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Individual, socio-cultural and structural factors associated with cervical cancer screening and treatment in Tanzania

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INDIVIDUAL, SOCIO-CULTURAL AND STRUCTURAL FACTORS ASSOCIATED
WITH CERVICAL CANCER SCREENING AND TREATMENT IN TANZANIA

by

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INDIVIDUAL, SOCIO-CULTURAL AND STRUCTURAL FACTORS ASSOCIATED
WITH CERVICAL CANCER SCREENING AND TREATMENT IN TANZANIA

RENICHA MCCREE-HALE

HEALTH EDUCATION AND HEALTH PROMOTION

ABSTRACT

Most African countries including Tanzania have limited cervical cancer screening and treatment programs. Only about 5% of women have ever been screened for cervical cancer. A constellation of individual and structural factors contributes to the challenge of cervical cancer screening and treatment in countries that bear significant burdens of disease. Yet, little is known about country specific factors that may constrain or facilitate scale up of health services. This dissertation is an attempt to identify and understand the country specific individual and structural barriers along with facilitators to cervical cancer screening and treatment in Tanzania. Individual, institutional and structural level influences are explored to better understand barriers and facilitators to secondary prevention of cervical cancer. This dissertation is comprised of three interrelated studies– one quantitative and two qualitative studies.

Keywords: cervical cancer, screening, treatment, health services

DEDICATION

This dissertation is dedicated to my best friend and amazing husband, Dr. Timothy M. Hale and my loving parents, Rev. & Mrs. Ronald O. McCree. Your encouragement, guidance, prayers and love kept me motivated and determined to do this meaningful work.

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Sciences. I am also grateful to the study participants who shared their views about cervical cancer screening and treatment with me.

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LIST OF ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
CIDRZ	Center for Infectious Diseases Research Zambia
CTC	Care and treatment clinic
LSIL	Low-grade squamous intraepithelial lesions
HIV	Human immunodeficiency virus
HPV	Human papillomavirus
HSIL	High-grade squamous intraepithelial lesions
IEC	Information, education & counseling
MDH	Management and development for health
MOHSW	Ministry of health and social welfare
ORCI	Ocean road cancer institute
PAP	Papanicolaou
PEPFAR	President's emergency plan for AIDS relief
SEM	Social ecological model
SIL	Squamous intraepithelial lesions
VIA	Visual inspection with acetic acid
VILI	Visual inspection with Lugol's iodine

INTRODUCTION

Cervical cancer is attributable to infection caused by several carcinogenic genotypes of genital human papillomavirus (HPV) (Bosch, Manos, Munoz, et al., 1995; Walboomers, Jacobs, Manos, et al., 1999). It is the second most common cause of cancer deaths among women worldwide. There are approximately 493,000 new cases of cervical cancer worldwide each year and about 452,900 (91%) of these cases occur in less developed regions (Globocan, 2008). Nearly 80% of the 273,000 annual deaths attributed to cervical cancer occur in low resource settings (Parkin, Bray, Ferlay & Pisaini, 2005). Overall age adjusted incidence and mortality rates of cervical cancer have declined over the last 40 years largely due to routine population level screening programs in developed countries. However, in resource poor settings and particularly in East and sub-Saharan African countries, cervical cancer is the leading cause of cancer mortality among women (Globocan, 2008; Sankaranarayanan, 2006).

Of the approximately 80,400 incident cases of cervical cancer in Africa, 40% occur in East Africa (Globocan, 2008). Tanzania bears the highest burden of cervical cancer in the region (Globocan, 2008). In 2008, approximately 20% of new cases in East Africa occurred among Tanzanian women compared to 7% among East African neighbors in Kenya (Globocan, 2008). The age-standardized incidence rate of cervical cancer in Tanzania is 50.9 per 100,000 compared to 5.7 per 100,000 in the US (Globocan, 2008). The number of reported cases in Tanzania is likely conservative, because it may

underestimate cervical cancer incidence given the lack of national cancer surveillance and population level registry data available in African countries (Parkin, Sitas, Chirenge, et al., 2008; Reeler & Mellstedt, 2006). Taken together, the epidemiological data that are available indicate an urgent need to identify factors that may constrain or facilitate scale up of cervical cancer screening and treatment in Tanzania.

Most African countries including Tanzania have limited cervical cancer prevention programs. Only about 5% of women have ever been screened for cervical cancer. Of those who have been screened, 80% present with advanced stage cervical intraepithelial neoplasia (CIN) (Parkin et al., 2005; Sankaranarayanan, 2006). If left untreated, CIN can progress to invasive cancer. In many African settings, traditional cytology-based Pap smear screening programs are not a feasible solution, due to inadequate health services, poor laboratory infrastructure, and a myriad of service delivery challenges (Denny, Kuhn, De Souza, et al., 2005; Moodley, Kawonga, Bradley, & Hoffman, 2006; Sherris, Wittet, Sellors, et al., 2009). Alternatives to cytology-based screenings, including visual inspection-based see-and-treat methods, offer potentially promising solutions for population-level scale up of cervical cancer screening and treatment (Sherris et al., 2009). Commonly used see-and-treat methods are comprised of screening utilizing visual inspection with acetic acid (VIA) (Sankaranarayanan, Gaffikin, Jacob, et al., 2005) and visual inspection with Lugol's iodine (VILI) (Sankaranarayanan et al., 2005) along with treatment of precancerous cervical lesions using cryotherapy or freezing (Luciani, Gonzales, Munoz, Jeronimo & Robles, 2007).

VIA is also referred to as "cervicoscopy," "direct visual inspection," and the "acetic acid test" (Sankaranarayanan et al. 2005). VIA involves visual inspection with the

naked eye of the cervix using a bright light and application of a 3–5% acetic acid. The acetic acid is applied to the cervix using a spray or cotton swab. After 1 minute, the cervix can be examined for the appearance of dense, well-defined acetowhite areas that are illuminated by the application of the acetic acid (Sankaranarayanan et al., 2005). The VIA screening method is combined with cryotherapy when treatment for precancerous lesions is necessary, criteria for treatment are met, and when invasive cancer is not present (Sankaranarayanan et al., 2005). Cryotherapy is a low-technology method using a metal probe cooled by a refrigerant gas, and is used to freeze and remove suspicious lesions. The combination of visual inspection followed by treatment is often referred to as see-and-treat or screen-and-treat methods for cervical cancer screening and treatment.

Visual inspection using Lugol's iodine (VILI) is a variation of the VIA procedure. Instead of using acetic acid and looking for acetowhitening, clinicians use Lugol's iodine and look for areas of yellow non-iodine uptake and growths in the transformation zone or near the cervical os (Sankaranarayanan et al., 2005). VIA and VILI methods can be performed on an outpatient basis with hardly any equipment. The learning curve is low; therefore, a range of health workers can be trained to effectively perform the tests. A meta-analysis shows that screening with VIA or VILI detects the presence of cervical cancer and its precursors with an accuracy as good or even better than the standard Pap smear test (Arbyn, Sankaranarayanan, Mugwonge, et al., 2008; Sauvaget, Fayette, Muwonge, et al., 2011).

Visual inspection approaches coupled with same visit cryotherapy have been found to be suitable for clinic-based implementation by trained providers (Gaffikin, Blumenthal, Emerson & Limpaphayom, 2003, Ngoma, Muwonge, Mwaiselage, et al.,

2010; Mwanahamuntu, Sahasrabuddhe, Pfaendler, et al., 2009). Test results are also available immediately and treatment can be performed as soon as the lesions are visualized but only if adequate resources are available. While visual inspection and related treatment methods appear safe, providers exercise a degree of subjectivity that may impact quality assurance if training and quality control measures are inadequate (Chamot, Kristensen, Stringer & Mwanahamuntu, 2009; Muwonge, Mbalawa, Keita, et al., 2009; Sankaranarayanan, Esmy, Rajkumar, et al., 2007). When criteria for treatment are not met, women are often referred for loop electrosurgical excision procedure (LEEP) and histological evaluation (Pfaendler, Mwanahamuntu, Sahasrabuddhe, et al., 2008).

Newer and possibly more efficacious methods for cervical cancer screening and treatment using HPV DNA testing have emerged (Qiao, Sellors, Eder, et al., 2008; Sankaranarayanan, Nene, Shastri, et al., 2009; Schiffman & Wacholder, 2009). HPV DNA testing may provide a more objective screening method compared to visual inspection tests, and is more sensitive than cytology-based screenings (Schiffman & Castle, 2005). However, the current Hybrid Capture 2 (Qiagen, Inc.) HPV DNA test is expensive and requires an established, high-quality laboratory infrastructure (Louie, Sanjose & Mayaud, 2009; Sherris et al., 2009). Until the portable, more rapid and potentially more feasible *care*HPV test is available in African settings, screen-and-treat methods can serve as good alternatives and may offer the best solution for cervical cancer prevention (Sherris et al., 2009) in resource limited environments. The *care*HPV test may become available to market in 2011. (Sherris, et al., 2009). HPV DNA testing is likely to significantly change the way cervical cancer screening is performed over time (Schiffman & Wacholder, 2009; Sankaranarayanan et al., 2009).

Despite potential improvements in cervical cancer screening and treatment, implementations of population level screening programs have lagged in many African countries including Tanzania. A constellation of individual and structural factors contributes to the challenge of cervical cancer screening and treatment in countries that bear significant burdens of disease. Yet, little is known about country specific factors that may constrain or facilitate scale up of health services. In addition, no study has been conducted to explore the socio-cultural norms and perceptions of cervical cancer among Tanzanian women and men, although men's perspectives have been shown to influence women's health seeking behaviors (Dudgeon & Inhorn, 2004; Msuya, Mbizvo, Hussain, et al., 2006; Barker, Ricardo, Nascimento, et al., 2009).

The high disease burden of cervical cancer in Tanzania, the paucity of research on women's and men's perceptions and intentions toward cervical cancer prevention, and the lack of a population-level screening program are issues that clearly merit investigation. Additionally, evaluating existing cervical cancer screening and treatment programs may be useful for improving service delivery over time. Therefore, the aim of this dissertation is to identify multi-level influences on cervical cancer screening and treatment in Tanzania. Individual, socio-cultural and structural level influences are explored to better understand barriers and facilitators to secondary prevention of cervical cancer. This dissertation is comprised of three interrelated studies–one quantitative and two qualitative studies. The primary data collection for this dissertation was started in June 2008 and data analyses were completed in July 2011.

The three levels of influence or factors that are explored in this dissertation can be characterized broadly as individual and socio-cultural, institutional and structural or

system level factors. Structural factors pertain to social and environmental influences that are often systemic and beyond any one person's control. Individual influences pertain to barriers and facilitators that are under people's personal control. Socio-cultural influence is shared by groups of people from similar backgrounds and cultures and may help explain perceptions and attitudes of a group about phenomena (Dein, 2004). Individual, socio-cultural and structural levels of influence work together to help explain health behaviors and related systemic factors that may exacerbate health outcomes (McLeroy, Bibeau, Steckler & Glanz, 1988). The Social Ecological Model (SEM) proposed by McLeroy and colleagues (1988) provides a useful theoretical framework for exploring the research questions that form the foundation of this dissertation research. The SEM (McElroy, Bibeau, Steckler & Glanz, 1988) argues that social and environmental factors at the individual, institutional, and policy levels influence health behavior. The SEM was based on Urie Bronfenbrenner's (1979) idea that behavior is shaped by several levels of influence.

In addition to an investigation of levels of influence on cervical cancer screening and treatment in Tanzania, the growing burden of cancer in low resource settings formed the basis for this dissertation research. Surprisingly, 70% of projected cancer cases in 2020 will occur among people living in developing countries (Linwood, Boyle, Milburn et al., 2008). Of these estimated new cases, approximately 1 million will occur in sub-Saharan Africa (Linwood, Boyle, Milburn, et al., 2008; Globocan, 2008). In low resource African settings, cancer and other noncommunicable diseases will not displace infectious diseases; rather, they will represent a double burden of diseases likely to exacerbate

health outcomes over time (Orem & Wabinga, 2009; Yach, Hawkes, Gould & Hoffman, 2004).

This dissertation is an attempt to identify and understand the country specific individual and structural barriers along with facilitators to cervical cancer screening and treatment in Tanzania. This dissertation research is designed to identify barriers and facilitators that may impact cervical cancer screening and treatment in Tanzania, and is comprised of three related manuscripts:

Manuscript #1: uses in-depth interview data from key stakeholders including Tanzanian clinicians, policymakers and academicians to identify the perceived barriers and facilitators to cervical cancer screening and treatment;

Manuscript #2: uses in-depth interview data to explore of socio-cultural representations of cervical cancer and perceptions of and attitudes towards screening and treatment among a sample of men and women seeking care in Dar es Salaam, Tanzania;

Manuscript#3: evaluates the follow up rates for diagnosis of precancerous lesions of the cervix among women receiving HIV care and treatment in Dar es Salaam, Tanzania.

Research Questions

1. What factors may affect the scale-up of cervical cancer screening and treatment according to health services stakeholders in Dar es Salaam, Tanzania? The manuscript titled: *Perceptions of structural influences on scale up of cervical cancer screening and treatment in Tanzania* was written to answer this research question.

2. What are the dominant socio-cultural, lay perceptions of cervical cancer among men and women ages 19-49 in Kinondoni district, Dar es Salaam, Tanzania? The manuscript titled: *Perceptions and attitudes of women and men in Kinondoni district, Tanzania about*

cervical cancer screening and treatment: An exploratory study was written to answer this research question.

3a. What are the health care seeking behaviors of HIV-infected women attending care and treatment clinics (CTC) for evaluation and treatment of cervical cancer at a referral site? 3b. What factors are associated with follow up among HIV-infected women for evaluation of precancerous lesions of the cervix at a referral site? The manuscripts titled: *Loss to follow up after diagnosis of cervical squamous intraepithelial lesions among women receiving HIV care and treatment in Dar es Salaam, Tanzania* was written to answer this research question.

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PERCEPTIONS OF STRUCTURAL INFLUENCES ON SCALE-UP OF CERVICAL
CANCER SCREENING AND TREATMENT IN TANZANIA

by

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PERCEPTIONS OF STRUCTURAL INFLUENCES ON SCALE UP OF CERVICAL
CANCER SCREENING AND TREATMENT IN TANZANIA

ABSTRACT

Tanzania has the highest burden of cervical cancer in East Africa. This study aims to fill
gaps in the literature by identifying perceived barriers and facilitators that influence
broadening of regional and population-level cervical cancer screening and treatment
programs in Tanzania. Purposive sampling was used to select participants for this cross-
sectional qualitative study. Twenty-eight stakeholders completed face-to-face interviews,
and a municipal health management team comprised of seven individuals participated in
a focus group discussion. The investigation identified themes related to the infrastructure
of health services for cervical cancer screening and treatment, capacity building, political
will, and socio-cultural influences on screening and treatment. Decentralizing service
delivery, improving timely access to treatment, and increasing the number of trained
health workers were perceived as key facilitators for enhancing and initiating screening
and treatment services. In conclusion, increasing capacity for screening and treatment of
cervical cancer are essential for greater access to these health services.

Key words: Cervical cancer, health services research, service delivery, screening

INTRODUCTION

In many African countries, cervical cancer remains the most common cancer
among women[1]. While progress has been made in cervical cancer prevention over the last
40 years, most African countries have not yet introduced comprehensive screening and

treatment programs[2,3]. Competing health needs, inadequate funding[4], social

disadvantages[5], and a low priority for cancer control and prevention vis-à-vis other health

care programs[3,6] are factors limiting programs at the population level. Country-specific

findings on program successes and challenges are necessary for development of

initiatives aimed at increasing delivery of services in countries with limited screening

coverage and high rates of cervical cancer[7]. For program development, country-specific

findings provide insight into likely challenges that may be associated with

implementation[8], facilitators of screening and treatment[7, 9-11], lessons learned in service

delivery[7,11] and sustainability of services[12].

In Africa, approximately 40% of new cases of cervical cancer occur in the region

of East Africa. Tanzanian women bear the highest burden of cervical cancer in this

region, with age-adjusted standardized incidence rates of 50.6 cases per 100,000[1]. In

response to the high burden of cervical cancer, a variety of pilot projects, regional

outreach clinics and research studies on cervical cancer have been conducted in

Tanzania[13]. Recently, the Tanzanian Ministry of Health and Social Welfare (MOHSW)

partnered with JHPIEGO, a nongovernmental organization, to develop national

guidelines for delivery of cervical cancer control and prevention[14]. Tanzania is one of the

few African countries participating in studies of HPV vaccine safety and

immunogenicity[13,15]. Recently, more than 10,000 women were screened in an evaluation

of the efficacy of visual inspection based 'see-and-treat' protocols for screening and

treatment of cervical cancer[16]. Visual inspection approaches [most prominently 'visual

inspection with acetic acid' (VIA)] can be linked to immediate treatment of precancerous

lesions with cryotheraphy for eligible women. Despite challenges and limitations (such as

under-detection and overtreatment)[17], VIA-based single-visit 'see-and-treat' approaches have been shown to be safe, relatively accurate, and feasible for scaling up cervical cancer screening and treatment services in low-resource settings[18-20].

Notwithstanding the limited country-specific data on cervical cancer screening and treatment programs in Tanzania and the East African region, it is important to understand the spectrum of challenges that influence enhancement of service delivery and expansion of screening coverage. Despite various demonstration projects and research initiatives for cervical cancer screening and treatment, there has been limited examination of the perceived structural and societal factors that continue to constrain implementation of population-level programs and the facilitators that have led to participation in large-scale programs. The purpose of this cross-sectional, qualitative study was to fill this gap in evidence by identifying perceived barriers and facilitators that influence broadening of regional and population-level cervical cancer screening and treatment programs in Tanzania.

METHODS

Study design

This cross-sectional study consisted of semi-structured face-to-face interviews and one focus group discussion. Qualitative forms of inquiry were selected to elicit data on participants' knowledge, perceptions and recommendations regarding cervical cancer screening and treatment in Tanzania. The Institutional Review Board at the University of Alabama at Birmingham and the National Institute for Medical Research in Tanzania approved the study protocol.

Participants

In total, 19 semi-structured face-to-face interviews were conducted for the study. Both individual (n=12) and group interviews (n=7) were conducted with 28 stakeholders working in public sector health facilities, academia, government, and nongovernmental organizations. Group key informant interviews were comprised of 2-4 participants each. To be eligible for the study, participants had to be stakeholders engaged in cervical cancer research in Tanzania, provide verbal informed consent, and agree to have their responses audio-recorded and transcribed for analyses. Participants were recruited via telephone and through face-to-face contact using purposive sampling based on profession and location of employment (Dar es Salaam, Tanzania). In addition, the Community Health Management Team and administrative clinicians (n=7) from a municipal district in Dar es Salaam agreed to participate in a single focus group discussion. Verbal informed consent and permission to audio record the discussion were provided. The total study sample was comprised of 35 participants.

Procedures

The interviews lasted approximately one hour and thirty minutes, and the focus group discussion about one hour. One question guide comprised of twenty-three questions was used to conduct both the interviews and focus group discussion. Interview questions were based on findings from cervical cancer research conducted in low-resource settings[7,21-23]. Open-ended questions were developed to elicit data on barriers and facilitators to breast and cervical cancer screening and treatment, knowledge of available health services in public sector facilities for screening and treatment, and recommendations for population-level increases in delivery of services. Additional

questions were asked to determine level of support for cervical cancer screening and treatment. The question guide is shown in Table 1.

[Insert Table 1 about here]

In addition, five questions and additional probes related to clinical care for screening and treatment and community-based health education activities in the Kinondoni district were asked during the focus group discussion. These questions do not appear in the question guide, but are part of the focus group transcript. The principal investigator served as the facilitator for the interviews and focus group discussion. All interviews and the focus group discussion were conducted in English. Since confidentiality was necessary for participants to give complete and unbiased responses, limited demographic data were obtained.

Data analysis

Qualitative data were analyzed using framework analysis[24] and categorized and indexed using NVivo 8 qualitative software[25]. Ritchie and Spencer[24] developed framework analysis as a qualitative data analysis tool to allow for familiarization with data, thematic development, indexing/coding, charting, mapping and interpretation of qualitative data. Familiarization is an iterative process that involves a detailed review of transcripts, data collection tools, and field notes. This iterative process of reviewing the data was performed to create themes that represent larger phenomena reflected through the data. For this analysis, familiarization and thematic development were performed using hand coding of the data. NVivo[25] software was used to index the data and create codes. Data were analyzed independently by four cervical cancer researchers to determine verification[26] and trustworthiness[27]. Verification is performed to make sure

data reflect qualitative themes, and trustworthiness is a measure of the "truth value" and applicability of the data. Verification and trustworthiness are widely accepted measures used to establish validity and reliability in qualitative research[28]. Taken together, familiarization, thematic development, indexing/coding, and mapping are used to interpret the data[24].

RESULTS

Overall fifty-seven percent (20/35) of the participants were women and eighty-five percent (6/7) of participants in the focus group discussion were women. Ninety-one percent of participants (32/35) were black Tanzanians and the remaining participants were white American (2/35) and Tanzanian Indian (1/35). Thirty-four percent (12/35) reported working in public sector health clinics; an equal number worked for the government/Ministry of Health; 17%; (n = 6) worked in academia, and the remaining 14 (*n* = 5) reported working for non-governmental organizations. Participants were from non-governmental organizations that provided advocacy for breast and cervical cancer, women's reproductive health and HIV and reproductive health. Group composition was designed so that no one individual was likely to bias the responses of others in the group.

Data from the interviews and focus group discussion were analyzed to provide insight into multi-level factors that may constrain and facilitate cervical cancer screening and treatment in Tanzania. Selected quotes highlight the most prevalent themes that emerged during data analysis. These themes are used as headings for results.

Inadequate health services and service delivery constrain program implementation

Nearly all participants perceived that the lack of financial and human resources were major barriers to increasing cervical cancer screening and treatment. Lack of health

services resources were reported to constrain cervical cancer screening and treatment efforts. The following statements represent the most commonly reported views of participants:

> *"The problem of financial resources is always there. If the program is not part of the main budget, there is no way to fit it in."* (Male interview participant, oncologist, participant in a group interview)

> *"The best thing to happen is to see how we can arrest this problem. How can we make women take up early screening and improve treatment facilities? With increased screening we must have more treatment facilities. It's a question of human and financial resources."* (Male interview participant, cancer prevention specialist, participant in a group interview)

> *"Lack of widely available screening and treatment is a major barrier to cervical cancer prevention. We must change this situation."* (Female interview participant, physician, participant in the focus group discussion)

Participants suggested that building partnerships and enhancing existing reproductive health services were solutions for overcoming some of the challenges of insufficient resources for service delivery. One participant stated:

> *"[We] need to figure out what partnerships are already working and see if we can work with what already exists."* (Male interview participant, cancer prevention specialist, participant in a group interview)

Local capacity building is necessary for enhancing screening and treatment programs

Capacity building at the regional and district levels of the health system was reported as a key facilitator for improving access to early detection and timely treatment. Creating regional centers of expertise to expand the number of trained clinicians and health centers providing screening and treatment was considered to be an integral part of the long-term

plan for improving service delivery. Participants suggested that decentralizing health

services for cervical cancer prevention was the next step. Two participants commented:

> *"[We] need to designate institutions to do on-site cervical*
> *cancer screenings, and provide trainings at health centers*
> *to build capacity at the regional and district levels."*
> (Female focus group participant, participant in a group
> interview)

> *"The Ministry of Health wants this test in all areas of*
> *Tanzania. Therefore we are training teams to go out and*
> *train others."* (Male interview participant, senior physician,
> participant in one-to-one interview)

To illustrate ongoing capacity building for cervical cancer screening and treatment in

each geographic zone and region, a participant briefly explained the structure of

health services as follows:

> *"The country is divided into [several] regions with zones*
> *within them. So we train a zone in one region and move to*
> *the next region so there is training in all regions not just*
> *one."* (Female interview participant, physician, participant
> in a group interview)

Participants reported that immediate improvements in the referral system were needed

to treat cervical cancer at the district and regional levels. Creating regional services

was suggested as a way to improve access to care for women living farther away from

the national hospital and cancer center in Dar es Salaam. Participants also reported

that improving regional and district services would likely decrease the demand on the

referral system over time. Comments from two participants support this point.

> *"We must make the referral system more efficient including*
> *decentralization of treatment from the [national level] to*
> *making regional districts with cancer care capacities."*
> (Male interview participant, cancer prevention specialist,
> participant in a group interview)

> *"We need to focus training on health center and dispensary workers at the [regional and district levels].* (Male interview participant, physician, only participant in interview)

Socio-cultural factors influence cervical cancer prevention

Participants reported that socio-cultural factors influence acceptance of cervical cancer screening and treatment. Fatalism toward cancer diagnosis and treatment were perceived to influence people's health seeking behaviors and attitudes toward prevention. In addition, participants perceived that the religious beliefs of Tanzanian men and women shape attitudes about cervical cancer and cancer in general. Despite the reported importance of socio-cultural factors as potential barriers to care, participants indicated that Tanzanian women would seek screening and treatment if there were interventions to create awareness. Two participants had the following perceptions of the impact of socio-cultural influences on screening behavior.

> *"Religion is very important to most Tanzanians. If you can get to them through their religion, you have a better chance of success [with prevention]."* (Female interview participant, technical advisor, participant in a group interview)

> *"Some say that everyone that goes to [the national cancer center] dies, but they don't realize that everyone that comes to the [center] came with a late stage disease."* (Male interview participant, oncologist, participant in a group interview)

Participants reported that they perceived that socio-cultural factors related to religion and fatalism towards cancer may influence health behaviors. However, the majority of participants indicated that women would likely seek screening services if they knew the services were available. One participant stated:

> *"The gap is more in the health care system. The community*
> *is willing to uptake services. The major problem is the*
> *capacity to treat [women]."* (Female physician, participant
> in the focus group discussion)

Political will exists for cervical cancer screening and treatment

Political will for cervical cancer screening and treatment was perceived as a necessary

component for sustainability and integration of screening and treatment for women's

health. Comments from two participants illustrate this point:

> *"The government will start a cancer control unit with a*
> *department to deal with reproductive cancers. Currently,*
> *there is a lot of political [support] for cancer prevention."*
> (Male interview participant, participant in a group
> interview)

> *"For sustainability, the government is working on a*
> *package and funding from the health basket with the*
> *intention to sustain the program initiated by foreign*
> *organizations. Once their time is over, the government will*
> *take over for the long term."* (Male interview participant,
> participant in a group interview)

DISCUSSION

Through this study, we have identified the perceived structural barriers and

facilitators to increasing cervical cancer screening and treatment among a sample of key

stakeholders in Tanzania. The perspectives expressed by key stakeholders may inform the

development and improvement of public health programs for cervical cancer prevention

in Tanzania. The findings suggest that some of the most important factors influencing

cervical cancer screening and treatment relate to health services, capacity building, socio-

cultural influence, and political will. These findings are consistent with those reported in

similar studies on expanding and sustaining cervical cancer programs in Africa[21, 29-30].

Although participants reported several challenges to strengthening service delivery and

institutionalizing screening and treatment, they also provided examples of support for capacity building and increasing political will for cervical cancer screening and treatment.

Establishing training institutes at the regional and district levels of the health system was perceived as a feasible option for increasing the capacity of trained clinicians and increasing access to screening and treatment. Participants indicated that improving health services in the geographic zones and regions would likely increase early detection of precancerous cervical lesions and reduce the diagnosis of late-stage disease. As regional and district health facilities increase capacity for screening and treatment, participants perceived that women would be able to access services closer to their homes, and would be more likely to use these services.

The Grounds for Health organization along with ICAP, and the MOHSW are working in the Kigoma region of Tanzania to improve access to screen-and-treat services and prevent late state presentation, particularly for HIV-infected women[31]. In just about 9 months, over 2,200 women in the Kigoma region have been screened. The PATH, JHPIEGO and Management & Development for Health nongovernmental organizations, among others, along with the World Health Organization (WHO), the Kilimanjaro Christian Medical Centre and Peramino Mission Hospitals provide additional services for cervical cancer screening and treatment in Tanzania.

Use of existing health services for women and capitalizing on improvements in infrastructure as a result of public/private partnerships were reported as potential solutions for integrating cervical screening programs in Tanzania. Most participants suggested that creating public/private partnerships for cervical cancer prevention would

increase delivery of services. Examples of donor partnerships in Zambia and Rwanda support this finding. In Zambia, Parham and colleagues[10,12] have screened more than 58,000 women by integrating cervical cancer screening and treatment services within clinics operated through the President's Emergency Plan for AIDS Relief. The Rwandan government has announced a public/private partnership with Merck and Qiagen to create the first comprehensive cervical cancer prevention program in Africa. Merck will provide 2 million doses of the quadrivalent HPV vaccine (Gardasil®) for Rwandese girls, and Qiagen will provide 250,000 HPV DNA tests to screen older women for HPV[32]. Programs for cervical cancer screening and treatment in Zambia and prevention in Rwanda illustrate the potential of innovative partnerships for program development.

Political will for capacity building of screening and treatment was reported to influence the expansion and sustainability of health services. This has been consistently accepted as a key factor influencing cervical cancer prevention programs in low-resource settings[5,33]. The development of the first Tanzanian national guidelines for cervical cancer screening and treatment, an example of increasing political will for cervical cancer prevention, offers hope for more consistent delivery of services and wider screening. Increasing political will for screening and treatment may influence country-ownership and long-term sustainability of scaled-up prevention programs[12].

Results of this study indicate that various factors contribute to the challenge of cervical cancer screening and treatment in Tanzania. The study also suggests that there are new, systematic developments aimed at improving cervical cancer prevention and control in Tanzania.

This study is not without limitations. The lack of comprehensive socio-demographic data of the participants and purposive sampling preclude generalization of results. Because we did not collect detailed socio-demographic data, we cannot determine if there was bias in the way questions were answered, particularly when supervisors and their subordinates attended the same interviews or FGD. However, we believe the themes emerging from the results of this study may inform decisions for resource allocation and programmatic prioritization of cervical cancer screening and treatment.

CONCLUSION

While scaling up of population-level programs has lagged, ongoing demonstration and research projects at the regional level offer promise for building political advocacy, integrating delivery of services, and building platforms for future comprehensive cervical health programs in Tanzania. The feasibility and efficacy of screen-and-treat approaches at the Ocean Road Cancer Institute[16], the national cancer center in Tanzania, offers evidence of progress toward increased delivery of services. In the last year, the MOHSW developed a special unit to coordinate countrywide cervical cancer control and prevention efforts and providers. Regional training initiatives and the development of national guidelines for cervical cancer prevention also suggest that the capacity for screening and treatment is expanding[14]. Understanding the barriers and facilitators to cervical cancer screening and treatment in Tanzania will guide the development of public sector and non-governmental organization-led comprehensive programs for expansion and sustainability of cervical cancer prevention and control services.

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Table 1 Question guide for interviews and focus group discussion

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1. What are the most pressing health needs in Tanzania?
2. Who is involved in addressing those needs?
3. Who needs to be involved in addressing those needs?
4. How does cervical cancer rank among the needs important to you? To Tanzanians?
5. How does breast cancer rank among the needs important to you? To Tanzanians?
6. In your opinion, should cervical cancer be addressed? Why or why not?
7. In your opinion, should breast cancer be addressed? Why or why not?
8. What, if any, myths exist about cervical cancer screening?
9. How can we overcome these myths?
10. Who is involved in cervical cancer prevention and control activities?
11. Where do women seek cervical cancer screening and/or treatment? Who provides care?
12. What individual barriers exist for women seeking care?
13. What community-system barriers exist for women seeking care?
14. What health care barriers exist for women seeking care?
15. What systems are in place to help women overcome the barriers you mentioned?
16. If a cervical cancer program was developed and implemented in this area, how would it be carried out?
17. Who would need to be involved?
18. What resources would be needed prior to implementation?
19. When should planning begin?
20. Where do you suggest the program be implemented?
21. What potential (real or perceived) opposition would there be to a cervical cancer program being developed and implemented in Tanzania?
22. What would need to be done to overcome any opposition?
23. Is there anything else we need to know?

PERCEPTIONS AND ATTITUDES OF WOMEN AND MEN IN KINONDONI
DISTRICT, TANZANIA ABOUT CERVICAL CANCER SCREENING AND
TREATMENT: AN EXPLORATORY STUDY

by

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ABSTRACT

Objective: To describe the knowledge, attitudes and perceptions of cervical cancer screening and treatment among a sample of Tanzanian men and women who were seeking healthcare at the Magomeni health center in the Kinondoni Municipal District, the largest district in Dar es Salaam, Tanzania.

Study design: This was a qualitative study comprised of face-to-face structured interviews with a purposive sample of women (*n*=15) and men (*n*=15) ages 19-49 seeking health care. Each interview lasted thirty to forty-five minutes and was conducted by a same gender interviewer in Kiswahili. Interviews were back translated into English and analyzed to describe basic qualitative themes.

Main outcome measures: Perceptions of the etiology, risk factors and views of cervical cancer screening and treatment, and men's level of support for screening and treatment.

Results: Qualitative themes were related to positive and negative perceptions of cervical cancer screening and treatment. Women had positive perceptions of cervical screening, but associated treatment for cervical cancer with loss of life and infertility, and thus had negative attitudes toward treatment. Men were more likely to report having positive perceptions of screening and treatment for cervical cancer, and reported more accurate explanations of treatment options than women. Both men and women were uncertain of risk factors for cervical cancer or the main cause of disease.

Conclusion: As health services for cervical cancer screening and treatment in Tanzania improves, interventions should engage women and encourage male partner involvement to promote acceptability and uptake of timely screening and treatment.

Key words: Cervical cancer, screening, treatment, socio-cultural norms, and male

involvement

INTRODUCTION

Women in Tanzania bear the highest burden of cervical cancer in East Africa [1]. Approximately 20% of cases of cervical cancer in the region occur in Tanzania [1]. Nearly 80% of Tanzanian women with cervical cancer die within five years of diagnosis [2]. Poor survival outcomes are likely due to advanced stage presentation and limited screening coverage. Despite the high burden of cervical cancer in Tanzania, there is a paucity of research on the socio-cultural explanations of cervical cancer among women and men.

Socio-cultural explanations of cancer are based on culture-specific individual and group knowledge, attitudes and perceptions that may influence health behaviors and responses to disease control and prevention [3-4]. Exploring women and men's socio-cultural explanations of cervical cancer may inform program development, behavioral interventions and health education strategies [5]. In low resource settings with high cervical cancer disease burden, engaging men in research has been particularly useful for identifying key influences on women's behaviors toward screening and treatment [6-10]. In a study of male partner involvement on follow up rates for evaluation of precancerous cervical lesions by colposcopy, Mutyaba and colleagues [10] reported that male partner involvement reduced loss to follow up by 18% among Ugandan women.

As the Tanzanian Ministry of Health and Social Welfare (MOHSW) works to improve cervical cancer screening and treatment with the development of the first national screening and treatment guidelines [11], it is critical to understand and address individual level factors that may affect acceptability of health services. The purpose of

this study was to gain insights into socio-cultural explanations of cervical cancer, screening, and treatment among a health care seeking sample of Tanzanian women and men. Identifying individual factors that facilitate or constrain screening and treatment of cervical cancer may help inform prevention strategies and improve early detection and screening behaviors overtime. This research is particularly timely given recent efforts to expand cervical cancer screening and treatment in Tanzania [2,12].

METHODS

Study design

This qualitative study was comprised of face-to-face structured interviews with a sample of women (*n*=15) and men (*n*=15) seeking health care at the Magomeni Health Center in the Kinondoni Municipal District, Tanzania. The Institutional Review Board (IRB) at the University of Alabama at Birmingham (UAB) and the National Institute for Medical Research (NIMR) in Tanzania reviewed and approved the study protocol.

Study site

The Kinondoni Municipal District is one of three districts in Dar es Salaam, Tanzania. Kinondoni District is the largest district in Dar es Salaam, and has a population of approximately 1.3 million people (Kinondoni municipal health conference presentation). The Magomeni health center is one of about 43 public health clinics in Kinondoni District, and provides outpatient services for reproductive health, tuberculosis (TB), dental health and HIV.

Participants and procedures

Study participants were between ages 19-49. The purposive sample of men (n=15) and women (n=15) was recruited from waiting areas in the reproductive health, TB,

dental and HIV outpatient clinics of the Magomeni Health Center. Same gender research assistants recruited participants into the study and obtained written informed consent prior to each interview. The face-to-face interviews lasted thirty to forty-five minutes and were audio-recorded for data analysis. Participants received a nominal amount of money (3000 Tanzanian shillings ≈ $2.00) after completing the interview.

Instrumentation and measures of interest

A male and female interviewer were hired and trained to conduct the 30 individual face-to-face structured interviews. Both interviewers were trained in public health research and attended a two-day session on conducting structured interviews. Researchers used an interview guide to: 1) determine perceptions of cancer with a particular focus on cervical cancer; 2) identify cultural explanations (knowledge, attitudes, and perceptions) of cervical cancer screening and treatment; 3) determine men's level of support for cervical cancer screening and treatment; and 4) identify barriers and facilitators toward cervical cancer prevention.

The interview guides were comprised of open-ended questions (32 on the men's guide and 39 on the women's guide) covering the four areas above and 11 socio-demographic items–Age, marital status, education, employment, income, religious affiliation, parity, concurrent sexual partnerships, ever tested for HIV, HIV status, and HIV status of partner. Interview guides were pilot-tested for understandability and cultural relevance with two women and two men recruited from the Sinza Health Center in Kinondoni district. Participants received a nominal monetary amount for their participation in pilot testing. All interviews were conducted in Kiswahili and back translated into English for analysis.

Data analysis

Descriptive statistics using SAS 9.13 statistical software [13] were conducted to characterize the study sample (Table 1) using the twelve demographic questions. The non-demographic data were categorized using NVivo 8 qualitative software [14]. The qualitative descriptive method proposed by Sandelowski [15] was used to analyze the data. The qualitative descriptive method provides a systematic approach for describing data and making basic inferences. Qualitative description is a method that can stand-alone as a basic form of qualitative data analysis. Qualitative description produces a basic yet detailed analysis that accurately describes qualitative data [15]. With qualitative description, researchers are not required to represent the data with conceptual frameworks or high abstraction, the goal is to present a description of the data and make generalizations that "do not require reading into, between and over the data" [15].

Sandelowski [15] suggests that the qualitative descriptive method can produce a valuable product that can be easily used by practitioners and policy makers for its straightforward, close interpretation of the data. In addition, researchers can build on qualitative descriptive data and explore phenomena of interest in greater detail. Given that the purpose of this study was to identify and describe Tanzanian women and men's knowledge, attitudes and perceptions of cervical cancer prevention, this method provides a useful approach for qualitative analysis. Salient findings that best describe perceptions of and attitudes towards the key areas of interest are arranged under headings that characterize the data.

[INSERT TABLE 1 ABOUT HERE]

RESULTS

This study was comprised of women (n=15) and men (n=15) seeking care at a

public-sector health center in Dar es Salaam, Tanzania. The mean age for men was 32

years and the minimum and maximum ages were 21 and 49 years. The mean age for

women was 30 years and the minimum and maximum ages were 20 and 39 years. The

majority of participants were married 63% (19/30). Most women had a secondary

education 53% (8/15), but were less educated than men, as 40% (6/15) of men had some

college education and 13% (2/15) had post graduate training. While the majority of the

participants were employed (60%, 18/30) about a quarter of them were unemployed.

Over half of participants (56%,17/30) made the equivalent of $50 US dollars or less per

month. The majority of participants had been tested for HIV 73% (22/30), and all but

26% (8/30) knew the HIV status of their main sexual partner. All participants indicated

some religious affiliation to either Christian or Muslim faiths. Twenty percent (3/15) of

women had ever been screened for cervical cancer. Detailed descriptive statistics describe

participant characteristics and are presented in Table 1.

Qualitative descriptions of key themes

Men and women's cultural representations of cancer and cervical cancer

All participants reported having heard of cancer. Descriptions of cancer ranged

from biomedical to lay categorizations. The majority of participants associated cancer

with death. The following quotes characterize participants' lay descriptions of cancer.

One man stated:

> "I think cancer is a disease which always ends up killing
> those who are affected by it. I don't know, maybe if you
> comply with the advice of the health care providers you

may live a little longer, but eventually you die" (Married
man, aged 42).

A common lay description of cancer was that it rotted the body. One lady commented

that:

"Cancer occurs when part of the body is rotten and cannot
function" (Single woman, aged 23).

A male participant with a secondary education provided one of the few biomedical

descriptions of cancer. This participant commented that:

"Cancer is not a communicable disease, and generally it is
difficult to treat it. Usually there are abnormal cells which
multiply and may disseminate throughout the body" (Single
man, aged 21).

Men and women provided less detailed descriptions of cervical cancer then cancer

in general. Several men remarked that cervical cancer was a new disease.

"It is a new disease. As time goes by people will get to
know more about this disease. It's like what happened with
HIV/AIDS when it was discovered. People had a vague
knowledge about it and now everyone is aware" (Married
man, aged 42).

Women had even more general descriptions of cervical cancer, and mostly stated

anecdotal accounts of women they knew who had been affected by the disease. About

40% of women admitted that they had limited knowledge of cervical cancer, and were

not comfortable providing detailed explanations of the cause of the disease.

"For instance, I had my aunt, on my mom's side, who had 3
abortions and the last one was very bad, and later on she
was diagnosed to have cervical cancer" (Separated woman,
aged 31).

"For me, from what I have heard, maybe if you have
cervical cancer, you can have a wound, and it can take you
a long time to be okay. That's what I know, but for

knowing in detail, I don't know about cervical cancer"
(Separated woman, aged 31).

Men and women's perceptions of causes of cervical cancer and knowledge of risk factors

Participants commonly reported that bacteria caused cervical cancer. The

following quote characterizes this perception.

"What I know is that the uterus is being eaten up by
bacteria which leads to rotting of the uterus (Married
woman, aged 36)".

Types of food in the diet, particularly fried foods, were associated with causing cervical

cancer. A few men and women described poor diet as the disease etiology of cervical

cancer. One woman described types of food and urbanization as possible causes of

cervical cancer. She explained:

"On my side the thing that contributes to making the
problem bigger is the type of foods we are eating. There are
a lot of chemicals in them. Another reason is the kind of
life we are living–congestion of people at one place. But,
the most important cause is the food with chemicals for
preservation" (Married woman, aged 36).

Participants less commonly reported folk myths as a cause of cervical cancer. However,

about 20% of participants had comments similar to this statement:

"Women think that they are bewitched and go to the witch
doctors and use local herbs. If they don't get relief, this is
when they go to the hospital when the problem is
advanced" (Married woman, aged 37).

Among women, three of them had accurate and succinct descriptions of several of the

risk factors associated with cervical cancer. Accurate descriptions of risk factors were as

follows:

"Cervical cancer occurs in women especially for women
who started sexual intercourse at a young age, [who are]
alcohol drinkers, cigarette smokers, and [had] frequent

deliveries (small gaps between babies), and many children"
(Married woman, aged 36).

"It is caused by using contraceptives, pills and injectables"
(Married woman, aged 31).

Participants also provided their perceptions of how cervical cancer is talked about

in their communities. The majority of women reported that the community had fatalistic

views of cervical cancer and thought it would destroy the womb. Many of the

descriptions suggest that stigma may be associated with cervical cancer in the

community. One woman commented that women in the community say:

"There is like a boil inside the vagina, but they don't talk
much about it" (Separated woman, aged 35).

One man commented that:

"Most men don't know about it [and] I have never met any
woman who talked about cancer of the cervix" (Married
man, aged 29).

A different perspective by a highly educated man with an above average income

compared to the study sample included the following description of community

members' views about cervical cancer. He explained:

"The majority of women associate this disease with
witchcraft. More than 80% of women believe that if they
get cancer of the cervix, then someone must have
bewitched them. And, usually, they will suspect that the
husband is having an affair and that the other woman is
trying to do [her] harm so as to run away with the husband"
(Married man, aged 33).

This was not a predominant view, and none of the women in the sample had this

perception. However, it illustrates the range of cultural perceptions and ideas in the

community about cervical cancer.

Men's perceptions of screening and treatment for cervical cancer

Men had positive perceptions of screening and treatment for cervical cancer. The majority of men commented that cervical cancer was treatable or "curable" and supported early detection and preventive behaviors. The following quotes describe men's perceptions and attitudes towards treatment for cervical cancer.

> "I think most cancers can be cured nowadays provided they are diagnosed early" (Single man, aged 21).

> "There are some traditional drugs and herbals. Some people opt for hospital drugs like injectables and pills" (Married man, aged 49).

> "There is nothing impossible in this world. I think a woman will get proper treatment if she goes to a hospital" (Married man, aged 37).

When asked if women could get pregnant after being treated for cervical cancer, the majority of men believed that it was possible. One man enthusiastically commented:

> "No doubt about that" (Single man, aged 21).

A few men were less sure about whether a woman could conceive after cervical cancer, but did not rule out the option. One man explained:

> "I think it [will be] difficult, because the cancer is in the womb, and a woman needs a healthy womb to conceive" (Married man, age 37).

Women's perceptions of screening and treatment for cervical cancer

Women reported positive attitudes toward cervical cancer screening, and all women answered that they would receive a free cervical screening if it were available at a health center. However women did not have positive attitudes toward treatment. With the exception of three women, participants described cervical cancer as an untreatable

disease that was not "curable". The majority of comments can be characterized by the following quotes:

> "I have never seen anyone cured of cervical cancer, and my
> grandmother died from it" (Married woman, aged 28).

> "If it is advanced even if they remove the uterus, it will not
> help" (Married woman, aged 31).

The majority of women also perceived that a woman could not get pregnant after having cervical cancer mainly because her uterus would have been removed due to the cancer. One of the women screened for cervical cancer was not sure if treatment was available, and she was not convinced that a woman could get pregnant after receiving treatment, if it was available. However, she did comply with screening recommendations. She commented:

> "I was told to come after one year and today here I am, as I
> was checked last year" (Separated woman, aged 35).

Of the women who thought cervical cancer was treatable, one woman stated that:

> "Yes, cervical cancer can be cured by removing the
> uterus" (Cohabitating woman, aged 23).

Women's perceptions of social economic factors, gender and power and male partner influence

There was some indication of perceived gender and power imbalance by women, as the majority of female participants highly regarded their male partners' approval of their decisions and reported that they had to have their permission to seek health services. However, none of the women in the sample reported that this gender imbalance was linked to adverse outcomes. All women reported that they had the social and economic

support of their partners. Two women insisted that their male partners had to be informed about their behaviors. The women stated:

> "I have to let him know every time I go to the clinic, because sometimes he can call me. So, I have to tell him all the time" (Married woman, aged 31).

> "Yes, I have to tell him, because I can't just leave home without letting him know. Also, it is because he is the one who is paying for my treatment (Cohabitating woman, aged 22).

Men's perceptions of social economic factors and barriers to male partner involvement

The majority of the findings reported by men did not indicate gender power imbalance, nor were there suggestions of lack of social and economic support for female partner's reproductive health needs. Men were particularly willing to provide economic support for services related to childbirth and childcare at health clinics. The following quotes provide descriptions that summarize the most commonly reported perceptions of social and economic factors influencing male partner support for screening and treatment including perceived barriers to social and economic support.

> "Men have different understanding. Some of us understand the importance of this issue and some do not" (Married man, aged 37).

> "She is depending on me for many things and I always like to help her" (Married man, aged 39).

> "The majority of men think it is none of their business" (Married man, aged 34).

> "In a relationship it means a lot if you help your partner when she has a problem or when she is ill. She will never forget that type of kindness"(Single man, aged 29).

> "I think many men are too busy…Others may have fear to go [to the health center] with their wife. Other men ignore

their wives. They think she can go by herself" (Married
man, age 35).

DISCUSSION

The aim of this study was to describe key socio-cultural perceptions and attitudes
of men and women toward cervical cancer screening and treatment in Tanzania. The goal
was to gain insights into factors that may influence uptake of and support for screening
and treatment. Of the studies that have been conducted on socio-cultural factors that may
influence health behaviors toward cervical cancer screening and treatment in African
settings, only a few have explored the perceptions of men and women [8, 16-17]. In
previous research, men's influence has been shown to be associated with women's
screening behaviors [6-10,16, 18]. This study did not assess actual screening behavior to
determine if Tanzanian men's influence is associated with acceptance of cervical
screening. However, the majority of the men in the present study had positive perceptions
of both screening and treatment. This finding is similar to results from other studies [18].
In addition, men expressed a willingness to support their female partners to prevent
cervical cancer in the future. This finding is similar to results from other studies on men's
involvement in cervical cancer screening and treatment in African countries [10, 16-17].

All of the women in the study supported early detection and screening for cervical
cancer. However, they did not have as positive attitudes toward treatment as men.
Women were particularly concerned that treatment for cervical cancer would not save a
woman's life and would likely make her infertile. Women's negative attitudes may be
associated with the poor survival outcomes of Tanzanian women with cervical cancer.
Since about 80% of Tanzanian women present with late stage disease, most women die
within five years of diagnosis [2]. Regarding social and economic support, all women

reported that their male partners provided financial and social support when they needed reproductive health services. One possible explanation for the economic and social support from men may be because this was a sample of women who regularly attended health centers and who reported that their partners regularly attended health centers for health care.

While a few responses about risk factors from men and women were related to specific cultural myths, the majority of responses were accurate and similar to biomedical descriptions of risk factors. Interestingly, none of the participants mentioned the human papillomavirus (HPV) as the cause of cervical cancer. However, this finding is not surprising. Even among highly educated college students in Ghana, only 7.9% of the sample associated cervical cancer with HPV [19].

Overall, the findings indicate a need for interventions that engage women and their male partners to promote knowledge and positive attitudes and perceptions of cervical cancer screening and treatment. Health promotion strategies aimed at improving screening behaviors should focus on early detection and the success of timely treatment to preserve fertility and reproductive health. Interventions should also include cancer survivors to show woman that cervical cancer can be treated and women who present early have a better chance at continuing a healthy life.

Few studies related to cultural explanatory models (lay explanations, perceptions and attitudes) [3] of cervical cancer have focused on Tanzanian men and women. Only Kidanto and colleagues [20] attempted to identify Tanzanian women's knowledge of cervical cancer with a closed ended survey. The current study fills a gap in the research literature and provides qualitative descriptions of a sample of Tanzanian men and

women's knowledge, perceptions of and attitudes toward cervical cancer screening and treatment. However, this study is not without limitations. Data from closed ended questions were self-reported, and participants may have given socially desirable answers. In addition, women's screening behavior and men's support of screening behavior was not measured in this study. Despite these limitations, the study will be useful for development of cervical screen-and-treat programs in Kinondoni district and similar districts in Tanzania. The findings represent perceptions of Tanzanian men and women that will likely affect their decisions to support screening and treatment for cervical cancer.

Descriptions of men and women's explanations of screening and treatment can also help inform the development of information, educational and counseling (IEC) materials. For example, IEC materials that describe several treatment options for cervical cancer may change perceptions in the community that cervical cancer is not treatable. In Tanzania, such IEC materials are often used to help "sensitize" the community to a health issue and prompt health behaviors. Oftentimes IEC materials are available at health centers and at mobile health clinics in the community.

CONCLUSION

Given the burden of cervical cancer disease morbidity and mortality in Tanzania and recent regional and national efforts to scale up service delivery [11], it is timely to explore perceived factors affecting perceptions of and support for screening and treatment among women and men. To date, no study has been conducted in Tanzania using exploratory qualitative research to identify the constellation of factors that may influence uptake of cervical cancer screening and treatment among women and also

included assessments with men. Regional initiatives to promote screening and treatment
in Tanzania [12] should include men given their influence on women's intention to
screen and treat for prevention of cervical cancer.

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Table 1. Socio-demographic characteristics (n=30)

Socio-demographic variables		Overall	Women	Men
Overall		100% (30)	50% (15)	50% (15)
Age				
	Mean (Min-Max)	31 (20-49)	30 (20-39)	32 (21-49)
Marital status				
	Single	23% (7)	13% (2)	33% (5)
	Married	63% (9)	60% (9)	66% (10)
	Separated	6% (2)	13% (2)	-
	Cohabitating	6% (2)	13% (2)	-
Education				
	Primary (K-7)	20% (6)	40% (6)	-
	Secondary (8-12)	46% (14)	53% (8)	40% (6)
	Some college	33% (10)	6% (1)	40% (6)
	Four-year university	10% (3)	-	20% (3)
Employment				
	Self-employed	20% (6)	20% (3)	20% (3)
	Employed	40% (12)	33% (5)	46% (7)
	Stay at home spouse	13% (4)	26% (4)	-
	Unemployed	26% (8)	20% (3)	33% (5)
Income per month	Converted to USD per month			

$0	30% (9)	33% (5)	26% (4)
<$50	26% (8)	33% (5)	20% (3)
$51-100	20% (6)	20% (3)	20% (3)
$101-200	10% (3)	13% (2)	6% (1)
$201-300	3% (1)	-	6% (1)
$301-400	10% (3)	-	2% (3)
Number of children			
Yes	66% (20)	93% (14)	40% (6)
No	33% (10)	6% (1)	60% (9)
Religious affiliation			
Christian	33% (10)	40% (6)	26% (4)
Muslim	66% (20)	60% (9)	73% (11)
Ever tested for HIV			
Yes	73% (22)	86% (13)	60% (9)
No	26% (8)	13% (2)	40% (6)
HIV status			
Infected	-	-	-
Uninfected	80% (24)	86% (13)	73% (11)
Not sure/don't know	20% (6)	13% (2)	26% (4)
HIV status of partner			
Infected	6% (2)	13% (2)	-
Uninfected	66% (20)	66% (10)	66% (10)
Not sure/don't know	26% (8)	20% (3)	33% (5)
Ever screened for cervical cancer			
Yes	-	20% (3)	-
No	-	80% (12)	-

LOSS TO FOLLOW UP AFTER DIAGNOSIS OF CERVICAL SQUAMOUS
INTRAEPITHELIAL LESIONS AMONG WOMEN RECEIVING HIV CARE AND
TREATMENT IN DAR ES SALAAM, TANZANIA

by

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ABSTRACT

Background: Women with the human immunodeficiency virus (HIV) are more likely to have persistent oncogenic HIV infections that can lead to cervical cancer. Women in Tanzania share the highest burden of cervical cancer in East Africa, and have a 6.6% prevalence of HIV infection. Papanicolaou (Pap) smears were performed to screen HIV infected Tanzania women attending HIV care and treatment clinics. The purpose of this paper was to identify the rate of follow up for diagnosis among women who had squamous intraepithelial lesions (SIL) on Pap smear, and to determine compliance with treatment recommendations.

Methods: Between December 2006 and August 2009, physicians in HIV care and treatment clinics (CTC) in Dar es Salaam, Tanzania performed conventional Pap smears on 1440 women who voluntarily accepted a cervical screening. Slides were prepared and sent to the histopathology lab at the Muhimbili National Hospital, Dar es Salaam, for examination. Positive smears included the detection of low-grade SIL (LSIL) and high-grade SIL (HSIL). Normal results were defined by the absence of precancerous lesions. A retrospective review of charts was performed for all women who received a Pap test at the Management and Development for Health (MDH) CTC. For women with SIL who were referred for treatment, a second retrospective chart review was performed at the referral site. MDH patient trackers were used to track women who were lost to follow up after referral for diagnosis and treatment.

Results: A total of 1440 PAP tests were examined, and 121 (8%) women had SIL. On cytology, 72 (5%) had LSIL and 49 (3%) had HSIL. None of the women were found to have invasive cancer. Of the 121 women with SIL, 5 (4%) presented for follow up and

treatment at the national cancer center in Dar es Salaam, 6 (5%) died of an unrelated illness. The remaining 116 (96%) of women had to be tracked using a district tracking mechanism comprised of trained lay health workers.

Conclusion: Even in highly efficient HIV clinics with good health services, cervical screening programs based on cytology do not provide adequate screening coverage and timely access to treatment. *Single visit/screen-and-treat* models including immediate treatment with cryotherapy are more effective and context appropriate. The findings indicate the importance of integration of best practice *screen-and-treat* approaches into HIV care and treatment programs.

INTRODUCTION

 HIV infected women are more likely to have persistent, oncogenic human papillomavirus (HPV) infections that lead to precancerous cervical lesions and invasive cervical cancer (ICC) (Vermund, Kelley, Klein, et al., 1991; Sun, Kuhn, Ellerbrock, et al., 1997; Hawes, Critchlow, Sow, et al., 2006; Parham, Sahasrabuddhe, Mwanahamutu, et al., 2006). The risk of cervical pre-cancer is higher in HIV infected women than among HIV uninfected women (Parham, Sahasrabuddhe, Mwanahamutu, et al., 2006; Didelot-Rousseau, Nagot, Costes-Martineau, et al., 2006;). Additionally, women with HIV tend to have more aggressive ICC and poorer survival outcomes (Maiman, Fruchter, Serur, et al., 1993; Schwartz, Carcangiu, Bradman, & Schwartz, 1991).

 Of the incident cases of cervical cancer in Africa, 40% occur in East Africa (Globocan, 2008). Tanzanian women bear the highest burden of cervical cancer in the region, with age-standardized incidence and mortality rates of 50.9 and 37.5 cases per 100,000 women (Globocan, 2008). In 2008, approximately 20% of new cases of cervical

cancer in East Africa occurred among Tanzanian women (Globocan, 2008). These epidemiological data represent an unnecessary disease burden given that cervical cancer is a preventable malignancy.

The prevalence of HIV among sexually active men and women in Tanzania aged 15-49 years is 5.7% (Tacaids, 2008). Tanzanian women have a higher prevalence of HIV than men (6.6% vs. 4.6%, respectively (Tacaids, 2008)). Kahesa and colleagues (2008) reported a 32% incidence of HIV among Tanzanian women 18 years and older being treated for histologically confirmed cervical cancer at the Ocean Road Cancer Institute (ORCI), the only public sector hospital in Tanzania that specializes in cancer care. Women attending the ORCI who had cervical cancer were three times more likely to be co-infected with HIV than women in the general population with similar socio-demographic characteristics (Kahesa et al., 2008).

High screening coverage, early detection and timely follow up for treatment of cervical lesions are important predictors of success of cervical cancer screening and treatment programs. Tanzanian women attending public sector HIV clinics in Dar es Salaam between December 2006 and August 2009 had access to cervical cancer screening with the PAP test. Women with cervical SIL were referred to the ORCI for follow up diagnosis and treatment. The aim of this study was to evaluate rates of follow up and compliance with treatment for SIL after referral from public-sector HIV clinics affiliated with the MDH, Harvard President's Emergency Plan for AIDS Relief (PEPFAR) program to the ORCI in Dar es Salaam.

METHODS

Study setting and participants

MDH provides comprehensive HIV care and treatment services as part of the Harvard University PEPFAR program to approximately 66,115 women attending 29 public sector clinics in each of the three districts of Dar es Salaam. Approximately 66% of MDH clients are women aged 15 years and older, and about 64% of these women receive combination antiretroviral therapy (ART). Between December 2006 and August 2009, physicians at MDH HIV care and treatment clinics (CTC) offered conventional Pap smears to women who voluntarily accepted a cervical screening. The study included a retrospective review of charts from 1440 HIV infected women who were screened for cervical cancer at one of the 29 public sector HIV clinics. All women who accepted the Pap test had serologically confirmed HIV infection, an intact cervix, were healthy enough to attend the Pap screening, and were enrolled in CTC at MDH. For women with SIL who were referred for treatment, a second retrospective chart review was performed at the referral site, the Ocean Road Cancer Institute (ORCI). MDH patient trackers were used to track women who were lost to follow up for diagnosis and treatment after referral.

Study design

The research team used the MDH data repository to conduct a retrospective review of women's Pap smear results. The repository included cytology results reported by the pathology department at the Muhimbili National Hospital, the national tertiary care hospital in Dar es Salaam. For women who were referred to the ORCI, the data team at the ORCI performed a retrospective review of their cancer database to determine follow up for colposcopy, histopathology and treatment of women referred with SIL from MDH. To reduce error, at least two research assistants from the ORCI data team reviewed the cancer database and paper-based charts to verify data entry and results. In addition, MDH

patient trackers performed tracking of women who did not follow up for diagnosis and treatment at the ORCI. Figure 1 illustrates the study design in a flow diagram.

[Insert Figure 1 about here]

MDH patient trackers are comprised of men and women who work as district and regional lay health workers. Patient trackers often facilitate efforts to encourage adherence to HIV care and treatment and a spectrum of other support services including palliative care at MDH. Women who were tracked were provided with health education and were advised to present to the ORCI for follow up diagnosis of SIL and return to MDH for routine care. Women were assured that additional counseling and health education were available from the ORCI and MDH clinicians who administer their monthly HIV care and treatment. Women were encouraged to focus on the pros of follow up for treatment of SIL. However, women were made aware that they could discuss any barriers or perceived cons that might prevent them from utilizing free treatment at the ORCI and counseling with MDH clinicians.

Statistical methods

The primary outcomes for the study were rate of follow up diagnosis of SIL after referral from MDH clinics to the ORCI and compliance with treatment recommendations. Socio-demographic data from the MDH database are included to characterize the sample and are presented in Table 1. Estimates of SIL, inflammation and cervicitis are reported to identify the proportion of cervical disease based on cytology of the participants. Data analysis including mean scores and frequency counts were performed using SAS 9.13 statistical analysis software (SAS Institute, Cary, North Carolina, USA).

[Insert Table 1 about here]

RESULTS

Characteristics of participants by Pap smear results

The median age of the 1440 participants was 35 years. Of women with abnormal Pap tests, the median age was 37 years. The majority of the participants were married 38% (551/1440) and nearly 30% (428/1440) were single. The median number of children was 1. The median World Health Organization (WHO) Clinical Stage of HIV/AIDS was III. The median CD4 was 160(/μL). About 91% (1317/1440) of the participants were receiving ART at the time of the Pap screening.

Of the 1440 women who voluntarily accepted a cervical screening, 474 (33%) had abnormal results. Among women with abnormal results, 121 (8%) had low or high-grade SIL. Pap smear results are reported in Table 2. On cytology, 72 (5%) had LSIL and 49 (3%) had HSIL. Of those who were positive for SIL, 55 (76%) with LSIL and 36 (73%) with HSIL had concurrent cervicitis or inflammation. None of the women were found to have invasive cervical cancer. Women with SIL were referred for follow up evaluation and treatment at no monetary cost to the ORCI in Dar es Salaam. Women with abnormal results including inflammation or cervicitis received appropriate management at MDH HIV clinics and returned to routine care.

[Table 2 about here]

Follow up for treatment of SIL

Of the 121 women with SIL, retrospective chart review showed that five (4%) presented for follow up and treatment at the national cancer center in Dar es Salaam on their own. The five women who presented to the ORCI received a confirmation diagnosis of SIL by colposcopy and immediate treatment with cryotherapy. No adverse outcomes

were recorded. Of the remaining 116 women who did not follow up, six (5%) women

with LSIL died. The cause of death was not recorded, but may likely have been due to

HIV related illnesses. MDH used its HIV patient tracking team to locate the remaining

110 (91%) women at risk of loss to follow up. Of the 110 (91%) eligible for tracking,

84/121 (69%) were tracked and referred for follow up diagnosis at the ORCI and for

routine care at MDH. The remaining 26 (22%) could not be tracked and were lost to

follow up. For purposes of quality assurance and to strengthen program implementation,

women were asked to identify the barriers that kept them from following up with

treatment of SIL. Results of patient tracking including reports on barriers to follow up are

beyond the scope of this study and will be presented in a separate publication.

DISCUSSION

The aim of this study was to evaluate the rate of follow up for diagnosis of SIL and

compliance with treatment after referral from public-sector HIV clinics to the ORCI in

Dar es Salaam. Our findings showed that 4% of 121 women with SIL followed up for

treatment at the ORCI. This finding suggests that cervical screening programs should be

linked with immediate treatment and include a strong referral component to help HIV

infected women navigate treatment for specialized cancer care at referral sites. Linking

cervical screening with immediate treatment, coined *screen-and-treat* and *single-visit*,has

been widely advocated as a way to improve secondary prevention of cervical cancer in

low resource settings (Denny, Kuhn, De Souza, et al., 2005; Sherris, Wittet, Kleine, et al.,

2009; Mwanahamuntu, Sahasrabuddhe, Pfaendler at al., 2009). Even in highly efficient

HIV clinics with good health services, cervical screening programs based on cytology do

not provide adequate screening coverage and timely access to treatment. This finding is

consistent with those reported in similar studies on cytology-based programs in low resource settings in African countries (Sankaranarayanan, Budukh & Rajkumar, 2001; Moodley, Kawonga, Bradley, et al., 2006; Denny, Quinn & Sankaranarayanan, 2006).

Single visit approaches based on visual inspection with acetic acid (VIA) and visual inspection with Lugol's iodine (VILI) that are linked to immediate treatment with cryotherapy are more effective and context appropriate. VIA and VILI coupled with same-visit ablative treatment by cryotherapy provide relatively safe, cost-effective and feasible alternatives to cytology-based prevention (Goldie, Gaffikin, Goldhaber-Fiebert, et al., 2005; Denny, Kuhn, DeSouza, et al., 2005; Denny, Quinn & Sankaranarayanan, 2006; Sankaranarayanan, Rajkumar, Esmy, et al., 2007; Chamot, Kristensen, Stringer & Mwanahamutu, 2009; Sherris, Wittet, Kleine, et al., 2009).

The study is not without limitations. The nature of retrospective chart reviews may have resulted in error. Some participants may have presented for care at the cancer center, and the follow up may not have been included in the participant's chart. Some referral processes at MDH and ORCI are recorded using paper-based methods. As well, some patients may not have been referred for services, and this potential oversight in clinical care could not be determined retrospectively. In addition, errors in reviewing and recording data from charts may have occurred. As noted under Methods, we attempted to minimize these errors by conducting verification of data entry by two research assistants from the ORCI. To reduce errors while reviewing charts, at least two research assistants reviewed the cancer database and paper-based records at the ORCI to determine attendance for follow up diagnosis and treatment of SIL. Alternatively, it is a study

strength that data collection did not rely on self-report which would be subject to both recall error and social desirability bias.

The most striking finding from this study relates to poor follow up for treatment of SIL. A major programmatic limitation is that a cytology-based program was initiated for cervical screenings when *screen-and-treat* models were available. Given challenges of integrating a Pap screening program, MDH transitioned to a cervical *screen-and-treat* model in September 2009. Currently, women are offered voluntary screening with VIA/VILI within 14 days of enrollment into HIV care and treatment services. MDH has also trained nurses and other clinicians to perform VIA/VILI to increase capacity for screening in CTC. Women who do not meet the requirements for ablative therapy of precancerous cervical lesions are referred for treatment at the ORCI.

The low attendance to treatment suggests the need to integrate a comprehensive approach to cervical cancer screening and treatment into HIV care. Additionally, there is a need to improve management of women who require referral services. Mwanahamuntu and colleagues (2009) have made significant contributions to cervical cancer prevention among HIV-infected and uninfected women in Zambia. At the Centers for Infectious Diseases Research in Zambia (CIDRZ), *screen-and-treat* services are linked to the HIV care and treatment infrastructure sponsored by PEPFAR. In about four years, more than 52,000 Zambian women have been screened at CIDRZ (Parham, Mwanahamuntu, Sahasrabuddhe et al., 2010).

Despite the significant improvements that have been made in cervical cancer *single visit* and *screen-and-treat* programs, loss to follow up for confirmatory diagnosis by histology and completion of treatment for cryotherapy-ineligible lesions remains

relatively high. Even in a successful *screen-and-treat* program such as the one at CIDRZ, loss to follow up for histological evaluation among 367 women who were ineligible for cryotherapy was 25% (Parham, Mwanahamuntu, Sahasrabuddhe et al., 2010). Parham and colleagues (2010) also reported that 459 (22%) of women attending CIDRZ who were eligible for cryotherapy opted not to have the treatment and did not return to the clinic. Screening programs in South Africa and Uganda among others also struggle with patient retention for utilization of screening and treatment (Moodley, Med, Kawonga et al., 2006) and confirmatory diagnosis by colposcopy (Mutyaba, Mirembe, Sandin et al., 2009).

Socio-cultural myths about cervical cancer may influence acceptance of screening and follow up for treatment (Chirwa, Mwanahamuntu, Kapambwe et al., 2010). Lack of knowledge and counseling among HIV infected women have also been suggested as possible barriers to utilization and follow up of cervical screenings among HIV infected women in Southeastern Nigeria (Dim, Dim Ezegwui et al., 2009) However, system level factors related to the integration of comprehensive services may explain many of the barriers to follow up care. Arguably, inadequate systems for cervical cancer screening and treatment prompted the use of alternative screening approaches in an attempt to improve access to screening and timely treatment given the high burden of cervical disease in low resource settings (Denny, Quinn & Sankaranarayanan, 2006).

Despite advances in cervical screening approaches in low resource settings, challenges remain with patient retention for attendance to diagnosis and treatment of precancerous cervical lesions. Such challenges illustrate the need to improve the referral system for treatment services that are not commonly included in *screen-and-treat* and

single-visit programs. Women attending *single-visit* programs who are ineligible for cryotherapy are more likely to need referral for treatment. Given that HIV infected women are more likely to present with cryotherapy ineligible lesions (Pfaendler, Mwanahamuntu, Saharabuddhe et al., 2008) and to have higher rates of recurrence of oncogenic HPV infections (Firnharber & Michelow, 2009), stronger patient support approaches to help women navigate compliance with referral may be a necessity for decreasing loss to follow up.

Provisions for women with cryotherapy-ineligible cervical lesions such as LEEP will require a range of resources to be incorporated into CTC and be sustained over time. Pfaendler and colleagues at CIDRZ (2008) have demonstrated that specialized cancer care including LEEP can be integrated into HIV clinics. Similar novel approaches for creating comprehensive cervical cancer control and prevention programs are urgently needed. Cervical cancer is a preventable and treatable malignancy that in many regards illustrates a public health failure (Tsu & Levin, 2008).

CONCLUSION

Within the context of HIV care and treatment programs, loss to follow up was higher than expected. This study showed that 96% of women who were referred for cancer treatment from a HIV care and treatment program did not follow up for services at the ORCI. Innovative patient retention approaches will be necessary to increase attendance for treatment procedures that do not meet the criteria for cryotherapy and require follow up at referral hospitals. Improvements in and efficacy of diagnostic technologies for oncogenic HPV adapted for low resource settings offer promising solutions for early detection of cervical cancer in HIV infected and uninfected women (Sherris, Wittet,

Kleine et al., 2009; Kuhn, Wang, Tsai et al., 2010). Additionally, efforts to make primary prevention of cervical cancer through HPV vaccination more cost-effective for low-income countries have the potential to significantly improve rates of mortality and morbidity attributed to cervical cancer over time. In the age of ART, young girls with HIV infection may especially benefit from primary prevention of cervical cancer, as they are likely to live longer and potentially be exposed to oncogenic HPV types. Better diagnostic technologies and patient retention programs for adherence to treatment, may have a significant impact on cervical cancer prevention. Improvements in the social and economic status of women (Howson, Harrison, Hotra et al., 1996; Tsu & Levin, 2008) and population level screening infrastructure and coverage (Gakidou, Nordhagen & Obermeyer, 2008) are even more likely to dramatically change adverse trends in cervical cancer in Tanzania and other low-income African countries in the long-term.

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Table 1. Sociodemographic characteristics at initial screening (N=1440)

Characteristics	n (%)
Married	
Yes	536 (39)
No	842 (61)
Age (years)	
Median (Range)	35 (16-97)
< 30	309 (21)
30-39	675 (47)
40-49	349 (24)
>=50	107 (7)
WHO Stage	
I	123 (9)
II	308 (21)
III	869 (61)
IV	136 (9)
On Antiretroviral therapy	
Yes	1317 (91)
No	123 (9)
CD4 count, cells/mm^3	
< 50	209 (15)
50-99	203 (15)
100-199	445 (33)
>=200	509 (37)
Number of children Median Interquartile range (IQR)	1 (0,2)

Table 2. Pap smear results

Outcome	n (%)
Total women undergoing cytology (Pap smears)	1440 (100)

Prevalence of SIL on Pap smear
No SIL
SIL (follow up needed)
  -LSIL
 	
  -HSIL
	
	1319/1440 (92)
	121/1440 (8)
	72/121 (60)
	
	49/121 (40)

Presence of concurrent cervicitis/inflammation on Pap smears Among women with no SIL Among women with LSIL Among women with HSIL	n (%) 889/1319 (67) 55/72 (76) 36/49 (73)

Figure 1. Study design and flow of patient follow up
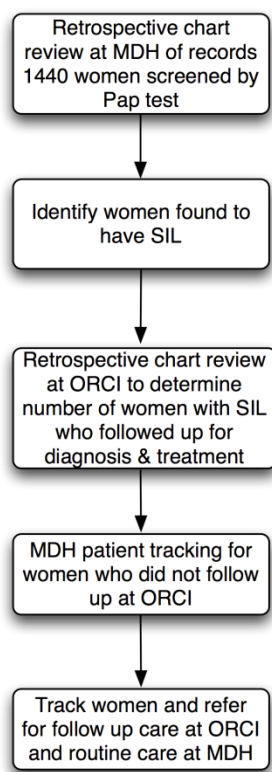
SUMMARY OF DISSERTATION

Cancer has become a worldwide public health issue and a potential public health threat (Lingwood et al., 2008; Huerta & Grey, 2007; Sitas et al., 2008). Two seminal reviews of the literature (Parkin et al., 2008; Sitas et al., 2008) indicate the need to better understand the diversity of cancer in Africa, and focus on cancers with high distribution, burden, and trends. Unfortunately, the public health infrastructure in middle and low-income countries is not prepared to facilitate an emerging cancer epidemic (Lingwood et al., 2008; Sitas et al., 2008). Health services for cancer control and prevention programs in Africa have lagged compared to infectious disease prevention programs (Sitas et al., 2008). Many middle and low–income countries struggle to provide cancer prevention and control services (Huerta & Grey, 2007; Sankaranarayanan, Budukh & Rajkumar, 2001). Sitas and colleagues (2008) conducted a study on cancer causes and control in Africa, and found that no African country has a comprehensive cancer control program with provisions for prevention, radiotherapy, chemotherapy and palliative care.

In recent years, researchers have garnered increasing attention from policy makers; albeit slow going, to promote political will for cancer control and prevention in Africa (Lingwood et al., 2008; Wabaki, 2007). Lingwood and colleagues (2008) found that policy makers and officials in African Ministries of Health are more engaged than ever before in addressing the challenges associated with cancer care. Support from policymakers is critical to promote political will, and move the cancer control and

prevention agenda toward feasible strategic plans (Orem & Wabinga, 2009; Wakabi, 2007; Sankaranarayanan & Ferlay, 2006).

The first United Nations (UN) Summit on non-communicable disease including cancer was held in New York City, September 19-21, 2011. For the first time, the UN Political Declaration will advocate a commitment to improving cancer control and prevention in low and middle-income countries. This focus on global cancer prevention will likely help strengthen service delivery and health services for cancer in low resource settings over time. However, the challenge of combating the global cancer epidemic will require large-scale sustainable solutions (UICC Statement on the Political Declaration of the UN, September 2011).

This dissertation demonstrated that a constellation of individual, socio-cultural and structural level barriers contributes to the challenge of cervical cancer control and prevention in Tanzania, the largest country in East Africa. The Social Ecological Model (McElroy, Bibeau, Steckler, et al., 1988) provided a useful framework for this investigation of multi-level factors affecting the quality and scale up of cervical cancer screening and treatment in Tanzania. Key findings across the three studies in this dissertation indicated a need to: build capacity for screen-and-treat approaches at the regional and district levels, improve diagnostic screening for early detection of precancer, decentralize the referral process for specialized care, increase awareness of cervical cancer screening and treatment and increase access to timely treatment.

The combination of qualitative and quantitative methodologies used in this dissertation provided a range of data to answer the proposed research questions. Interviews and focus group discussions were used to elicit information and determine

patterns and generalizations based on the open-ended responses among key stakeholders (in manuscript 1) and individual men and women (in manuscript 2). Quantitative methods including retrospective chart reviews and secondary data analysis were used in the third manuscript to help interpret objectively the findings related to cervical cancer screening and treatment within the context of HIV care and treatment. Taken together, quantitative and qualitative approaches offered a more complete view of the perceived and observed factors that may act as barriers to and facilitators of cervical cancer screening and treatment in Tanzania.

Looking ahead, the findings from the three interrelated studies will be used to strengthen cervical cancer screening and treatment starting in Dar es Salaam, Tanzania. The outcomes from the third study in the dissertation prompted the lead investigators to secure extramural funding to improve patient retention and adherence to treatment. The funding will be used to evaluate whether the Patient Navigation Model advocated by the National Cancer Institute can be an acceptable and feasible mechanism for cancer care in Tanzania. The Tanzanian Ministry of Health and Social Welfare (MOHSW) has requested a copy of the second manuscript in this dissertation. The MOHSW will review the key findings from this manuscript to help develop national information, educational and counseling materials in public sector health centers in Dar es Salaam.

This dissertation was a first attempt to understand the myriad social, cultural and structural factors unique to cervical cancer screening and treatment in Tanzanian context. The hope is that this investigation will help inform ongoing cervical cancer screening and treatment efforts in-country. This research is particularly timely given the development of the first national cervical cancer control and prevention guidelines in Tanzania.

Understanding the barriers and facilitators to cervical cancer screening and treatment in Tanzania will guide the development of programs for the expansion and sustainability of cervical cancer prevention and control services.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL FORM

4-1-11 mailed

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

Form 4: IRB Approval Form
Identification and Certification of Research
Projects Involving Human Subjects

UAB's Institutional Review Boards for Human Use (IRBs) have an approved Federalwide Assurance with the Office for Human Research Protections (OHRP). The Assurance number is FWA00005960 and it expires on September 29, 2013. The UAB IRBs are also in compliance with 21 CFR Parts 50 and 56.

Principal Investigator: LISOVICZ, NEDRA F.

Co-Investigator(s):

Protocol Number: **X080421002**

Protocol Title: *Cervical Cancer Health Disparity Assessment in Tanzania*

The IRB reviewed and approved the above named project on **4-1-11**. The review was conducted in accordance with UAB's Assurance of Compliance approved by the Department of Health and Human Services. This Project will be subject to Annual continuing review as provided in that Assurance.

This project received EXPEDITED review.

IRB Approval Date: **4-1-11**

Date IRB Approval Issued: **4-1-11**

Marilyn Doss

Marilyn Doss, M.A.
Vice Chair of the Institutional Review
Board for Human Use (IRB)

Investigators please note:

The IRB approved consent form used in the study must contain the IRB approval date and expiration date.

IRB approval is given for one year unless otherwise noted. For projects subject to annual review research activities may not continue past the one year anniversary of the IRB approval date.

Any modifications in the study methodology, protocol and/or consent form must be submitted for review and approval to the IRB prior to implementation.

Adverse Events and/or unanticipated risks to subjects or others at UAB or other participating institutions must be reported promptly to the IRB.

APPENDIX B

INSTITUTIONAL REVIEW BOARD REQUEST FOR DETERMINATION
HUMAN SUBJECTS RESERACH

UAB THE UNIVERSITY OF
ALABAMA AT BIRMINGHAM

Institutional Review Board for Human Use

DATE: April 29, 2011

MEMORANDUM

TO: Renicha McCree-Hale
                Principal Investigator
                Diane Grimley, PhD
                Faculty Advisor

Sheila Moore, CIP

FROM: Sheila Moore, CIP
                Director, UAB OIRB

RE: Request for Determination—Human Subjects Research
                IRB Protocol # <u>N110413001 – Evaluation of Follow Up for</u>
                <u>Confirmatory Diagnosis and Treatment of Squamous Intraepithelial</u>
                <u>Lesions Among Women Receiving HIV Care and Treatment in Dar es</u>
                <u>Salaam, Tanzania</u>

An IRB Member has reviewed your application for Designation of Not Human Subjects
Research for above referenced proposal.

The reviewer has determined that this proposal is **not** subject to FDA regulations and is
not Human Subjects Research. Note that any changes to the project should be
resubmitted to the Office of the IRB for determination.

Please note: This determination does not extend to the researchers listed on your
application from Vanderbilt University and the University of Alabama. The researchers
should contact their respective IRBs for guidance.

SM

APPENDIX C

DISCUSSION GUIDE FOR KEY STAKEHOLDER PAPER #1

1. What are the most pressing health needs in Tanzania?
2. Who is involved in addressing those needs?
3. Who needs to be involved in addressing those needs?
4. How does cervical cancer rank among the needs important to you? To Tanzanians?
5. How does breast cancer rank among the needs important to you? To Tanzanians?
6. In your opinion, should cervical cancer be addressed? Why or why not?
7. In your opinion, should breast cancer be addressed? Why or why not?
8. What, if any, myths exist about cervical cancer screening?
9. How can we overcome these myths?
10. Who is involved in cervical cancer prevention and control activities?
11. Where do women seek cervical cancer screening and/or treatment? Who provides care?
12. What individual barriers exist for women seeking care?
13. What community-system barriers exist for women seeking care?
14. What health care barriers exist for women seeking care?
15. What systems are in place to help women overcome the barriers you mentioned?
16. If a cervical cancer program was developed and implemented in this area, how would it be carried out?
17. Who would need to be involved?
18. What resources would be needed prior to implementation?
19. When should planning begin?
20. Where do you suggest the program be implemented?
21. What potential (real or perceived) opposition would there be to a cervical cancer program being developed and implemented in Tanzania?
22. What would need to be done to overcome any opposition?
23. Is there anything else we need to know?

APPENDIX D

MEN'S INTERVIEW QUESTIONS PAPER #2

INTERVIEW QUESTIONS

TITLE OF PROJECT: Cervical cancer health disparity in Tanzania.

INVESTIGATOR: Renicha McCree-Hale

SPONSOR: University of Alabama at Birmingham (UAB)
                                      Department of Medicine, Division of Preventive
                                      Medicine.

DATE:_____   STUDY ID:___/#_____

I. Social cultural factors and cervical cancer

READ: *I am going to ask you some questions about a type of cancer that can affect women. Please feel free to give your opinions and answer to the best of your ability. Remember, your answers will be kept private and your name will not appear with your answers.*

Directions to the interviewer: Please read aloud each question exactly as listed to the participant. Text that appears in bold is not to be read aloud. Bold text indicates interviewer instructions or actions to be taken to get the most complete responses from participants. Please begin recording the interview before you read the first question. Thank you!

1. What do you know about cancer?
2. Tell me what you know about cervical cancer. **Probe: Ask the participant to**: Say anything that comes to your mind when you think of cervical cancer.
3. In your community, what other names do you have for cervical cancer?
4. What do men in your community think of cervical cancer?
5. What do women in your community think of cervical cancer?
6. What do you think causes cervical cancer? **Probe: Ask the participant:** Where did you get this information?
7. What do you think makes a woman have a high chance of getting cervical cancer?
8. What are the signs of cervical cancer?
9. Do you think cervical cancer can be cured? **Probe: If participant answers "YES," go to question #10. If participant answers "NO," then ask**: Why don't you think cervical cancer can be cured? Where did you hear this information? **Go to question#11**.
10. What is the best treatment for cervical cancer? **Probe**: Where did you hear this information?
11. Once a woman is treated for cervical cancer, do you think she can still get pregnant? **Probe: If participant answers "NO," then ask**: How does treatment

for cervical cancer keep a woman from getting pregnant? Where did you hear this information?

II. Health services and men's health

READ: *Now I am going to ask you questions about men's health issues and your use of health services.*

12. When you have an illness of the private parts (on or around your penis), where do you go for treatment? **If the participant answers, "I NEVER HAD AN ILLNESS OF MY PRIVATE PARTS," then skip to question#15. If participant gives the name of a place or person, then ask**: Why do you go to this place/person?

13. Who do you most trust to give you advice about illnesses of your private parts (on or around your penis)?

14. When you have an illness of the private parts(on or around your penis), do you ask any women in your family for advice? **Probe: If participant answers "YES," then ask**: Which women relatives do you ask for advice (mother, aunt, older sister)? Why do you ask these women? **If participant answers "NO," then ask**: Whom in your family do you ask for advice?

15. When you have a general health problem that needs to be treated, where do you go for treatment?

16. When you have a health problem, does your wife/female partner ever come to the health center with you? **Probe: Why or why not?**

17. Have you ever gone to a health center with your wife/female partner when she had a health problem? **Probe: Why or why not?**

18. How sure are you that you could go to a health center with your wife/female partner for her to get checked for cervical cancer? **Probe: If participant answers, "NOT SURE," then ask**: What makes you unsure that you could go with her?

19. If your wife/female partner was diagnosed with cervical cancer, how sure are you that you could go (to Ocean Road Cancer Institute/ Muhimbili) with you her for treatment? **Probe**: if she needed chemotheraphy, surgery, hysterectomy, cryotheraphy, etc?

20. What do you think are the most important reasons that may keep men from getting involved in their wives/female partners' medical care?

III. Economic factors and female partner influences

READ: *Now I am going to ask you questions about your female partner/wife and illnesses of the private parts.*

21. Do you tell your wife/female partner when you have an illness in your private parts (on or around your penis)? **If participant answers "NO,' then ask** What keeps you from telling her? **If participant answers " I NEVER HAD AN ILLNESS OF MY PRIVATE PARTS," skip to question#24.**

22. When you have an illness in your private parts (on or around your penis), what do you tell your wife/female partner about it? **Probe**: Do you describe the problem to your female partner/wife?

23. How does your wife/female partner act when you tell her about an illness of your private parts(on or around your penis)?

24. Does your female partner/wife tell you when something is wrong with her private parts? **Probe: If he answers "NOT SURE," then ask**: What do you think may keep her from telling you?

25. How many partners have you had vaginal sex with in the last 30 days? Do you use condoms when you have vaginal sex with your wife/main partner? Do you use condoms every time you have vaginal sex with a partner that you do not consider to be your wife/main sex partner?

26. Have any of the sex partners you have had sex with in the last 30 days been male? **Probe**: **If participant answers "YES," then ask** Did you use a condom?

IV. General sources of health information

READ: *Now I am going to ask you some general questions about health.*

27. What is your main source of health information?

28. What is the best way to get health information to your family/friends? Probe: Radio, magazine, brochures

29. Would you participate in a health education program with your wife/main female partner to learn about breast cancer? **If participant answers, "NO," then ask**; What would keep you from being in a program about breast cancer with your wife/main female partner?

30. Would you participate in a health education program with your wife/main female partner to learn about cervical cancer? **If participant answers, "NO," then ask**; What would keep you from being in a program about cervical cancer with your wife/main female partner?

31. Does your wife/main female partner use a douche (a liquid that is put up the vagina)? Have you ever told your wife/female partner to use a douche?

V. Personal health and demographic questions

READ: *This is the last section of questions. I will ask you about your martial and health status and general information.*

32. Have you ever been tested for HIV?
    □ Yes
    □ No
    □ I don't know/ Not sure
    □ **Refuse to answer**

33. Are you HIV positive?
    □ Yes

□ No
□ I don't know/ Not sure
□ **Refuse to answer**

34. Is your wife/ main female partner HIV positive?
    □ Yes
    □ No
    □ I don't know/ Not sure
    □ **Refuse to answer**

35. What is your age? _____ years old

36. What is your marital status?
    □ Single (never married)
    □ Married
    □ Separated
    □ Divorced
    □ Widowed
    □ Civil Union (not married but living together)

37. Do you have children?
    □ Yes
    □ No
    □ **Refuse to answer**

38. Do you currently have more than one female sex partner?
    □ Yes
    □ No
    □ **Refuse to answer**

39. Do you have a job?
    □ Yes
    □ No
    □ **Refuse to answer**

40. What is your monthly income? _____
    □ **Refuse to answer**

41. What is the highest level of education you received?
    □ No formal education
    □ Primary education (K-7)
    □ Secondary education (8-12)
    □ Some college
    □ Four-year university
    □ Other (Please specify): _____
    □ **Refuse to answer**

42. What is your religious belief/background?
    □ Christian
    □ Muslim
    □ Other: _____
    □ **Refuse to answer**

Thank you for your participation!

For questions related to this survey, please contact: Renicha McCree-Hale rmccree@uab.edu or Dr. Nedra Lisovicz nlisovicz@mail.dopm.uab.edu or by telephone at (205) 996-2850.

APPENDIX E

WOMEN'S INTERVIEW QUESTIONS PAPER #2

INTERVIEW QUESTIONS

TITLE OF PROJECT: Cervical cancer health disparity assessment in Tanzania.

INVESTIGATOR: Renicha McCree-Hale

SPONSOR: University of Alabama at Birmingham (UAB) Department of Medicine, Division of Preventive Medicine.

DATE:_____   STUDY ID:___/#_____

I. Social cultural factors and cervical cancer

READ: *I am going to ask you some questions about a type of cancer that can affect women. Please feel free to give your opinions and answer to the best of your ability. Remember, your answers will be kept private and your name will not appear with your answers.*

Directions to the interviewer: Please read aloud each question exactly as listed to the participant. Text that appears in bold is not to be read aloud. Bold text indicates interviewer instructions or actions to be taken to get the most complete responses from participants. Please begin recording the interview before you read the first question.

1. What do you know about cancer?
2. Tell me what you know about cervical cancer. **Probe: Ask the participant to**: Say the first thing that comes to your mind when you think about cervical cancer.
3. In your community, what other names do you have for cervical cancer?
4. What do women in your community think of cervical cancer?
5. What do men in your community think of cervical cancer?
6. What do you think causes cervical cancer? **Probe: Ask the participant:** Where did you get this information?
7. What makes a woman have a high chance of getting cervical cancer?
8. What are the symptoms of cervical cancer? **Probe**: How does a woman know she has cervical cancer?
9. Do you think cervical cancer can be cured? **Probe: If participant answers "YES," go to question #10. If participant answers "NO," then ask**: Why don't you think cervical cancer can be cured? Where did you hear this information?
10. What is the best treatment for cervical cancer? **Probe**: Where did you hear this information?
11. Have you ever been checked for cervical cancer? **Probe: If participant answers, "NO," then skip to question #14**. If participant answers "YES," go to question #12.**

12. What made you decide to get checked for cervical cancer? **Probe:** Where did you go for the checkup? Did you have to go for a follow-up visit?

13. Would you get checked for cervical cancer again? **Probe**: **If participant answers "NO," then ask:** What would keep you from getting checked for cervical cancer again? **Skip to question #15**.

14. Would you go to a health center to get a free checkup for cervical cancer? **Probe: If participant answers "NO," then ask**: Why wouldn't you get checked? What would keep you from getting checked for cervical cancer?

15. Once a woman is treated for cervical cancer, can she still get pregnant? **Probe: If participant answers "NO," then ask:** how does treatment for cervical cancer keep a woman from getting pregnant? Where did you hear this information?

II. Sources of knowledge and cervical cancer

READ: *Now I am going to ask you questions about how you learned about cervical cancer.*

16. How did you first hear about cervical cancer? **Probe**: Did you hear about it on the news or radio? Read about it? Did a friend or relative talk to you about it? A health care worker? Who was the first person to tell you about it?

17. Who has told you the most information about cervical cancer?

18. When you have an illness of the private parts (in your vagina), where do you go for help? **Probe:** What makes you seek help from this person/place?

19. When you have an illness of the private parts (in your vagina), where is the first place you go for treatment? **Probe:** What makes you seek treatment from this place/person?

20. Who do you most trust to give you advice about illnesses of your private parts (in your vagina)?

21. When you have an illness of the private parts (in your vagina), do you ask any women in your family for advice? **Probe: If participant answers "NO," ask:** Why don't you ask them for advice? **Go to question #22. Probe: If participant answers "YES," then ask:** Which female relative do you rely on to give you the best advice?

22. When you have an illness of the private parts (in your vagina), do you ask any of your husband's female relatives for advice? **Probe: If participant answers "NO," ask:** Why don't you ask them for advice? **Go to question #23. If participant answers "YES," then ask:** Which of your husband's female relatives do you ask for advice? Why do you ask these women?

III. Economic factors and male partner influences

READ: *Now I am going to ask you questions about your male partner/husband and illnesses of the private parts.*

23. Do you tell your male partner/husband when you have an illness in your private parts (in your vagina)? **If participant answers "NO," then ask** What keeps you from telling him?
24. When you have an illness in your private parts (in your vagina), what do you tell your male partner /husband about it? **Probe:** Do you describe the problem to your male partner/husband?
25. How does your male partner/husband act when you tell him about an illness of your private parts (in your vagina)?
26. Does your male partner/husband tell you when something is wrong with his private parts (the area around his penis)?
27. Who pays for medicines when you have to buy something to cure your private illnesses? **Probe: If participant answers "her husband or male partner" then ask:** Do you tell him why you need the money? **Probe: If she does not tell him the truth, ask:** What keeps you from telling your male partner/husband why you need the money?
28. Do you think that your male partner/husband would go to a clinic with you if you did have an illness in your private parts? **If the participant answers "YES," then go to question #29. If participant answers "NO," then ask:** What do you think keeps your male partner/husband from going with you? **Go to question #30.**
29. What do you think are the most important reasons that keep your male partner/husband from getting involved with your medical care when you have an illness in your private parts (in your vagina)?
30. Is there ever a time when your male partner/husband will go with you to visit a clinic? **Probe:** When is he most likely to go with you to visit a clinic?
31. Is there ever a time when you go with your male partner/husband when he visits a clinic? **Probe:** Do you think he always tells you when he visits a clinic? **Probe:** Why or why not?
32. Do you always tell your male partner/husband when you visit a clinic? **Probe:** Why or why not?

IV. General sources of health information

READ: *Now I am going to ask you some general questions about your health behaviors.*

33.   What is your main source of health information?
34. What is the best way to get health information to your family/friends?
35. Would you participate in a health education program to learn about breast cancer?
36. Would you participate in a health education program to learn about cervical cancer?

37. If you participated in a program and learned more about breast cancer, would you be willing to tell other women what you learned? **Probe: If participant answers "no," then ask**: What would keep you from telling women about breast cancer?

38. If you participated in a program and learned more about cervical cancer, would you be willing to tell other women what you learned about cervical cancer? **Probe: If participant answers "no," then ask**: What would keep you from telling women about cervical cancer?

39. Do you use a douche (put a liquid up your vagina)? **If "NO" go to #40. Probe: If "YES," then ask:** When do you use a douche? (after sex, after your period?) What is in the douche liquid you use? Who told you to use a douche?

IV. Personal health and demographic questions

READ: *This is the last section of questions. I will ask you about your martial and health status and general information.*

40. Have you ever been tested for HIV?
    □ Yes
    □ No
    □ I don't know/ Not sure
    □ Refuse to answer

41. Are you HIV positive?
    □ Yes
    □ No
    □ I don't know/ Not sure
    □ Refuse to answer

42. Is your husband/ main male partner HIV positive?
    □ Yes
    □ No
    □ I don't know/ Not sure
    □ Refuse to answer

43. What is your age? _____ years old

44. What is your marital status?
    □ Single (never married)
    □ Married
    □ Separated
    □ Divorced
    □ Widowed
    □ Civil Union (not married but living together)

45. Do you have children?
  □ Yes
  □ No
  □ Refuse to answer

46. Do you currently have more than one male sex partner?
  □ Yes
  □ No
  □ **Refuse to answer**

47. Do you have a job?
  □ Yes
  □ No
  □ **Refuse to answer**

48. What is your monthly income? _____

49. What is the highest level of education you received?
  □ No formal education
  □ Primary education (K-7)
  □ Secondary education (8-12)
  □ Some college
  □ University
  □ Other (Please specify): _____

50. What is your religious belief/background?
  □ Christian
  □ Muslim
  □ Other (Please specify): _____

Thank you for your participation!

For questions related to this survey, please contact: Renicha McCree-Hale
rmccree@uab.edu or Dr. Nedra Lisovicz nlisovicz@mail.dopm.uab.edu or by
telephone at (205) 996-2850.