% (45)	7.7% (4)
	Not at all or a little willing % (n)	**Fairly or Very willing % (n)**	**Don't know or Missing % (n)**
How willing is your facility to work hard to implement this change?	5.8% (3)	86.5% (45)	7.7% (4)
	Not at all or a little committed % (n)	**Fairly or very committed % (n)**	**Don't know or missing % (n)**
How committed is your facility to implementing this change?	9.7% (5)	80.8% (42)	9.6% (5)
	Not at all or a little motivated % (n)	**Fairly or very motivated % (n)**	**Don't know or missing % (n)**
How motivated is your facility to implementing this change?	11.5% (6)	80.7% (42)	7.7% (4)

[a] Survey responses presented in Table 4 were collapsed (e.g., "not at all confident" and "a little confident" were merged). Survey items were reorganized into two categories – organizational motivation and management tasks. Within each category, survey items were then ordered from highest percentage of confidence to lowest percentage of confidence.

Resource Availability

Respondents were asked to report on perceived availability of resources needed for development of the cancer registry (Table 5). When asked about the availability of pathologists, approximately half of respondents indicated they "have none and resource is not attainable." Respondents were asked about the availability of staff to collect, enter, follow up on and audit cancer registry patient data. For each of these items, most respondents reported that the organization had insufficient staff, but the resource was attainable; specifically, staff to collect patient data (44%, n = 23), staff to enter patient data (46%, n = 24), staff to follow up on registered patients (35%, n = 18) and staff to audit the registry (44%, n = 23). The resource assessment also inquired about the availability of computers, software, and staff with computing expertise. In each of these categories, the most common response category was that the resource was insufficient but attainable. Respondents were also asked about the availability of funds to maintain the registry. Interestingly, answers were more evenly distributed across response categories for this survey item than for any other.

Table 5. Resource availability (n = 52)

	Have none and resource is not attainable % (*n*)	Have insufficient, but resource is attainable % (*n*)	Already have sufficient resource % (*n*)	Not necessary % (*n*)	Don't know % (*n*)	Missing % (*n*)
	48.1% (25)	38.5% (20)	5.8% (3)	0.0% (0)	1.9% (1)	5.8% (3)
Pathology technicians	9.6% (5)	63.5% (33)	13.5% (7)	1.9% (1)	3.9% (2)	7.7% (4)
Staff to collect patient data	11.5% (6)	44.2% (23)	28.9% (15)	0.0% (0)	5.8% (3)	9.6% (5)
Staff to enter patient data	13.5% (7)	46.2% (24)	26.9% (14)	0.0% (0)	5.8% (3)	7.7% (4)
Staff to follow up on registered patients	17.3% (9)	34.6% (18)	25.0% (13)	1.9% (1)	13.5% (7)	7.7% (4)
Staff to audit the registry	19.2% (10)	44.2% (23)	15.4% (8)	0.0% (0)	13.5% (7)	7.7% (4)
Computers	9.6% (5)	57.7% (30)	17.3% (9)	0.0% (0)	7.7% (4)	7.7% (4)
Software	17.3% (9)	48.1% (25)	11.5% (6)	0.0% (0)	15.4% (8)	7.7% (4)
Staff with computing expertise	17.3% (9)	44.2% (23)	17.3% (9)	0.0% (0)	13.5% (7)	7.7% (4)
Funds to maintain the registry	34.6% (18)	19.2% (10)	5.8% (3)	0.0% (0)	32.7% (17)	7.7% (4)

Bivariate Analysis

Due to the small sample size, we utilized Fisher's exact test to examine whether professional role (e.g., physician, administrator) was associated with differences in perception regarding availability of resources. For the majority of resources, there was no association between professional role and perception of resource availability. However, there was an association between professional role and availability of pathology technicians (p=.04). Further, we assessed differences in reported change efficacy and professional role. For each of the 13 change efficacy questions, there was no association between reported confidence in an organization's ability to implement the registry and professional role.

We then examined whether specialty (e.g., internal medicine, surgery) was associated with reported change efficacy. Of 13 items, differences between specialties were found for only four measures. Significant differences were found for the following items: support clinicians as they adjust clinical practice in response to the program (p=.01), keep the momentum going in implementing this change (p=.00), assign the right tasks to the right people (p=.04), and coordinate tasks so that implementation goes smoothly (p=.02).

Discussion

Overall, respondents reported a high degree of change commitment and change efficacy, suggesting that KCMC clinicians and administrators expressed confidence in their shared ability to organize and implement the process needed to develop and implement the cancer registry. Furthermore, responses were consistent among people of varied professional roles; clinicians, nurses, trainees and administrators all conveyed similar responses regarding their organization's readiness and ability to implement systematic cancer registration. In general there was also agreement between professionals of different medical specialties. Readiness to change and organizational endorsement are strong predictors of success in making a change (Kotter 1996; Sweeney and Whitaker 1994; Weiner 2009). This consensus among a multidisciplinary team suggests that KCMC is an organization with a drive to change. While each institution in low- and middle-income countries is unique, identifying strengths and concerns at KCMC may inform other, future cancer registration projects in similar environments.

The two measures with the highest reported levels of confidence were, first, to encourage clinicians to try using the registry (e.g., refer patients to the registry) and, second, to support clinicians as they adjust their clinical practice in response to the registry. Comparatively lower levels of confidence were reported for three measures: (1) effectively solve problems that might arise, (2) keep track of how things are going, and (3) manage the politics of implementing this program. This suggested that there was perceived support for clinicians, but respondents were not as confident about the organization's ability to manage change throughout implementation. When we collapsed and classified the change efficacy items into two categories – organizational motivation versus management – a clear threshold presented itself. Over 80% responded positively (e.g., "fairly confident" or "very confident") for each of the motivational survey items; respondents indicated that KCMC was very committed to registry implementation, very willing to work hard to implement it, and wanted very much to implement the registry. However, when asked about issues of management such as task coordination and problem solving, respondents responded positively far less frequently.

This distinction between organizational motivation and task management is important to understand, particularly in the context of cancer registry development in low- and middle-income countries. In learning healthcare organizations, managers must extend beyond traditional management roles and must serve as designers and teachers (Hernandez et al. 2000). This may be particularly true in the resource-limited settings where managers must be innovative. Organizations must communicate goals and values to their employees in an effort to build a sense of organizational belonging. To that end, it is essential that those internal and external stakeholders are involved early in the implementation process and that there is organizational endorsement. Relevant stakeholders within low- and middle-income countries must be identified, and their attitudes toward the change, such as cancer registry implementation, must be assessed (Hernandez et al. 2000). Moreover, it is critical that the political climate both internal and external to the organization is aligned well to support cancer registration activities. There must be clear delineation of responsibilities, an understanding of decision-making patterns, and a balance of tasks between employees (Charns and Gittell 2000; Hernandez et al. 2000).

Despite the high level of change efficacy, limited resources were available for all human resources except pathologists (e.g., staff to collect and enter patient data); the largest percentage of respondents indicated that currently the resource was insufficient but that it was obtainable. We surveyed a wide variety of professionals ranging from medical records technicians to hospital administrators. Respondents' professional role may limit their knowledge of certain resources. For example, a medical records technician may not be as knowledgeable about the availability of funds to maintain the registry, compared to the hospital administrator. Interestingly, we found similar responses across professional roles for most items. From a change-management perspective, the assessment of perception of resource availability may be particularly important. If resources are truly unavailable, change efficacy may be undermined. Nearly half of respondents reported that they had no pathologists and none were obtainable. However, pathology residents

from KCMC are currently undergoing training to return as staff pathologists; clearly, a communication gap exists between perception and actual availability of resources. Despite this communication gap, the assumption of KCMC staff is likely based on the known shortage of trained pathologists in sub-Saharan Africa (Awadelkarim et al. 2012). For example, the entire country of Tanzania has only 15 pathologists; this equates to one pathologist per 2.5 million people (Okesina 2009; Rambau 2011). This shortage needs to be addressed on a broader scale. A potential solution to shortage of trained pathologists involves telepathology, where pathologic slides are prepared and images are transmitted to pathologists located off-site (Hazin and Qaddoumi 2010), and working partnerships with high-income countries (Knaul et al. 2012).

Slightly more than one-third of respondents indicated that there were no funds to maintain the registry and funds were not obtainable. This sentiment is echoed in many LMICs, so lessons learned at KCMC may be more broadly relevant. Allocating scarce resources to a cancer registry can create additional strain in a system already stretching funds to provide appropriate health care. However, an initial investment in cancer registration is critical to understanding the disease burden, and unless disease burden is understood, appropriate resources cannot be allocated to cancer control. In order to ensure sustainable funding for population-based cancer registries, those leading cancer registration should involve health ministry officials in their respective countries early on (Anderson et al. 2011). Furthermore, long-term partnerships between high- and low-income countries have led to successful implementation of cancer control and treatment programs (Carlson et al. 2010). In order to bridge the resource gap, smaller-scale, hospital-based cancer registries can be initially developed and later scaled up for more comprehensive population coverage. Information obtained in our survey supports the aims of the NCI and other organizations aimed at facilitating lessons learned in low- and middle-income settings for broader dissemination in the implementation of cancer registry development (National Cancer Institute 2012). To that end, we posit that conducting a needs assessment is a critical early-stage component when beginning or expanding a cancer registry program, particularly in LMICs where resources are scarce. Perspectives gained from a survey like ours may be useful in conducting intra-institutional educational programs and/or prioritizing resource acquisition. While each country and institution is unique, our survey design and methodology may be suitable for other contexts.

There are a number of successful cancer registries in LMICs that serve as an exemplar for aspiring cancer registration program like KCMC's. An example of one such registry is the Gharbiah regional cancer registry in Egypt. For well over a decade, the Gharbiah registry has achieved over 90% population coverage. Data from the Gharbiah registry have informed several publications describing patterns of cancer in the region, including a monograph describing cancer incidence in several Middle Eastern countries and comparing that information with the US-based Surveillance Epidemiology and End Results (SEER) cancer registry (Freedman et al. 2006). There are two unique attributes of the Gharbiah registry that may have facilitated its success. First, in 1996 ministers of health in Egypt, Israel, Jordan, Cyprus and the Palestinian Authority established the Middle East Cancer Consortium (Middle East Cancer Consortium 2010). These registries use common software called CANREG, which was developed by IARC. Second, the registry is affiliated with Cairo University. These strategic alliances bolster resources and provide collaborative partnerships that will help developing cancer registry programs in low- and middle-incomes countries succeed. KCMC is uniquely positioned in its affiliations with Tumaini University and Kilimanjaro Christian Medical College. Despite this, respondents reported a perception that their organization is generally supportive of change regarding the cancer registry program but lacks many tools needed to expand it. This information shapes our approach in terms of interaction with KCMC staff and registry expansion. Though not geographically proximal to KCMC, Dar es Salaam in Tanzania is also home to a referral cancer centre. KCMC may partner with local institutions and those in higher income countries to increase its capacity for cancer registration.

This study has several limitations. KCMC is a single institution, and survey results from KCMC may not be generalizable to other organizations. Surveys were self-administered. While

no identifying information was collected, it is possible that respondents were hesitant to disclose responses that might reflect negatively on their organization. Given the consistency of responses across surveys, however, this is not a significant concern. We utilized a cross-sectional survey technique. Change efficacy and readiness to change will evolve longitudinally. It is possible that, even within a single institution, results would differ if measured over time. Because of the two-week survey administration time period and the sampling strategy, it is possible that important potential survey participants were not contacted. Effort was made to mitigate this limitation by sending electronic, e-mailed surveys.

In conclusion, administrators and medical staff at a large referral centre in sub-Saharan Africa believed strongly in the utility of cancer registration. However, they expressed concerns regarding registry management and sustainability. These are valid concerns that likely translate across borders to other institutions or regions in LMICs looking to develop cancer registries. Identifying such strengths and concerns prior to initiating cancer registration will help focus resources and improve chances of long-term success.

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