CONCEPTUALIZATION OF CERVICAL CANCER AND SCREENING EXPERIENCES AMONG ZAMBIAN WOMEN ATTENDING A CERVICAL SCREENING PROGRAM

by

HEATHER L. WHITE

ERIC A. CHAMOT, CHAIR
DIANE M. GRIMLEY
MIRJAM-COLETTE KEMPF
LINDA MONEYHAM
MOSES SINKALA

A DISSERTATION

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Invasive cervical cancer (ICC) is the second most commonly diagnosed malignancy worldwide, and approximately 85% of the disease burden occurs in underdeveloped countries. A growing body of evidence has demonstrated that women can be effectively screened and clinically managed for ICC using non-cytological modalities. In 2006, the Zambian government launched a cervical screening program within primary health clinics using visual inspection with acetic acid (VIA) coupled with same-day treatment via cryotherapy. The objective of this dissertation was to determine whether the VIA screening program is responsive to the needs and concerns of Zambian women in an effort to improve screening uptake, and for human immunodeficiency virus (HIV) positive women who are potentially subject to increased ICC screening and treatment, increase long-term retention in ICC preventative services.

Understanding women’s disease conceptualization, associated causal beliefs, and perceived disease risk provides a basis for care providers to formulate or refine patient-centered communications regarding screening benefits and risks. A qualitative study design was employed using focus group discussions (FGD) and in-depth interviews (IDI) with women who accepted to undergo VIA screening and with care providers to elicit women’s conceptualization of ICC, including perceived disease risk. Additionally, women discussed their primary motivation for screening, their screening preferences, and the influence of social networks on their decision for cervical screening. Between Sep-
tember, 2009 and July, 2010, a total of 60 women eligible for screening, 10 screening nurses, and 11 lay peer educators participated in 8 FGD and 10 IDI.

Common perceived symptoms of ICC included prolonged bleeding, stomach pain, and weakness. Illness causation incorporated both traditional and biomedical elements, and departed from other lay causation models worldwide. Few women appeared to understand the concept of precancerous cervical lesions. Women were motivated to undergo cervical screening for numerous reasons, often prompted by peers and immediate family members. Women clearly articulated their screening preferences. The decision to undergo cervical screening was largely influenced by spouses, friends, and women who had already undergone screening. Interventions to formally integrate family members, particularly spouses, in the screening process and encourage peers to serve as screening ‘role models’ are warranted.

Keywords: Cervical Cancer, Prevention, Screening, Zambia
DEDICATION

To Surya, with love.

May you come to appreciate that creativity, hard work and perseverance will lead you to the destinations of your dreams.
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TABLE OF CONTENTS

Page

ABSTRACT ....................................................................................................................... iii

DEDICATION ..................................................................................................................... v

ACKNOWLEDGMENTS ................................................................................................. vi

LIST OF TABLES ............................................................................................................. ix

LIST OF ABBREVIATIONS .............................................................................................. x

LITERATURE REVIEW .................................................................................................... 1

Introduction .................................................................................................................. 1

RESEARCH AIMS ............................................................................................................ 10

Research Aims ............................................................................................................ 10

MATERIALS & METHODS ............................................................................................ 11

Study Design ............................................................................................................... 11

Study Setting ............................................................................................................... 11

Recruitment Procedures ............................................................................................ 12

Data Analysis .............................................................................................................. 13

Human Subjects Considerations ................................................................................. 14

‘WORSE THAN HIV’ OR ‘NOT AS SERIOUS AS OTHER DISEASES’?
CONCEPTUALIZATION OF CERVICAL CANCER AMONG WOMEN
ATTENDING CERVICAL CANCER SCREENING IN ZAMBIA ................................. 16

ZAMBIAN WOMEN’S EXPERIENCES WITH CERVICAL CANCER
SCREENING AND THE INFLUENCE OF SOCIAL NETWORKS......................... 47

SUMMARY & CONCLUSIONS ...................................................................................... 74

Overall Conclusions .................................................................................................... 74
GENERAL LIST OF REFERENCES ........................................................................................................75

APPENDICES

A INSTITUTIONAL REVIEW BOARD APPROVAL FORM ...........................................79
## LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘WORSE THAN HIV’ OR ‘NOT AS SERIOUS AS OTHER DISEASES’?</td>
<td></td>
</tr>
<tr>
<td>CONCEPTUALIZATION OF CERVICAL CANCER AMONG WOMEN ATTENDING</td>
<td></td>
</tr>
<tr>
<td>CERVICAL CANCER SCREENING IN ZAMBIA</td>
<td></td>
</tr>
<tr>
<td>1 Sample questions from focus group discussions and in-depth interviews held with Zambian women attending a VIA cervical screening program</td>
<td>45</td>
</tr>
<tr>
<td>2 Summary of findings from focus group discussions and in-depth interviews held with Zambian women attending a VIA cervical screening program</td>
<td>46</td>
</tr>
<tr>
<td>ZAMBIAN WOMEN’S EXPERIENCES WITH CERVICAL CANCER SCREENING AND THE INFLUENCE OF SOCIAL NETWORKS</td>
<td></td>
</tr>
<tr>
<td>1 Quotes focus group discussions and interviews with screening attendees and care providers on initial motivation for cervical cancer screening</td>
<td>70</td>
</tr>
<tr>
<td>2 Quotes from focus group discussions and interviews with screening attendees and care providers on positive contributors to the cervical screening experience</td>
<td>71</td>
</tr>
<tr>
<td>3 Quotes from focus group discussions and interviews with screening attendees and care providers on negative contributors to the cervical screening</td>
<td>72</td>
</tr>
<tr>
<td>4 Quotes from focus group discussions and interviews with screening attendees and care providers regarding influence of social network on decision to undergo cervical screening</td>
<td>73</td>
</tr>
</tbody>
</table>
LIST OF ABBREVIATIONS

AAT  Acetic Acid Testing
CIN  Cervical Intraepithelial Neoplasia
CIDRZ Centre for Infectious Disease Research in Zambia
DNA  Deoxyribonucleic Acid
FGD  Focus Group Discussions
HAART Highly Active Antiretroviral Therapy
HIV  Human Immunodeficiency Virus
HPV  Human Papillomavirus
ICC  Invasive Cervical Cancer
IDI  In-depth Interviews
LEEP Loop Electrosurgical Excision Procedure
Pap  Papanicolaou
PEPFAR President’s Emergency Plan for AIDS Relief
SCJ  Squamocolumnar Junction
STI  Sexually Transmitted Infection
UTH University Teaching Hospital, Lusaka
USD  United States Dollar
VIA  Visual Inspection with Acetic Acid
VILI Visual Inspection with Lugol’s Iodine
LITERATURE REVIEW

Introduction

Invasive cervical cancer (ICC) is the most common malignancy and is the leading cause of cancer-related mortality among women in developing countries (Arbyn et al., 2011). Eighty-three percent of all incident ICC cases worldwide and 85% of associated mortality occur in developing countries where the lifetime risk for the development of this disease is estimated between 2%-4% (Anorlu, 2008; Arbyn et al., 2011; Denny, et al., 2005; Goldie et al., 2003). While ICC incidence and mortality rates have declined substantially in developed countries due to successful cytology-based screening programs, rates of ICC incidence and mortality in developing countries remain high (Arbyn et al., 2011; Ferlay et al., 2008). Due to a lack of effective cervical screening and treatment strategies and poor screening coverage worldwide, women in resource-poor settings are often diagnosed at an incurable stage of the disease, perpetuating high mortality rates among women (Mwanahamuntu et al., 2009).

In industrialized countries, ICC prevention has proven largely successful through the use of the Papanicolaou (Pap) smear test to detect cervical abnormalities; however, the Pap smear screening method is generally not feasible in resource-poor settings for numerous reasons (Blumenthal, et al., 2007; Cronje at al., 2001). The costs associated with implementing and sustaining a successful cytological screening program are prohibitively high. Laboratory infrastructure in most developing countries is too limited to support cytological screening, both in terms of the lack of physical equipment and in
the technical expertise needed to process cytological samples. Equipment such as
colposcopes, used to examine the cervix among screen-positive women, is not commonly
found in these settings. Even microscopes, necessary to perform histopathology of Pap
smears, are not routinely available. Third, cytology has been documented as having
comparatively low sensitivity in resource-poor settings. Cronjé et al. (2001) found the
sensitivity of cytological screening to be 19.3%, as compared with 49.4% for acetic acid
testing (AAT). Finally, in the event of detecting cellular abnormalities or inconclusive
smear results, multiple follow-up visits may be required to diagnose and treat the problem
appropriately (Cardenas-Turanzas, Follen, Benedet, & Cantor, 2005). This places a
considerable burden on women who face logistic and financial difficulties to be able to
present to clinics for subsequent follow-up visits (Cronjé, 2004).

Development of effective cervical screening programs for low-resource countries
with high rates of HIV among women is particularly urgent. The most important risk
factor for the development of ICC is the acquisition of oncogenic subtypes of human
papillomavirus (HPV), a common sexually transmitted infection (STI) (Walboomers,
Jacobs, & Manos, 1999). Infection with HPV is persistent and pre-cancerous lesions are
recurrent due to lowered immune function among HIV-infected women (Fruchter et al.,
1996; Mayaud et al., 2001; Petry, et al., 1994). Studies performed in several sub-Saharan
African settings have shown a disproportionately high prevalence of HPV among HIV
positive women (Parham et al., 2006; Singh et al., 2009). While the cure rates for cervical
intraepithelial neoplasia (CIN)-1 have reached 90% for HIV-negative women in some
studies, these rates are considerably lower amongst HIV positive women (Tebeu, Major,
Mahwich, & Rapiti, 2006). Available evidence suggests that HIV positive women have a
significantly higher rate of CIN and are more likely to progress to ICC as compared to HIV negative women (Fruchter et al., 1996; Gichangi et al., 2003). This phenomenon seems to persist even amongst women who have initiated highly active antiretroviral therapy (HAART) (De Vuyst et al., 2008). HIV-infected women are also at a higher risk for recurrence of precancerous lesions, and it is unclear as to whether being placed on HAART provides a better prognosis (De Vuyst et al., 2008; Russomano, Reis, Camargo, Grinsztejn, & Tristão, 2008). Repeated ICC screening is essential for HIV positive women due to lower cure rates, ranging between 40-80%, for CIN following cryotherapy or loop electrosurgical excision procedure (LEEP) and vary according to the level of immunosupression (Cronjé, 2004). Depending on their level of immunosuppression, women may also have to defer treatment for any abnormalities until their CD4+ count rises to an acceptable level, i.e., >200 cells/µL, under the provision of HAART.

Acknowledging both the complexity of cytological screening and the significant disease burden of ICC in developing countries, particularly among HIV positive women, there has been a resurgence of interest in affordable, low-technology ICC prevention and screening tools for use in low-resource settings over the past fifteen years. It should be noted that while HPV vaccines now exist that protect against two of the most commonly known oncogenic subtypes of the virus, types 16 and 18, costs associated with the vaccine procurement and distribution are currently prohibitive for use in resource-limited settings (Andrus, Sherris, Fitzsimmons, Kane, & Aguado, 2008) and do not protect women already infected with HPV. Research in these countries has largely focused on low-tech, affordable screening tools including visual inspection with diluted 3-5% acetic acid (VIA), visual inspection with Lugol’s iodine (VILI), and HPV deoxyribonucleic acid
(DNA) testing to detect the presence of CIN, precursors to ICC (Cuzick et al., 2008). A growing body of evidence suggests that cervical inspection using VIA provides a safe, well-tolerated and highly cost-effective means of preventing ICC in resource-poor settings that does not require laboratory infrastructure and can be performed by trained nurses or midwives (Alliance for Cervical Cancer Prevention (ACCP), 2008; Denny et al., 2005; Sankaranarayanan, Gaffikin, Jacob, Sellors, & Robles, 2005). Perhaps the most important advantage of VIA is that, if indicated, immediate care can be provided using a “screen and treat approach” in which women presenting with mild to moderate cervical lesions can undergo immediate treatment with cryotherapy thereby reducing the likelihood of loss-to-follow-up and the need for additional clinic visits (ACCP, 2008; Sankaranarayanan et al., 2005; WHO, 2002).

Briefly, VIA is a process whereby a solution of 3-5% acetic acid (vinegar) is applied directly to the cervix and examined by the naked eye, with the aid of a bright light source, to detect the presence of aceto-whitening of areas in close proximity to the squamocolumnar junction (SCJ) or “transformation zone” (Cuzick et al., 2008). Screen-positive clinical management, depending on the severity of the finding, can include cryotherapy (freezing) of the affected area or removal of lesions using LEEP.

In spite of its potential benefits for low-resource settings, VIA screening also has limitations which are important to acknowledge. One notable limitation is the risk of overtreatment of false-positive women due to comparatively low test specificity compared to other screening modalities. Critics of the VIA approach also assert that wide-scale visual screening programs are being initiated throughout the developing world without fully understanding the potential impact of overtreatment of women (Suba,
Nguyen, Nguyen, & Raab, 2001). Some have argued that supplemental digital cervicography can increase the accuracy of detection when used as a second level screening step performed in tandem with standard VIA screening (Bomfim-Hyppolito, Franco, Franco, de Albuquerque, & Nunes, 2006; Cremer et al., 2005). Digital images can also serve as a tool for perfecting the training of the screening nurses, facilitate communication between nurses and gynecologists in case of patient referral, and document screening activities for quality assurance (Parham et al., 2010). Nevertheless, while the efficacy of the VIA-based screen and treat protocols are encouraging, there are only limited data regarding the long-term feasibility of cervical screening programs using VIA in low-resource settings. Finally, it is important to contextualize the use of VIA alongside other existing screening modalities. Comparative randomized clinical trial data from Sankaranarayanan et al. (2009) showed that among 131,000 Indian women, a single round of HPV DNA testing reduced ICC incidence and mortality by 50% versus no significant reduction in ICC incidence or mortality among women screened with Pap smear or VIA testing. Given its higher sensitivity compared with cytology or VIA testing (Denny et al., 2005; Sankaranarayanan et al., 2009), HPV DNA testing is clearly a screening tool of interest; however, in its current form, the test has many of the same practical limitations as cytology and is not feasible for widespread use in developing countries. As rapid, affordable HPV DNA screening tools are developed, tested, and widely disseminated, they may replace VIA testing altogether or serve as a primary screening tool with VIA testing meant to assist in treatment triage (AACP, 2009). Such issues will largely depend on the local needs, infrastructure, and resources of individual programs.
As affordable, low-tech screening options expand in resource-poor settings, an urgent need exists for ICC screening coverage in countries dually impacted by elevated ICC incidence coupled with high HIV rates among women. ICC rates in the Eastern sub-Saharan African country of Zambia are among the highest in the world. The estimated age-adjusted standardized incidence rate of ICC in Zambia is 53 per 100,000 women, making its ICC incidence second worldwide only to the African nation of Guinea (Arbyn et al., 2011). In addition, the country also has extremely high HIV prevalence among women 15-49 years, 16.1% nationally and 23.1% in the capital of Lusaka (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2010). In response, the government of Zambia launched a pilot cervical screening program in 2006 within several primary care clinics in Lusaka with financial support from the U.S. Centers for Disease Control (CDC) and the President’s Emergency Plan for AIDS Relief (PEPFAR). The goal of the program is to integrate ICC prevention services within existing public primary care clinics throughout Lusaka and, for HIV positive women, link them with concurrent HIV treatment and prevention services (Mwanhamuntu et al., 2009). As of December 2010, 55,000 women have been screened in the 15 participating clinics throughout Lusaka (Parham et al., 2010).

Current guidelines by the World Health Organization (WHO) and The Alliance for Cervical Cancer Prevention recommend that ICC screening be offered to all women living in resource-poor settings at least once in their lifetime around age 30-35 years (ACCP, 2008; WHO, 2002). The Zambian screening protocol was developed using current accepted international standards set forth by the AACP and provides free routine VIA-based screening using a screen-and-treat protocol to women meeting specific
inclusion criteria (Parham et al., 2006). If eligible and once providing informed consent, patients undergo a complete physical and pelvic examination before VIA testing is conducted. Following VIA testing, a nurse performs digital cervicography by taking an image of the visualized cervix through a digital camera stabilized on a tripod stand and connected to a regular television screen for enhanced visualization (Parham et al., 2010). Women who have lesions suitable for immediate treatment undergo cryotherapy (freezing of affected areas) in the same visit. Women whose lesions are better suited for treatment by LEEP (lesions occupying an area larger than 75% of the cervix) or endocervical curettage (lesions extending into the endocervical canal) are referred to the gynecology clinic at a tertiary care center, The University Teaching Hospital (UTH), for these procedures to be performed by trained gynecologists (Pfaendler et al., 2008). Finally, women whose cervical findings are suggestive of ICC are referred to the UTH gynecology clinic for further evaluation. According to the local protocol, all HIV negative women who undergo cryotherapy, LEEP, or endocervical curettage are scheduled for 6-week follow-up visits and advised to repeat screening at 12 months. HIV positive women treated with cryotherapy or LEEP are asked to return for a 6-week follow-up and repeat screening at 6 months. HIV positive women who screen negative are advised to return to the clinic annually to repeat screening.

While the Zambian screening program seems to be generally well-received in terms of initial uptake, there is evidence to suggest that there is considerable loss-to-follow up amongst screening attendees. This is especially important for HIV positive women who should remain in preventive care for consistent, repeated ICC screening at yearly intervals. From 2006-2008, almost two-thirds (64.9%) of the 21,000 screening
attendees were either documented as HIV positive (31.3%) or with unknown HIV serostatus (35.1%) (Parham et al., 2010). Among all screening attendees, 38% of HIV negative and 54% of HIV positive women were considered ‘VIA positive’ and eligible for cryotherapy; of these, almost one-fourth (23%) of women never returned for treatment, irrespective of HIV status (Parham et al., 2010). Almost one-fifth of all screening attendees (18%) were referred for histologic evaluation at the UTH based on their screening assessment; of these, over half (51%) never presented to the UTH for evaluation (Parham et al., 2010). Finally, long-term follow-up rates reported among HIV positive women were only modest during the study period: Of those treated with cryotherapy or LEEP, 80% did not return for their follow-up visit at 6 months, and roughly only 10% who initially screened VIA-negative returned for a repeat screening at 12 months (Parham et al., 2010).

To date, few systematic efforts have been undertaken to document African women’s lay representations of ICC and to study the potential influences of these representations on women’s cervical screening behaviors. Publications on the topic suggest that many African women either have little awareness of the disease or express perceptions that depart markedly from the biomedical model (Francis et al., 2010; Gichangi et al., 2003; Mangoma, Chirenje, Chimbari, & Chandiwana, 2006; McFarland, 2009; McFarland, 2003; Nnodu et al., 2010). A greater understanding of local conceptions of ICC is needed to understand what might motivate or inhibit HIV positive women to remain in preventive care after having been screened for cervical abnormalities for a first time, and, more generally, to develop screening promotion messages that are culturally appropriate that resonate with the general population. Likewise, given the
recent advent of non-cytological ICC screening programs in African settings, understanding women’s screening experiences as well as the influence of social networks on women’s screening behaviors is an important step in ensuring initial cervical screening uptake, and for HIV positive women, retaining women in preventative ICC care. This present research study employed qualitative methods to elicit women’s conceptualization of ICC and their screening behaviors associated with the VIA screen and treat cervical program offered at a local primary care clinic in Zambia.
RESEARCH AIMS AND HYPOTHESES

Research Aims

The purpose of this research study was to determine whether the VIA screen-and-treat program currently offered in primary care clinics in Lusaka, Zambia is responsive to the needs and concerns of local Zambian women to increase uptake and, for HIV positive women, to ensure continuity of care to increase the likelihood of long-term retention in ICC prevention programs. The specific aims of this study were to: 1) characterize representations of ICC among Zambian women who accepted an invitation for cervical screening labeled as “cervical cancer”; 2) describe the attributes that women attached to their representations of ICC; 3) identify women’s primary motivation for cervical screening; 4) document women’s screening preferences; and 5) determine the potential influence of social networks on women’s decision to undergo cervical screening. These aims were not hypothesis-driven; however, they were meant to contextualize the findings from the parent study examining self-reported psychosocial outcomes among women attending cervical screening.
MATERIALS AND METHODS

Study Design

This cross-sectional study employed qualitative methods to elicit perceptions of ICC, women’s experiences with the VIA screen-and-treat program, including primary motivation for ICC screening, and the potential influence of social networks on the decision to undergo screening. The study sample included women who accepted to undergo VIA cervical screening at the Kanyama primary care clinic. Additionally, separate discussions were held with screening providers, specifically screening nurses and volunteer, lay peer educators, to discuss their perceptions of women’s conceptualizations of ICC as a disease and their interactions with women in the screening program. Focus group discussions (FGD) and in-depth interviews (IDI) were conducted with women and health care personnel separately.

Study Setting

This research was conducted at the public primary care clinic of Kanyama located on the outskirts of Lusaka, the capital city of Zambia (population approximately 1.5 million). Kanyama is a poor and densely populated urban settlement with an estimated population of more than 150,000 inhabitants (Zambia Ministry of Health (MOH), 2008). The compound is situated in a flood prone area bordering Lusaka’s largest outdoor commercial market. The social environment is characterized by high unemployment, makeshift housing, and inconsistent utility services (Zambia MOH, 2008). Cholera outbreaks are frequent during the rainy season (Sasaki, Fujino, Kimura, & Cheelo, 2009); HIV and tuberculosis rates are among the highest in Lusaka (Godfrey-Faussett et al., 2002; Koethe et al., 2010). Kanyama clinic is one of 25 health centers managed by the
Lusaka District Health Management Team under the authority of the Ministry of Health. The clinic provides general outpatient services, including HIV, tuberculosis, antenatal, and pediatric health care. By late 2006, Kanyama clinic was dispensing ART to nearly 3,000 patients (Koethe et al., 2010).

Recruitment Procedures

On recruitment days, selected based on convenience to the clinic’s personnel, screening peer educators referred potentially eligible women presenting at the clinic to study team members. To be eligible for the study, women had to be 18-49 years of age, eligible for VIA screening (Parham et al., 2006), consenting to undergo a pelvic examination, and able to comprehend either Bemba or Nyanja, the two local languages most commonly spoken in Lusaka. Women were invited to take part in FGD, regardless of whether they had actually undergone the screening process. Interested women were given date/time reminder cards to come back to the clinic for the group discussions. HIV serostatus was documented for all women who accepted to provide this information.

Following informed consent, women were grouped according to language preference (Bemba versus Nyanja) and HIV status (positive versus negative or unknown/undisclosed). Separate FGD were held with HIV positive women assuming that these women might have different experiences with the local health care system and, possibly, unique concerns in association with their increased risk for cervical cancer. All FGD were held in pairs in order to validate findings of the initial FGD during a second discussion.

Each of the FGD included 10-12 women and lasted 1-2 hours on average. All discussions were held in private rooms within the clinic and were conducted by
experienced Zambian staff trained specifically for this protocol. A moderator asked the
pre-scripted, open-ended questions to the group, encouraged balanced group discussions,
and used probes to clarify any unclear or unresolved statements (e.g., “can you tell us
more?” or “what exactly do you mean by…”); in parallel, an observer documented the
general atmosphere, group dynamics, and individuals’ non-verbal cues. With women’s
permission, each FGD was recorded using a digital recorder for transcription and
translation purposes.

Once all FGD were transcribed, translated in English and rapidly
reviewed, the research team gathered to discuss recurrent themes and compile a list of
topics to be further explored through IDI to both explore key FGD themes more
extensively and to confirm the findings of the FGD using member checking techniques.
All women who participated in the group discussions were asked to consider participating
in an in-depth interview. Women who agreed were given an appointment reminder card
to return for the interview. Interview procedures matched those used for FGD, with
regard to transcription and translation.

Data Analysis

Low-level content analysis was used to summarize initial categories, followed by
a summary of progressively more substantive themes as agreed upon by the research
team. Three investigators (2 U.S.-based and 1 Zambian-based) independently coded the
data using QSR Nvivo 8.0© software and, then, developed the group coding schematic. A
fourth U.S. investigator familiar with the dataset was used to adjudicate any
disagreements amongst the research team.
Human Subject Considerations

Ethics committees from both the University of Alabama at Birmingham (UAB) and the University of Zambia (UNZA) approved the research protocol. Screening nurses and lay peer educators referred interested women to one of study personnel. The research assistant confirmed eligibility criteria and informed about the study, the nature of the discussions, how the information will be used, and about their right to refuse to respond to any question and to opt out at any moment without penalty.

All informed consent documents were written in three languages: Bemba, Nyanja, and English, and were distributed according to women’s stated language preference. Study research assistants read the informed consent document aloud to every potential participant. Written informed consent was obtained from each woman after she was debriefed about the study, had the opportunity to answer questions and seek clarification on any unresolved issues. For women who were unable to sign their name, they were asked to mark the consent document with an “X” to signify their willingness to participate in the study. Respondents were then given date/time reminder cards to return to the clinic to participate in FGD or IDI.

All FGD and IDI took place in private rooms dedicated for this purpose at Kanyama Health Clinic. Just before proceeding with the FGD and IDI, research assistants explained that participants did not need to present their opinions as personal, but rather as views expressed by members of their community. The interviewer also stressed that participation was strictly voluntary, and that women could refuse to respond to any question. They were also free to leave at any time. Finally, women were reminded not to share the details of any of the discussions during FGD or IDI with others in the
community. To ensure confidentiality, women who took part in FGD and IDI were not asked to provide any personal identifiable information in the context of the discussions that took place. Once all recorded data was translated and transcribed, the data was removed from digital recorders. Strict measures were taken to maintain privacy and confidentiality of participants at all times.
‘WORSE THAN HIV’ OR ‘NOT AS SERIOUS AS OTHER DISEASES’?
CONCEPTUALIZATION OF CERVICAL CANCER AMONG WOMEN ATTENDING
CERVICAL CANCER SCREENING IN ZAMBIA

by

HEATHER L. WHITE, CHISHIMBA MULAMBIA, MOSES SINKALA, LINDA
MONEYHAM, MIRJAM-COLLETTE KEMPF, DIANE GRIMLEY, MULINDI
MWANAHAMUNTU, GROESBECK PARHAM, AND ERIC CHAMOT

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ABSTRACT

Invasive cervical cancer (ICC) is the second most commonly diagnosed cancer worldwide, with approximately 85% of the disease burden occurring in underdeveloped countries. To date, few systematic efforts have been undertaken to document African women’s representations of ICC and their influence on screening behaviors. In this study, qualitative methods were used to elicit women’s causal representations of ICC, associated physical signs and symptoms, perceived physical and psychological effects, and social norms regarding the disease. A total of 60 women eligible for screening took part in focus group discussions and in-depth interviews between September, 2009-July, 2010. Common perceived symptoms of ICC included prolonged bleeding, stomach pain, and weakness. The lay model of illness causation portrayed by Zambian women departed from causal models of ICC described in other parts of the world. Causal conceptualizations included both lay and biomedical elements, suggesting a possible shift from a purely traditional causal model to one which incorporates both traditional and biomedical concepts. Women largely equated ICC with death so few women appeared to understand the concept of precancerous cervical lesions. ICC was perceived to be a highly stigmatized disease in Zambia because of its anatomic location, dire natural course, connections to socially-condemned behaviors, and association with HIV/AIDS. No substantive differences of disease conceptualization existed according to HIV serostatus, though HIV positive women acknowledged that their disease status makes them more aware of their health and more likely to seek medical attention.
INTRODUCTION

Invasive cervical cancer (ICC) is primarily caused by persistent infection of the uterine cervix with oncogenic sub-types of human papillomavirus (HPV) (Bosch et al., 2008). With an annual incidence of 533,000 cases, ICC is the second most commonly diagnosed cancer worldwide (Arbyn et al., 2011). To mitigate this public health problem in underdeveloped countries where approximately 85% of the disease burden occurs (Ferlay et al., 2010), important efforts have been made over the past 15 years to develop simple and affordable screening strategies that rely on non-cytological modalities of cervical abnormality detection (Blumenthal et al., 2005; Sankaranarayanan et al., 2004).

Effective ICC prevention programs are especially needed in Eastern sub-Saharan Africa where ICC incidence and associated mortality rates are among the highest in the world. In this region, however, ICC secondary prevention is hindered by high rates of HPV/HIV dual infection in young women. In HIV positive women coinfected with HPV, rates of high-grade cervical precancerous lesions are up to 5-times higher than in HIV negative women (De Vuyst et al., 2008). Treatment failure for such lesions are also much more common in HIV-infected versus HIV-uninfected women (Tebeu et al., 2006); progression to ICC is not significantly affected by antiretroviral therapy; and, finally, ICC diagnosis is frequently made before age 30 in HIV positive women—some 10 years earlier than is typical in HIV negative women (Clifford et al., 2005; Frish et al., 2000). Consequently, general recommendations by the World Health Organization for a single screening visit between 30-39 years of age (Alliance for Cervical Cancer Prevention, 2009)
are likely to be of limited benefit to many HIV-infected African women on antiretroviral therapy who might now live long enough to develop ICC (De Vuyst et al., 2008). Instead it appears that HIV-infected women will need to be screened at regular intervals from a young age, possibly as frequently as once a year, and monitored closely for post-treatment recurrence of lesions (De Vuyst et al., 2008; Omar et al., 2011). Even within the context of integrated services of HIV care and treatment, ensuring that HIV-infected women in Africa receive the continuity of care that they need to undergo regular cervical screening presents formidable challenges.

Ordinary people from all cultures have understandings of illnesses that are in part personal and in part shared among members of their community. Largely based on intuitions, private experiences, local history and current social circumstances, these understandings, or lay models of illness, can be seen as representing “what feels right” about a health condition for a person or a group of persons at a given time. In response to the continuous exposure to new information and experiences, each model constantly evolves in terms of scope and sophistication. From a public health perspective, lay illness representations are known to strongly influence people’s perceptions of personal risk, as well as their interpretations of symptoms, and their help-seeking behaviors (Petrie & Weinman, 2006). More generally, lay models of illness have multiple other functions in daily life, such as providing personal meaning to illness, help maintain or restore emotional balance, assigning responsibility for suffering, and regulating interpersonal relationships between the sick and the members of their social network. To date, few systematic efforts have been undertaken to document African women’s lay representations of ICC and to study the potential influences of these representations on cervical screening behavior. Publications on the topic suggest that many
African women either have little awareness of the disease or express perceptions that depart markedly from the biomedical model in terms of causal attributions and risk perception (Francis et al., 2010; Gichangi et al., 2003; Mangoma et al., 2006; McFarland, 2009; McFarland, 2003; Nnodu et al., 2010). A greater understanding of local conceptions of ICC is needed to understand what might motivate HIV-infected women to remain in preventive care after having been screened for cervical abnormalities for a first time, and, more generally, to inform development of screening promotion messages that are culturally appropriate and make sense to the general population.

In Zambia, estimated age-adjusted cervical cancer incidence is 52.8 per 100,000 annually (Ferlay et al., 2010). HIV prevalence among women 15-49 years is extremely high, at 16.1% nationally and 23.1% in the capital of Lusaka (Joint United Nations Programme on HIV/AIDS, 2010). To respond to this crisis, the government of Zambia launched a pilot initiative in 2006 that introduced ICC screening services within existing primary health care facilities in Lusaka and linked them with concurrent HIV treatment and prevention services (Mwanahamuntu et al., 2009). The present study was conducted at an urban primary care clinic in the outskirt of Lusaka, in parallel with a population-based survey of barriers to screening (Chirwa et al., 2010). Our study employed qualitative methodologies to: 1) characterize the illness entity, if any, that Zambian women who accepted an invitation for cervical screening labeled as “cervical cancer”; 2) describe the attributes that these women attached to their representations of ICC; and 3) evaluate the implications of these representations in terms of ICC screening organization and promotion.
MATERIALS AND METHODS

Study setting

This research was conducted at the public primary care clinic of Kanyama on the outskirts of Lusaka, the capital city of Zambia (population approximately 1.5 million). Kanyama is a poor and densely populated urban settlement with an estimated population of more than 150,000 inhabitants (Zambia Ministry of Health, 2008). The compound is situated in a flood prone area bordering Lusaka’s largest outdoor commercial market. The social environment is characterized by high unemployment, makeshift housing, and inconsistent utility services (Zambia Ministry of Health, 2008). Cholera outbreaks are frequent during the rainy season (Sasaki et al., 2009); HIV and tuberculosis rates are among the highest in Lusaka (Godfrey-Faussett et al., 2002; Koethe et al., 2010).

Kanyama clinic is one of 25 health centers managed by the Lusaka District Health Management Team under the authority of the Ministry of Health. The clinic provides general outpatient services, including HIV, tuberculosis, antenatal, and pediatric health care. By late 2006, Kanyama clinic was dispensing ART to nearly 3,000 patients (Koethe et al., 2010).

Since January 2006, a cervical screening program based on visual inspection with acetic acid (VIA) and same-visit treatment of cervical precursor lesions has been introduced in 15 government health centers throughout Lusaka, including Kanyama clinic. As of October 2010, a total of 52,000 women had been evaluated using VIA screen-and-treat methods in clinics where cervical screening was offered (Parham et al., 2010).

At Kanyama clinic, the screening program is managed by a nurse assisted by a small team of volunteer, lay peer educators who provide promotional talks on cervical health and
circulate through the clinic daily to invite women for screening (Mwanahamuntu et al., 2009; Pfaendler et al., 2008). Once providing informed consent, eligible women are seen by the nurse who takes a brief clinical history. Following a complete physical and pelvic examination, the nurse visually inspects the patient’s cervix after application of dilute 3% acetic acid. A picture of the visualized cervix is captured using a digital camera connected to a monitor for enhanced visualization, documentation and quality assurance purposes (Parham et al., 2010). Women diagnosed with aceto-white lesions are offered immediate treatment with cryotherapy, as appropriate, or referred for further gynecological evaluation at the local tertiary care center, University Teaching Hospital (UTH) (Mwanahamuntu et al., 2009; Pfaendler et al., 2008).

**Study Design**

This cross-sectional study employed qualitative methods to elicit perceptions of ICC held by Zambian women attending screening services at Kanyama’s primary care clinic. Focus group discussions (FGD) and in-depth interviews (IDI) were used to obtain women’s detailed responses to broad, open-ended questions about ICC and the VIA screening program. In particular women were asked to describe their perceptions about ICC and its manifestations, course and consequences (both physical and psychosocial). In addition, women were asked how serious they considered ICC to be compared to other diseases that affect women; whether they felt personally at risk; and how to avoid getting the disease. (See Table 1 for sample questions from the group discussions). Ethics committees from both the University of Alabama at Birmingham (UAB) and the University of Zambia (UNZA) approved the research protocol.
Study sample

On recruitment days, selected based on convenience to the clinic personnel, screening peer educators referred potentially eligible women presenting at the clinic to study team members. To be eligible for the study, women had to be 18-49 years of age, eligible for VIA screening (Parham et al, 2006), consenting to undergo a pelvic examination, and conversant in either Bemba or Nyanja, the two local languages most commonly spoken in Lusaka. Women were invited to take part in FGD, regardless of whether they had actually undergone the screening process. Interested women were given date/time reminder cards to come back to the clinic for the group discussions. HIV serostatus was documented for all women who chose to provide this information.

Focus group discussions

Following informed consent, women were grouped according to language preference (Bemba versus Nyanja). Separate FGD were also held based on HIV status (positive versus negative or unknown/undisclosed) assuming that women who disclose their HIV positive status might have different experiences with the local health care system and, possibly, unique perceptions in association with their increased risk for ICC. All FGD were held in pairs in order to validate findings of the initial FGD during a second discussion.

Each of the FGD included 10-12 women and lasted 1-2 hours. All discussions were held in private rooms within the clinic and were conducted by experienced Zambian staff trained specifically for this protocol. A moderator asked the pre-scripted, open-ended questions to the group, encouraged balanced group discussions, and used probes to clarify
any unclear or unresolved statements; in parallel, an observer documented the general atmosphere, group dynamics, and individuals’ non-verbal cues. With women’s permission, each discussion was recorded using a digital recorder for transcription and translation purposes.

**In-depth interviews**

Once all FGD were transcribed, translated in English and rapidly reviewed for emergent themes, the research team gathered to compile a list of topics and findings to be further explored through IDI’s (see examples of interview topics in Table 1) or confirmed using member checking techniques. All women who participated in the FGD were asked to consider participating in an IDI. Women who agreed were given an appointment reminder card to return for the interview. Interview procedures matched those used for FGD, with regard to transcription and translation.

**Data Analysis**

Low-level content analysis was used to summarize initial categories, followed by a summary of progressively more substantive themes as agreed upon by the research team. Three investigators (2 U.S.-based and 1 Zambian-based) independently coded the data using QSR Nvivo 8.0© software and, then, developed the group coding schematic. A fourth U.S. investigator familiar with the dataset was used to adjudicate any disagreements amongst the team.
RESULTS

Between September 2009 and July 2010, a total of 60 women eligible for ICC screening participated in 6 FGD; of these women, 10 also completed IDI in June and July 2010. Each woman belonged to the community in which the VIA cervical screening was offered. Key findings are summarized in Table 2. Results are presented using Leventhal’s categories of illness identity, causes, controllability and consequences (Leventhal, Meyer, & Nerenz, 1980).

Identity and manifestations

ICC and cervical cancer screening have been the object of intense health education efforts in Lusaka since 1996, while also drawing increasing attention from the local media and various civil society groups. Among our study participants—a group of women who had been recently exposed to screening promotion messages and who had decided to undergo screening—ICC was clearly seen as a recognizable disease, typically referred to in the community either using the English term “cervical cancer” or various Nyanja/Bemba colloquial metaphors pointing to “diseases of the female private parts”. No participant could propose any Nyanja/Bemba term widely accepted as having precise ascribed meaning of “cervical cancer”. Descriptions of ICC by study women generally included elements of medical knowledge, but in various amounts and expressed with variable levels of confidence. The most common perceived physical symptom of ICC was bleeding, either as prolonged menstruation or as a spontaneous occurrence: “This cancer gives women prolonged periods which do not finish. And others will have the periods for a few months then they will stop and start again after some months”. [Postmenopausal women] “will start having periods all
over again”. Other vaginal symptoms were reported, including sores or a rash on the vagina, discharge, itching, and vaginal odor. Pain and/or bleeding during intercourse were suggested by several women as symptoms of ICC. Women also described stomach pain, weakness, and pain throughout the body as common manifestations of the disease: “Generally one gets weak, you experience a backache, legs paining and generally the whole body is in pain”. Several women mentioned that a unique characteristic of ICC is its long latency period: “When you are infected with cervical cancer, it takes long to notice…about four to five years before you know that you have the disease”.

Respondents strongly associated ICC with HIV/AIDS, pointing out that a widely held belief in the community is that if a woman tests positive for VIA screening of the cervix, then she also has HIV:

…a lot of people think when you come for [VIA cervical] screening then you are HIV positive….because in the community, cancer is associated with HIV/AIDS. So a lot of women fail to come for screening for fear of being found with cancer lesions because it means they are HIV positive.

**Perceived causes**

When asked to cite causes of ICC, women offered a variety of explanations. The most common reason given was the use of traditional herbs or medicines which, according to respondents, are used to make sexual intercourse more pleasurable for male partners: “Herbs we put in the porridge to make our body temperatures rise so that a man can enjoy sex with us and the herbs that we insert into the vagina to tighten it [cause cervical cancer]”.

26
The second most common cause of ICC offered was having multiple sex partners, as indicated by comments such as “I have heard…cancer of the mouth of the womb comes through having sexual intercourse with men” and “[cancer] comes about if a woman is having sex with different men because the sperms of men mix and this brings cancer”. Women often used the term “promiscuous” when describing those with multiple sexual partners. In this context, some respondents mentioned that the disease is caused by a sexually transmitted virus:

What I know is that there is a virus called HPV which comes from men, which gives a disease to men, but as for women it goes and stays just at the mouth of the womb, so if a woman doesn’t go for screening it turns into cancer.

Several women noted that men, though responsible for transmitting HPV virus to women, could not be affected by the virus itself. As one woman said, “…there is a virus called HPV which comes from men, but it does not give cancer to men only to women”. Some women suggested that having sex during menstruation or early parity could cause the disease.

A very different facet of the relationships between men and women was also offered as an explanation for ICC among women, namely, that a woman who began to experience prolonged menstrual periods or bleeding may become convinced that another woman is bewitching her (using sorcery) to try to steal her husband:

…let’s say the husband has a girlfriend and the girlfriend did some black juju so that the woman can be experiencing prolonged periods, then the man will not be going to the wife. So then girlfriend is going to have the man”.

In this case, women would most likely choose to see a traditional healer in order to mitigate the effects of witchcraft.
Along with sexual activity, family planning, e.g., the use of birth control pills and condoms, was described by several women as a cause of ICC. Some women said that use of the pill “over a very long time” was the cause of ICC in women. Others attributed it to the use of condoms: “What I have also heard is that condoms bring problems to the cervix, and one can have cancer because of using condoms.” One woman offered, “…they [men and women in the community] say the medicine put on condoms brings about cancer”.

According to our respondents, there seemed to be a considerable amount of fear and distrust in the community surrounding contraceptive use. Besides the deleterious effect of condoms, other direct physical or chemical aggressions to the cervix were identified as causes of the disease. Bathing practices, in particular, were often cited. Among these, the act of a woman touching the vagina with her fingernails while bathing, causing abrasions, was most commonly mentioned. As a woman described, “At the same time the nails from your fingers can cause bruises inside as you wash, some of these bruises do not heal and eventually turn into cancer”. Another common perception was that dirt from a woman’s hands while bathing would damage the cervix and lead to disease, including cancer:

But the finger leaves dirt inside, sometimes you may have a sore inside and as such the dirt from the finger can be accumulating on the sore…the dirt from the finger remains in the womb and over some period of time a woman starts to develop complications and diseases.

Several women explained that the use of soap could lead to cancer, “I also heard that bathing with very strong bath soaps can put a woman at risk [for cervical cancer]”. Similarly, the use of baby powder was mentioned as a risk factor for cancer, and so were using dirty or “rusty” water when washing the vagina, and wearing wet underwear or wet clothes.
Finally, practices of using commercial and noncommercial absorbents during menstruation carried a perceived risk of affecting the cervix and causing ICC. These included inserting tissue, cotton wool, or tampons into the vagina during menstruation. As one woman remarked, “I have also heard that cotton wool gives cancer. If you are using cotton wool during menstruation, if the cotton wool gets inside it gives cancer” or, in the case of tampons:

There are those who use tampons. When the blood is coming out, the tampons stops the blood from coming out, as a result the blood remains inside, this also causes problems. The blood that remains inside remains sterile and this brings cancer.

**Controllability**

Given that many women attributed ICC both to the effect of objects/substances coming into direct contact with the vagina and to “promiscuity”, when asked how to avoid the disease, women commonly stated that to avoid ICC was to refrain from putting anything into the vagina and to avoid having sex with “a lot of men”. Although several women suggested that using condoms can cause ICC, one respondent said that it was necessary to use a condom during sexual intercourse and another asserted that the use of condoms lessened the risk for ICC.

A small number of women mentioned the importance of coming to the clinic for screening even in the absence of symptoms. One respondent said that women should get screened for ICC as soon as they begin to feel symptoms. This latter view appeared to be implicitly shared by many other women who believed that receiving positive VIA screening results was the equivalent of hearing that they had cancer. When asked whether women
understood that a positive screening result is not necessarily indicative of ICC, respondents said that “some, but not all women” understood and made the distinction between pre-cancerous lesions and malignancy.

In response to questions about what they would do if they thought they had ICC, participants disagreed considerably as to whether women would come to a health clinic for screening or go to a traditional healer. One respondent described this dilemma:

And [women] start to feel scared and start thinking of going to traditional healers. Others just think of coming straight to the hospital, but others it takes time to convince them to come to the clinic and it is also difficult to share with your husband about the disease or tell him the problem that you have. Mostly we keep the problem to ourselves.

Many women attributed increased education and awareness as a reason to visit the clinic versus a traditional healer:

Without people knowing about cervical cancer, people long ago used to go to traditional healers…since people have started knowing that this is cervical cancer and have knowledge about it, and they have started coming for screening. People in the past used to stay with the disease for a long time before going to the hospital to seek help.

No woman mentioned being aware of the recent opening of a modern oncology center at the Lusaka University Teaching Hospital, a medical unit providing affordable options for potentially dramatically altering the course of ICC in women diagnosed with this condition. ICC was widely perceived as an incurable disease and viewed as fatalistic, as summarized by one woman:
There is so much fear surrounding cancer because most women know that it cannot
be treated. When one starts having prolonged periods, backaches and the whole body
paining, what comes to their minds is death because there is no way to be treated.
Another woman added, “Others think it’s all over, they are about to die because cancer
has got no cure. This disease can’t be cured, and so they start sharing their properties saying
they will die at any time”. This belief was conveyed in every contact with women and was
thought to be one of the main reasons that women avoid cervical screening. As one
participant noted, “Others fear to come to the hospital, saying that if I am screened I will
know the disease, so they prefer to stay at home. They fear to know their problem because
they feel they cannot live with it.” One woman described ICC as, “…worse than HIV”.

Not all women, however, shared this opinion about the severity of ICC. For instance
one woman felt that “it is not as serious as other diseases”, while another commented, “Yes,
but it is curable. I am not sure it is as serious as other diseases”. One woman offered both
points of view, stating, “It depends on the mind of the person, some do not take it seriously
because you do not experience any pain in the early stages, while others take it serious”. Given the common absence of discrimination between precancerous lesions and ICC, it was
unclear whether these women had in mind the cure of precursor lesions discovered through
screening or invasive cancer.

**Physical, psychological and social consequences**

When asked to describe the physical consequences of ICC, women most commonly
provided answers directly related to fertility and the ability to conceive: “This disease spoils
your womb severely and sometimes you may not have children because of this disease”.

Another woman stated, “This is a disease which comes about when the womb is spoiled, then it turns into cancer”. Beyond affecting the uterus directly, women spoke of other long-term effects: “[Cervical cancer] spreads throughout the body, can cause madness, and eventually you die”.

Women were also asked to discuss possible psychological effects of ICC. As previously noted, fear of death from cancer was the most common concern described by women. Other psychological consequences of being diagnosed with ICC included feelings of hopelessness, depression and anxiety. These emotions had a direct link in women’s minds as to whether one would seek cervical screening. One woman stated, “…some [women] are scared because there are beliefs that when you are found positive with cancer, it has no cure, so they even fear to go for screening, instead they choose not to know so they are not depressed”. Another felt, “You are never calm when they find you with a problem. You are always worried knowing it has no cure”.

**Differences in perceptions between HIV+ and HIV- women**

Contrary to our expectations, there were no marked differences between HIV+ women and HIV- women as to their perceptions of ICC, but HIV+ women were generally more assertive when describing attitudes and behaviors regarding their health. Hence, HIV+ women felt that their disease made them more aware of their health status and more confident in making decisions regarding their health.

There was some discussion about how HIV+ women might feel if told that they had a positive VIA screening result. One woman stated:
The most depressing thing is when you are already HIV+ then you also told that you have cancer, it feels so bad. We are scared because we don’t know how cancer can be cured, this brings much fear and it feels so bad.
DISCUSSION

Formulating effective health education and communication strategies is of crucial importance for successfully promoting programs of ICC prevention and motivating women diagnosed with a precancerous lesion to remain in follow-up care after treatment. As programs for non-cytological cervical screening expand in low-resource settings, an essential first step toward framing relevant and ethical program promotion interventions is to develop understanding of women’s lay conceptualizations of ICC in each target population.

Findings from this study of Zambian women who accepted a cervical screening invitation have important implications for public health experts and policy makers striving to maximize population benefits and minimize possible adverse consequences of cervical screening programs in Africa. All participants were familiar with “cervical cancer” and provided illness descriptions that overlapped substantially with the medical view. However, five years after inception of the pilot screening program in Lusaka, participants also held a wide range of lay perceptions about the disease, its causes, its consequences, and ways of reducing personal risk. Some of these views were unique; others were shared by women attending cervical screening in other African countries (Gatune & Nyamongo, 2005; Mangoma et al., 2006; van Schalkwyk, et al., 2008; Wood et al., 1997)

As often reported in resource-limited settings where the local health system has long been ill-equipped to provide effective cancer care, most study participants held fatalistic views of ICC. Typically the condition evoked images of pain, imminent death, fear, hopelessness and depression. In this group of women who had all witnessed profound suffering from HIV/AIDS around them, and might even themselves be infected with HIV, ICC was commonly described as the ultimate dreadful illness—a condition “worse than
AIDS” over which women have no control. As with cytological screening in other settings (Agurto et al., 2004; Ogedegbe et al., 2005; Woods et al., 1995), VIA examination was generally not viewed as a screening test and a way to prevent ICC, but rather as a diagnostic procedure that women experiencing symptoms evocative of ICC would consider undergoing, in hopes of being reassured that they do not have the disease.

Not all participants shared this somber representation of ICC, however. Accounts from several women suggested that they were in the process of revising their perceptions of ICC. They questioned the notion that ICC was more serious than other diseases—always leading to death—and seemed to view screening as a means to gain control over cancer. For these women, coming to the screening clinic was considered to be a sign of education and modern thinking. Nonetheless, few women in the sample appeared to grasp the concept of precancerous cervical lesions and few suggested that ICC can be present in the absence of symptoms. Identifying and treating cervical lesions while they are precancerous and asymptomatic is the essential premise upon which cervical screening is based. Furthermore, fear of cancer is known to be associated with self-defeating forms of coping (e.g., “preferring not to know”), delay in seeking information from relatives and friends, and delay in seeking care. Our findings, therefore, underscore the need to uncover barriers and facilitators to the assimilation of information about the natural history of ICC, the mechanism by which screening prevents ICC, and the options that now exist in Lusaka to improve disease outcomes.

In this study, causal attributions were dominated by physical and chemical damage to the female genital organs, by infringing upon the limits of acceptable sexual and relational behaviors, and by meddling with reproductive matters. As in other parts of the world, lay
causal representations partially overlapped with the biomedical causal model. Most women saw a possible causal relationship between having many sexual partners and ICC, explaining the disease as being sexually transmitted. A handful of women specifically attributed the illness to HPV infection. Although women sometimes attributed symptoms of genital infection to ICC and appeared ready to integrate HPV in their existing causal framework, possibly as a new source of trauma to the female genital organ, they never explicitly described HPV infection as being a sexually transmitted infection (STI). Similar findings about the reluctance of using the label of STI when referring to ICC have been reported in various settings (Waller et al., 2005; Wood et al., 1997).

Sexual activity, trauma to the genital organs, and birth control methods are perceived to be dominant causes of ICC in multiple cultures (e.g., Latin American culture; Chavez et al., 1995). In many ways, however, the causal explanations formulated by Zambian women departed from those described in other parts of the world. Salient lay causal mechanisms not commonly expressed by our participants included fate, sin (Wong et al., 2008, Ramanakumar et al., 2005, Ratanasiri et al., 2000) or divine punishment (Ashing-Giwa et al., 2004); carelessness and negligence (Goldman & Risica, 2004) taboo food (Wong et al., 2008; Ratanasiri et al., 2000); and other lifestyle factors such as stress, physical activity, or smoking (Ashing-Giwa et al., 2004; Chavez et al., 1995). Causes cited by other Zambian women but not noted amongst our participants include lack of routine hygiene (Chirwa et al., 2010). Finally, in this study, no woman explicitly indicated that HIV/AIDS is a cause of ICC. Many participants, however, perceived ICC to be the kind of illness that HIV-infected women would get. This finding, also cited by Chirwa and colleagues (2010), is likely to reflect the extremely high prevalence of HIV infection in Lusaka and its effect on the local.
epidemiology of ICC. In comparison, few women made an explicit connection between HIV infection and ICC in previous qualitative studies conducted in Africa, though women elsewhere did cite fear of HIV testing as a barrier to cervical screening (Gatune & Nyamongo, 2005; Mangoma et al., 2006).

Non-medical options proposed by study participants for preventing ICC were in line with their main lay causal attributions, ranging from refraining from inserting anything into the vagina to limiting one’s number of sexual partners. Of note in a community impacted by HIV/AIDS, participants were highly distrustful of condoms and, with the exception of a single respondent, did not see a role for them as a protection against ICC. We did not gather any evidence suggesting that women had awareness of the limited efficacy of condoms for reducing HPV transmission. Instead, women’s attitudes regarding condom use may be reflective of multiple concurrent social, cultural, and economic factors. Large family size as accepted fertility norms, resistance from male partners, and lack of female decision-making power have each been associated with low condom use in sub-Saharan Africa (Grabbe et al., 2009; Stephenson et al., 2007).

People are universally concerned with making sense of their illnesses; that is with finding responses to questions such as “why me?” or “why now?”. “Common sense” lay causal attributions such as viewing any direct aggressions to the cervix as a potential cause of ICC provides women with a range of possible responses. ICC is a highly stigmatized disease in Zambia because of its anatomic location, dire natural course, connections to socially-condemned behaviors, and association with HIV/AIDS. It is also difficult for women to manage a health risk, such as HPV infection, that is acquired from men but does not affect men directly. For many women, acknowledging personal risk status with regard to sexual
transmission is therefore fraught with social consequences. Rationalizing the use of “strong soap”, for instance, as the source of the problem allows them to deflect felt or enacted blame, thus protecting their self-image, social status, and intimate relationships. Similarly, Thomas (2008) has suggested that witchcraft and the idea of being “bewitched” by a husband’s mistress or girlfriend may prove to be more socially acceptable explanations than admission of a highly stigmatized disease and shifts blame away from an individual.

We did not observe marked differences between women’s perceptions of ICC according to their HIV serostatus; however, many HIV-infected women appeared more prone to take responsibility in preventing ICC than other women. By analogy, among women at high genetic risk for a life threatening disease, it is likely that HIV-infected women accepted the idea of being “at risk persons” and by developing skills to manage uncertainty, were thus able to get on with their lives. Whereas these women wrestle with the distressful emotions caused by their personal vulnerability, they might also feel better prepared to receive the news of a cervical lesion compared to the general population.

CONCLUSION

Women in this study had a clear understanding of ICC as a disease, with causal beliefs that overlapped with a biomedical model and with some views not commonly expressed in the literature previously. Women had mixed opinions as to the severity of the disease; though most women equated ICC with death, few women seemed to grasp the highly preventable nature of the disease through screening efforts. A challenge moving forward for care providers will be to put together ICC screening messages that resonate for women in this population.
LIMITATIONS

Our study has several limitations. We did not assess the extent to which the perceptions expressed by any given woman were shared by the other participants in the study. Due to practical constraints, we interviewed a limited number of women conveniently sampled from a single clinic in which VIA cervical screening is performed. This sample of respondents represents only a small proportion of women eligible for screening and does not necessarily reflect the views of the larger population; however, because women were asked to reflect on our questions both personally and as a member of their community, we believe that women conveyed both personal and general perspectives on the topics discussed.

Second, we limited our sample to women presenting to the clinic for screening who may be more inclined to view screening positively. Women actively opposed to screening may possess different attitudes or opinions. Finally, there is the possibility of social desirability bias as women may have given opinions ‘acceptable’ to the research team, though our findings indicate a frank and wide range of opinions on the topics discussed.
ACKNOWLEDGEMENTS

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REFERENCES CITED


Table 1. Sample questions from group discussions and in-depth interviews held with Zambian women eligible for VIA cervical screening.

<table>
<thead>
<tr>
<th>Focus Group Discussion Questions</th>
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<td><strong>Conceptualization of ICC</strong></td>
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</table>
| What is cancer of the mouth of the womb<sup>a</sup>?
| How might a woman know that she has cancer of the mouth of the womb? 
| How might having cancer of the mouth of the womb make a woman feel? 
| In your opinion, is this disease as serious as other diseases that affect women? |
| **Controllability and risk**     |
| What kinds of things might put a woman at risk for cancer of the mouth of the womb? 
| What can a woman do, if anything, to prevent this disease? 
| If a woman thought she had cancer of the mouth of the womb, what would she do? |
| **In-Depth Interview Questions** |
| **Perceived cervical cancer severity and personal susceptibility** |
| Is cancer of the mouth of the womb as serious as other diseases? 
| Are you worried that you may one day have this disease? 
| Do you believe that you can prevent yourself from getting this disease? If so, how? |
| **Characteristics of HIV+ women** |
| Would you say that your HIV status makes you more aware of your health than others? |

<sup>a</sup>Local terminology for the cervix
Table 2. Summary of findings from focus group discussions and in-depth interviews with Zambian women attending a cervical cancer screening program.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Women's Responses(^a)</th>
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<tr>
<td>Perceived physical signs and symptoms of cervical cancer</td>
<td>Bleeding (spontaneous or prolonged periods)</td>
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<td></td>
<td>Vaginal discharge</td>
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<td>Vaginal odor</td>
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<td>Pain during intercourse</td>
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<td>Stomach pain</td>
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<td>Pain throughout the body</td>
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<td>Sores on vagina</td>
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<tr>
<td></td>
<td>General weakness</td>
</tr>
<tr>
<td>Perceived attributes of cervical cancer</td>
<td>Incurable</td>
</tr>
<tr>
<td></td>
<td>Linked to sexual intercourse; HPV</td>
</tr>
<tr>
<td></td>
<td>Do not feel ill at first</td>
</tr>
<tr>
<td></td>
<td>Cancer = HIV</td>
</tr>
<tr>
<td></td>
<td>Highly stigmatized</td>
</tr>
<tr>
<td></td>
<td>transmitted by men</td>
</tr>
<tr>
<td>Perceived causes of cervical cancer</td>
<td>Traditional herbs/medicines</td>
</tr>
<tr>
<td></td>
<td>Multiple sexual partners</td>
</tr>
<tr>
<td></td>
<td>Abrasion to vagina from fingernails/fingers, soaps, Tampons</td>
</tr>
<tr>
<td></td>
<td>Sorcery/witchcraft</td>
</tr>
<tr>
<td></td>
<td>Prolonged birth control measures (pills, condoms)</td>
</tr>
<tr>
<td>Perceived physical effects of cervical cancer</td>
<td>Destroys womb</td>
</tr>
<tr>
<td></td>
<td>Spreads throughout the body</td>
</tr>
<tr>
<td></td>
<td>Cease to have children</td>
</tr>
<tr>
<td>Perceived psychological effects of cervical cancer</td>
<td>Fear of death</td>
</tr>
<tr>
<td></td>
<td>Fear of having cancer</td>
</tr>
<tr>
<td></td>
<td>Hopelessness, worry, anxiety</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
</tr>
</tbody>
</table>

\(^a\)Not all responses shown.
ZAMBIAN WOMEN’S EXPERIENCES WITH CERVICAL CANCER SCREENING AND THE INFLUENCE OF SOCIAL NETWORKS

by

HEATHER WHITE, MOSES SINKALA, CHISHIMBA MULAMBIA, CHIBESA WAMALUME, LINDA MONEYHAM, MIRJAM-COLLETTE KEMPF, DIANE GRIMLEY, MULINDI MWANAHAMUNTU, GROESBECK PARHAM, AND ERIC CHAMOT

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Format adapted for dissertation

47
Background: Invasive cervical cancer (ICC) remains the leading cause of cancer-related morbidity and mortality among women in developing countries. In 2006, the Zambian government launched a visual inspection with acetic acid (VIA) cervical screening program to integrate ICC prevention services within existing primary health care facilities.

Objective: Qualitative methods were employed to: 1) identify women’s primary motivation for cervical screening; 2) document women’s screening preferences; and 3) determine the potential influence of social networks on women’s decision to undergo cervical screening.

Design & Methods: Focus group discussions (FGD) and in-depth interviews (IDI) were conducted with women who accepted screening and care providers. Low-level content analysis was performed to summarize initial categories, followed by a summary of progressively more substantive themes.

Results: Between September, 2009 and July, 2010, a total of 60 women eligible for ICC screening and 21 care providers participated in 8 FGD and 10 IDI. Women presented for screening with variable needs and expectations, prompted by husbands and friends. Women clearly articulated screening preferences. Their acceptance of screening was mediated, in part, by the influence of social networks within the community.

Conclusions: Interventions designed to integrate influential family members and peers into the cervical screening process are warranted.
INTRODUCTION

Invasive cervical cancer (ICC) is the second leading female malignancy worldwide and remains the leading cause of cancer-related morbidity and mortality among women in developing countries. A growing body of evidence has demonstrated that women can be effectively screened and clinically managed for ICC using direct visualization techniques coupled with immediate treatment using cryotherapy or with human papilloma (HPV) DNA testing. Such screening tools can detect pre-malignant cervical abnormalities, with comparable, and in some cases superior, sensitivity and specificity values as compared with conventional cytology.

An urgent need exists for effective ICC screening programs in countries impacted by high HIV rates among women. HIV-infected women are at higher risk for infection with oncogenic strains of HPV and development of cervical intraepithelial neoplasia (CIN) compared to HIV-uninfected women. HIV-infected women also generally exhibit poorer treatment outcomes and higher rates of CIN recurrence compared to HIV negative women, and are therefore subject to increased cervical screening and treatment. In Zambia, age-adjusted ICC incidence rates are 52.8 per 100,000 women. HIV prevalence among women 15-49 years has been reported as 16.1% nationally and 23.1% in the capital of Lusaka. Disproportionately high rates of HPV and CIN have previously been reported among HIV-infected Zambian women. In response, the government of Zambia launched a visual inspection with acetic acid (VIA) cervical screening program in 2006 to integrate ICC prevention services within existing primary health care facilities in Lusaka and, for HIV positive women, link them with concurrent HIV treatment and prevention services.
Despite expanded access to screening, ICC screening coverage worldwide remains low. Estimates indicate approximately 19% coverage for women in low-income countries as compared to 69% of women in developed countries, with wide disparities amongst individual countries \(^{16}\). In studies conducted among African populations to date, women convey limited understanding or appreciation of secondary disease prevention through existing cervical screening programs or HPV vaccine coverage \(^{17-20}\). Given the recent advent of non-cytological ICC screening programs in African settings, understanding women’s screening experiences as well as the influence of social networks on women’s screening behaviors is an important step in ensuring initial cervical screening uptake, and for HIV positive women, retaining women in preventative ICC care. This study employed qualitative methods to: 1) identify women’s primary motivation for cervical screening; 2) document women’s screening preferences; and 3) determine the potential influence of social networks on the decision to undergo cervical screening.
MATERIALS AND METHODS

Study setting

This study was conducted at the government primary health center offering VIA screening in the Kanyama compound, a densely populated, peri-urban settlement of approximately 105,000 inhabitants (2008 estimate) located on the outskirts of the capital city. Unemployment rates are high, and basic sanitary health provisions are lacking. Only two-thirds of Kanyama’s residents have access to clean drinking water.

A single nurse is responsible for daily clinical management of the cervical screening program at Kanyama clinic. Volunteer, lay peer educators (PE) circulate daily throughout the clinic to provide ICC educational talks and invite women for screening. Following informed consent, the nurse takes a brief clinical history and explains screening procedures. Women undergo VIA screening procedures according to international accepted standards. Referral to a gynecology clinic at a local tertiary care center, the University Teaching Hospital (UTH), is recommended for more extensive lesions requiring further evaluation and treatment.

Study Design

A cross-sectional design and qualitative methods were employed to document women’s motivation for cervical screening, their screening preferences, and to determine the potential influence of social networks on the decision to undergo cervical screening. Within-method triangulation using focus group discussions (FGD) and in-depth interviews (IDI) with three separate populations (screening nurses, PEs, and women invited for screening) allowed the research team to compare internal consistency of findings. Ethics committees from the University of Alabama at Birmingham (UAB) and the University of Zambia (UNZA) reviewed and approved the research protocol.
**Study sample**

To be eligible for the study, women had to be 18-49 years and able to undergo VIA cervical screening. In addition, women had to be conversant in either Bemba or Nyanja, two common local languages spoken in the capital. Women who met these criteria were approached by study team members to participate in the study. All women who participated in FGD and IDI had previously attended cervical health education sessions with screening staff, though women were not required to undergo cervical screening to participate in an FGD. Separate FGD were held with screening nurses and peer educators, in accordance with their schedules and availability.

**Focus group discussions**

Women who agreed to take part in the FGD were instructed to return to the clinic and were given date/time reminder cards. Women were grouped according to their stated language preference, Bemba or Nyanja. Two separate FGD were held with HIV positive women, also divided according to language preference. For each group of women (Bemba, Nyanja, HIV+) two FGD were held in order to compare responses from the initial discussions using member checking techniques and to further investigate topics that may have been unresolved or were unclear.

Each discussion was led by an experienced Zambian female facilitator who asked a series of pre-scripted, open-ended questions, encouraged balanced group discussions, and probed respondents. An observer/recorder noted the general atmosphere, group dynamics, and individuals’ non-verbal cues. Discussions were recorded on a digital recorder, with participants’ permission and were conducted in a private room at the clinic. Each FGD included 10-12 women per group and lasted approximately 1.5 hours.
**In-depth interviews**

Following the completion of FGD, the research team gathered to identify recurrent themes and compiled a prioritized list of topics to be explored through IDI. Interview questions were scripted into a semi-structured format and translated into local languages. All women who participated in the FGD were asked to consider participating in an interview. Women who agreed were chosen by the research team using purposeful sampling and given an appointment reminder card to return for the interview. Upon her return, after obtaining consent, each woman was escorted to a private room in the clinic along with an interview moderator and observer/recorder who conducted each of the interviews. All interviews were recorded for later translation and transcription for the purposes of data analysis.

**Data Analysis**

Audio recordings of the discussions and interviews were downloaded onto a password-protected computer and erased from the digital recorders. Observer notes and recordings from FGD and IDI were translated from the local language into English and subsequently transcribed verbatim. Low-level content analysis was used to summarize initial categories, followed by a summary of progressively more substantive themes as agreed upon by the research team. Three investigators (2 U.S.-based and 1 Zambian-based) independently coded the data using QSR Nvivo 8.0© software and developed a group coding schematic. A fourth U.S. investigator familiar with the dataset was used to adjudicate any disagreements amongst the research team as to the coding scheme.
RESULTS

Between September, 2009 and July, 2010, a total of 60 women eligible for ICC screening and 21 care providers (10 nurses, 11 peer educators) participated in 8 FGD and 10 IDI to discuss women’s motivation for screening, individual screening preferences, and the influence of social networks in relation to the decision to undergo cervical screening. Responses elicited from both groups indicate that women are motivated to undergo cervical screening for varying reasons, often prompted by peers or family members. Women clearly articulated their screening preferences. Their decision to undergo ICC screening is, in part, influenced by social networks.

Initial motivation for screening

When asked to articulate their primary motivation for cervical screening, women’s descriptions were comprised of five main categories: 1) to know VIA status (most commonly described as ‘knowing whether she has cervical cancer’ or not; 2) to facilitate or protect future pregnancy; 3) to take advantage of free screening and treatment services; 4) recognized the importance of screening, e.g., that a woman could not know her ICC status unless she is screened; 5) to seek resolution of an existing health problem, including genital symptoms. (See Table 1 for a list of corresponding quotes from women and care providers). Responses implied that women did not understand or fully grasp the concept of precancerous lesions, as most women described a common fear of being ‘told that they had cervical cancer’. Also, while a small proportion of women recognized screening as important even in the absence of symptoms, most agreed that women do not come to the clinic unless prompted by physical pain or illness: ‘If you feel well, you do not come to the clinic’. 

54
Another motivation for screening was that these services were provided free of charge. Women recognized the value of these services, stating that they were ‘expensive elsewhere’ and expressed their appreciation for the free screening program. Of note, women who are found with genital infections are provided with standard course of treatment at no charge and asked to return for screening when the symptoms have resolved. This service was used quite frequently, as nurses stated that some women come solely for resolution of STI symptoms. Respondents generally agreed that free screening and treatment was a strong motivator for screening; however, a minority of women stated that free health services offered at clinics often have an attached stigma of ‘Satanism’ associated with them, making people ‘doubtful’ of such services.

**Contributors to positive experience with the screening process**

When asked which aspects of the screening process women preferred, comfort and supportive attitudes of the screening staff were most commonly cited by respondents. Women described clinic staff as ‘caring’ and ‘hospitable’, offering words of encouragement and taking time to explain procedures in detail. Confidential communication with staff was also highly valued amongst respondents. Nurses, in particular, were viewed as reliable confidantes with whom women could discuss problems related to their ‘private areas’, an important consideration given that ICC was not considered to be a disease which women can discuss openly. Several nurses commented that women often presented for screening in hopes of being treated for an STI, an indication that women likely perceived screening services to be private and confidential. Respondents credited the support offered by staff members, both peer educators and nurses, as facilitating their screening experience,
especially during painful or embarrassing parts of the exam. This exchange between women and providers was viewed as extremely positive by both groups (Table 2, Quotes 1-3).

In relation to the actual screening exam, women positively described the experience of viewing images of their cervix on a screen, perceived to be both a novel experience for women and an informative tool to enhance their understanding of clinical findings (Table 2, Quotes 4-6). Providers agreed that women were motivated by viewing pictures of their cervix; however, in a few cases, women found with extensive lesions were upset by these images. Overall, though, this technology was felt to be a positive addition to women’s cervical screening experience. A few women also said they enjoyed the feeling of vinegar being applied to their cervix, describing this process as ‘cleaning the mouth of the womb’ (Table 2, Quote 9). Nurses confirmed that women reported that they enjoyed this aspect of the exam. One nurse offered an explanation: ‘Maybe it even feels dry because vinegar is a bit acidic, so somehow it gives one a kind of sensation like constricting, so maybe [women] like that feeling’. Finally, women appreciated that the screening exam was performed quickly (Table 2, Quote 10). Given that women typically wait for several hours before being seen by clinic staff, this was cited as a positive practical feature of the cervical screening program at Kanyama.

Directly following the exam, women commonly remarked that they were relieved to receive their screening results (Table 2, Quotes 7-8). While the majority of women associated positive feelings of relief with being told that they were free of cervical abnormalities, it should be noted that others expressed a sense of frustration at being told that they were VIA-negative if they had come seeking resolution of an ongoing health problem. This scenario is described by a nurse: ‘When you say she is negative she will still insist to say, ‘What is this
that I am feeling because I thought that when I come here I would be found with something’.

**Contributors to negative experience with the screening process**

When asked about which aspects of cervical screening women liked least, respondents cited three categories of negative experiences directly related to screening procedures: 1) women objected to having to undress for the exam; 2) women were afraid of the pain caused by the vaginal speculum, referred to as a *chishimbi* or ‘steel rod’; 3) women believed that they could contract diseases, e.g., HIV, from unsterilized screening instruments. Nurses confirmed that they spent considerable time explaining to women how instruments are sterilized daily. Women objected to undressing both for cultural and pragmatic reasons; that is, Zambian cultural norms do not permit women to be seen nude by anyone but her husband, unless during childbirth (Table 3, Quote 1). Additionally, nurses stated that women unaware of having to undress for screening simply refused on the grounds that they needed to bathe before doing so (Table 3, Quote 2).

The most commonly cited negative aspect of screening was attributed to women’s fear of the vaginal speculum or “*chishimbi*”. Women were afraid of the pain when the speculum was inserted during the pelvic exam, based on stories heard within the community (Table 3, Quotes 3 and 6). Following the exam, women often stated that the pain of the speculum described by other women in the community was grossly exaggerated: ‘Some say that the *chishimbi* used in the exam pains. This is a lie’. Other reasons given for why women were afraid of the speculum were associated with a minority of women who believed the speculum was used to both remove and re-insert the cervix after it had been cleaned by a nurse (Table 3, Quote 4). Finally, women perceived that the clinic was understaffed and expressed their concern (Table 3, Quote 11) at the minimal staffing.
Additional negative experiences elicited by our respondents not directly related to the screening exam itself were offered. Each of these had serious implications for women that could preclude screening. These included a fear of testing for HIV and cancer-related stigma. (Table 3, Quotes 9-10). Women stated that ICC is closely associated with HIV/AIDS in the community, so women were hesitant to present for cervical screening for fear of being tested for HIV (Table 3, Quote 9). Similarly, women did not want to be seen at a ‘cancer clinic’ because, as some suggested, ‘…people think when you come for screening then you are HIV positive’. Others believed that stigma would be directly related to cancer itself: ‘when [others] just see you at the cancer clinic they start saying, ‘we saw her at the cancer clinic’ and they start stigmatizing you’.

**Interpersonal communication regarding cervical cancer**

In this study, we enquired about social norms and interpersonal communication regarding ICC. We also sought to identify those persons who might have influenced the decision of women to undergo VIA cervical screening. When asked whether women feel comfortable openly discussing this disease, respondents replied no, stating that ICC deals with ‘private areas’ of the body. The disease has, until recently, been extremely stigmatized in the general population: ‘Before everybody was scared even when you have relatives who have cervical cancer, it was just like someone who has HIV.’ When asked to whom, if anyone, a woman might confide if she felt that she may have this disease, women said that husbands, other family members, friends, clinic staff, and members of the church could all be considered potential confidantes. Friends were the most commonly described confidantes, though women had mixed views as to whether their friends could be trusted with personal information: ‘With us women when we quarrel, we even talk about confidential information,
and thus most women hesitate to tell their friends’. Because of fears of gossip, clinic staff members were viewed as a confidential source for women. Women stated that the most important quality in a potential confidante is that he or she be considered trustworthy.

**Influence of peers on decision to undergo screening**

Women were asked whether they were influenced by others concerning their decision to undergo screening. Not surprisingly, coming from women who had made the decision to be screened, most participants indicated having been encouraged rather than discouraged by members of their social networks, most often close friends and husbands (Table 4, Quotes 1-3). Seeking approval or permission for screening from a spouse was a source of debate among our respondents. On one hand, women described the need to seek permission as precautionary, e.g., in the event of screening positive and needing treatment: ‘After the screening, if you are found with the lesion and you are treated, your husband will understand if he gave you permission’. Others felt that approval from their husbands was a means of garnering emotional support.

A premise of this study is that women who undergo screening might share their positive and negative screening experiences, thereby influencing a woman’s decision to undergo cervical screening. Our results indicated both a positive and negative influence from peers. In a positive sense, several women who underwent screening described a sense of responsibility to act as screening role models; that is, to impart their experience to other women in the community, to convey the benefits of screening, and to dispel rumors related to the screening process. Care providers confirmed that women who had undergone screening were likely to encourage others because they had “become knowledgeable” about the process (Table 4, Quotes 4-5). In a negative sense, both providers and women felt that stories of
women’s negative screening experiences were likely to impart negative perceptions of cervical screening throughout the community and thereby influence a woman’s initial decision to come for cervical screening (Table 4, Quotes 6-8). Women believed rumors and negative stories about cervical screening to be widespread in the community.
DISCUSSION

The present study sought to understand motivation, preferences, and social influences on the decision for cervical screening among Zambian women who accepted VIA cervical screening offered at a peri-urban primary health center. Our results indicate that women presented for screening with variable needs and expectations, often prompted by friends and family members. Women clearly articulated their screening preferences. Women’s acceptance of screening is influenced, in part, by social networks within the community.

The majority of women in this study sought cervical screening to find out whether they had ICC or not, indicating that most of the respondents did not understand the objective of the screening program, e.g., to identify precancerous abnormalities at a treatable stage. While this has been reported in other African cervical screening programs, it remains a critical barrier to screening uptake and an ever-present challenge to care providers to convey the highly preventable nature of this disease through secondary prevention efforts.

Some women presented for cervical screening because of reproductive health concerns, e.g., to be reassured of their future ability to bear children. Loss of fertility as grounds for divorce has been cited as a major concern among African women; therefore, it is unsurprising that a subgroup of women sought cervical screening solely to be reassured about future pregnancies. Other women presented for screening to seek diagnosis for persistent or unresolved symptoms and became frustrated when told that they were screen-negative. By presenting with health problems or conditions beyond the scope of program, women’s perceptions of program effectiveness may be misaligned due to unrealistic expectations and potentially lead to negative impressions of the program.
This study sought to document women’s experiences with the screening process. Women in this population had extremely positive perceptions of health providers associated with the screening program. Our data suggest that a number of measures were taken to ensure that women had a positive experience of care by engaging with the patient throughout the screening process. Lay peer educators, who have proven to be successful in increasing cervical screening uptake among minority U.S. populations, were viewed as informative and supportive prior to screening. Nurses were seen as professional confidantes with whom women could express their health concerns freely in a private setting. These experiences contrast sharply with other African studies in which women felt intimidated, rushed, or unwelcomed by care providers. Trust in care providers has been cited as one of the most influential factors in a woman’s decision to undergo cervical screening.

In relation to the actual exam, women conveyed both positive and negative opinions. On one hand, having the opportunity to see one’s cervix was a clear motivating factor among respondents. Care providers viewed digital cervicography as a useful education tool, while women appreciated the novelty of viewing these images. Given the additional practical benefit of using enhanced images for quality control and diagnostic purposes, cervicography may be a successful feature of cervical screening to be emphasized in future screening promotion messages. Negative aspects of the screening exam included women’s discomfort from having their genitals exposed during the exam, viewed as a cultural taboo among our respondents and cited elsewhere as a barrier to cervical screening. Women objected to the use of the vaginal speculum for fear of pain and a belief that it was used to remove and clean the cervix. Also, women associated the speculum with potential
transmission of STIs, including HIV, a significant concern for screening participants in a
country with high HIV disease prevalence.

It is clear from our data that women communicate their screening experiences with
others. The opinions that they share with other women may influence their perception of
need for screening, serving as ‘predisposing factors’ \(^{34}\). Likewise, our evidence suggests that
many women, after being screened, may become role models for other women in their social
networks; however, it is crucial to pay attention to women’s experiences with the screening
process as only women who evaluate their experience positively are likely to play this role.

Women’s responses indicated that the decision to undergo screening was also
influenced by social networks, mainly from family members (spouses/boyfriends) and close
friends. A proportion of women sought their husband’s explicit permission for cervical
screening, signaling a need to create screening promotion messages and cervical educational
materials targeted to women’s partners. While few attempts have been made yet to formally
influence or include a women’s family into cervical screening promotion efforts in Zambia,
individual screening programs should determine the extent to which women’s decisions are
influenced by their social networks, and where appropriate, develop effective communication
messages to educate influential individuals regarding the risks and benefits of cervical
screening and treatment.

Our study data indicate that women seek cervical screening for heterogeneous reasons
and expectations that are partially mediated by the influence of peers who have already
undergone screening. Care providers are valuable resources as professional confidantes.
Understanding women’s motivation for cervical screening, their preferences, and influential
members of their social networks allows providers to adapt or refine screening promotion messages for women and the extended community.
LIMITATIONS

It is necessary to detail the limitations of the study. First, the information obtained was generated by self-report using a convenient sampling method. Our sample represents only a small proportion of women eligible for cervical screening and does not necessarily reflect the views of the larger population. Due to financial and logistical constraints, we interviewed women who presented to the clinic who may have more positive views of cervical screening than in the general community. In addition, we interviewed women in only one of fifteen government clinics in which screening is offered, so it is likely that we would have encountered different perspectives operating in multiple clinics throughout neighborhoods of Lusaka. To offset these limitations, however, we interviewed care providers from several screening clinics to obtain a broader view of the entire screening program.
ACKNOWLEDGEMENTS

The authors wish to thank participants, nurses, and peer educators from Kanyama Health Centre and other screening clinics who participated in this study. We also wish to thank our team of research assistants and data managers at the Institute for Economic and Social Research at the University of Zambia, and the Centre for Infectious Diseases in Zambia for their support on behalf of this study. Finally, we are grateful to the Lusaka District Health Management Team, under the direction of the Zambian Ministry of Health, for their support of this study. Financial support for this study was provided by grant no. 1 R21 CA124336 from the National Cancer Institute/National Institutes of Health, Bethesda, MD, USA.
REFERENCES


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<tr>
<th>Number</th>
<th>Quote</th>
<th>Theme</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Women what to know if they have cervical cancer.</td>
<td>Knowledge of ICC status</td>
<td>Woman</td>
</tr>
<tr>
<td>2.</td>
<td>You will be able to know if you have the lesions that cause cancer or not.</td>
<td>Knowledge of ICC status</td>
<td>Woman</td>
</tr>
<tr>
<td>3.</td>
<td>I came for tests because I want to have children.</td>
<td>Family planning</td>
<td>Woman</td>
</tr>
<tr>
<td>4.</td>
<td>It made me happy with the help they gave. It was absolutely free.</td>
<td>Free provision of services</td>
<td>Woman</td>
</tr>
<tr>
<td>5.</td>
<td>You cannot know unless you are screened.</td>
<td>Importance of screening</td>
<td>Woman</td>
</tr>
<tr>
<td>6.</td>
<td>Even when you’re not sick, you have to go for screening because you cannot know what is inside your body.</td>
<td>Importance of screening</td>
<td>Nurse</td>
</tr>
<tr>
<td>7.</td>
<td>They will come because they have an STI and feel we are the right people who will not disclose to other people.</td>
<td>Resolution of existing problem</td>
<td>Woman</td>
</tr>
<tr>
<td>8.</td>
<td>I wanted to know the reason why my health was deteriorating.</td>
<td>Resolution of existing problem</td>
<td>Woman</td>
</tr>
<tr>
<td>9.</td>
<td>When one is sick and does not know what is wrong with her, [she] is hoping they tell her she has cancer, and that’s why she is sick.</td>
<td>Resolution of existing problem</td>
<td>Woman</td>
</tr>
</tbody>
</table>
Table 2. Quotes from focus group discussions and interviews with care providers and women on positive contributors to the cervical screening experience.

<table>
<thead>
<tr>
<th>Number</th>
<th>Quote</th>
<th>Theme</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>We feel free and comfortable when we come here, and this encourages us a lot.</td>
<td>Comfort from providers</td>
<td>Woman</td>
</tr>
<tr>
<td>2.</td>
<td>They feel more comfortable to talk to us because they know that whatever we do is confidential.</td>
<td>Confidentiality of exam</td>
<td>Nurse</td>
</tr>
<tr>
<td>3.</td>
<td>When the nurse told me I was found with a problem I was afraid, but the nurse calmed me and encouraged me.</td>
<td>Encouragement of providers</td>
<td>Woman</td>
</tr>
<tr>
<td>4.</td>
<td>I loved it when I was shown the picture of my womb and how it is.</td>
<td>Digital cervicography</td>
<td>Woman</td>
</tr>
<tr>
<td>5.</td>
<td>The fact that they can see their cervix which they have never seen really excites women.</td>
<td>Digital cervicography</td>
<td>Nurse</td>
</tr>
<tr>
<td>6.</td>
<td>The nurse showed me how my womb was. I was happy because I know the problem I have.</td>
<td>Digital cervicography</td>
<td>Woman</td>
</tr>
<tr>
<td>7.</td>
<td>Knowing my [screening] results. You are relieved once you know.</td>
<td>Relief of screening result</td>
<td>Woman</td>
</tr>
<tr>
<td>8.</td>
<td>Also me, [after] knowing my results I was happy.</td>
<td>Relief of screening result</td>
<td>Woman</td>
</tr>
<tr>
<td>9.</td>
<td>[Women] know that the vinegar applied on their cervix helps to clean it.</td>
<td>Effects of vinegar</td>
<td>Woman</td>
</tr>
<tr>
<td>10.</td>
<td>At Kanyama clinic, they do not take too much time to do their work.</td>
<td>Screening efficient</td>
<td>Woman</td>
</tr>
</tbody>
</table>
Table 3. Quotes from focus group discussions and interviews with care providers and women on negative contributors to the screening experience.

<table>
<thead>
<tr>
<th>Number</th>
<th>Quote</th>
<th>Theme</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>It is not acceptable for someone to see your vagina except for when you’re giving birth.</td>
<td>Undressing</td>
<td>Woman</td>
</tr>
<tr>
<td>2.</td>
<td>Some say they need a bath before being examined. They think they are not clean enough to open their private parts.</td>
<td>Undressing</td>
<td>Nurse</td>
</tr>
<tr>
<td>3.</td>
<td>[Women] do not want pieces of metal inserted in the vagina.</td>
<td>Fear of speculum/pain</td>
<td>Peer educator</td>
</tr>
<tr>
<td>4.</td>
<td>The uterus is pulled out cleaned and treated and put back inside.</td>
<td>Fear of speculum/procedure</td>
<td>Woman</td>
</tr>
<tr>
<td>5.</td>
<td>Even just hearing the sound of the instrument [a woman] will jump.</td>
<td>Fear of speculum/procedure</td>
<td>Nurse</td>
</tr>
<tr>
<td>6.</td>
<td>The chisimbi (steel rod) when inserting in the vagina pains.</td>
<td>Fear of speculum/pain</td>
<td>Woman</td>
</tr>
<tr>
<td>7.</td>
<td>People say they use the same instruments on all women.</td>
<td>Infection from instruments</td>
<td>Woman</td>
</tr>
<tr>
<td>8.</td>
<td>The object that they push into the vagina, it brings other infections if it’s not well cleaned.</td>
<td>Infection from instruments</td>
<td>Woman</td>
</tr>
<tr>
<td>9.</td>
<td>Other women in the community they do not know that they screen for cancer here, they think that they only do HIV test.</td>
<td>Fear of HIV testing</td>
<td>Woman</td>
</tr>
<tr>
<td>10.</td>
<td>[Women] don’t want to be seen at the cancer clinic. They want it to be a secret.</td>
<td>Stigma</td>
<td>Peer educator</td>
</tr>
<tr>
<td>11.</td>
<td>There is only one nurse to do the screening, there are times when she is not there.</td>
<td>Understaffing</td>
<td>Woman</td>
</tr>
</tbody>
</table>
Table 4. Quotes from focus group discussions and interviews with providers and women regarding influence of social network on decision to undergo cervical screening.

<table>
<thead>
<tr>
<th>Number</th>
<th>Quote</th>
<th>Theme</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>For me, I was constantly ill so my friends encouraged me to come for screening.</td>
<td>Encouragement from friends</td>
<td>Woman</td>
</tr>
<tr>
<td>2.</td>
<td>Most [women] are coming because they have a complaint which they told a friend and the friend told them to try the cervical cancer clinic.</td>
<td>Encouragement from friends</td>
<td>Nurses</td>
</tr>
<tr>
<td>3.</td>
<td>I took the [screening] pamphlet to my husband, and he told me to come for screening.</td>
<td>Encouragement from husbands</td>
<td>Woman</td>
</tr>
<tr>
<td>4.</td>
<td>I was motivated [after screening], and I wanted to encourage my friends as an example.</td>
<td>Positive influence of screening experiences</td>
<td>Nurse</td>
</tr>
<tr>
<td>5.</td>
<td>It is important for us women to encourage one another to come for screening.</td>
<td>Positive influence of screening experiences</td>
<td>Woman</td>
</tr>
<tr>
<td>6.</td>
<td>Patients tell their friends that the steel [speculum] is very big and is put as if it can kill a person.</td>
<td>Negative influence of screening experiences</td>
<td>Woman</td>
</tr>
<tr>
<td>7.</td>
<td>Most women are scared to come because of the stories they hear from those who have been here before. They are very discouraging.</td>
<td>Negative influence of screening experiences</td>
<td>Peer Educator</td>
</tr>
<tr>
<td>8.</td>
<td>To be honest, there is so much that has been said in our compounds with regard to screening. It puts so much fear in most of us that you think twice before coming.</td>
<td>Negative influence of screening experiences</td>
<td>Woman</td>
</tr>
</tbody>
</table>
SUMMARY AND CONCLUSIONS

Overall Conclusions

Invasive cervical cancer is a disease that largely impacts women in resource-poor settings. In Zambia, ICC incidence is among the highest worldwide, coupled with elevated HIV background prevalence rates among women. Long-term retention in cervical preventative care is essential for HIV positive women given their increased risk for HPV acquisition and progression to ICC. To undergo cervical screening, women must perceive some level of personal disease risk and susceptibility and acknowledge that screening may detect sub-clinical disease. A challenge to care providers and program managers moving forward will be to emphasize the highly preventable nature of this disease and frame screening promotion messages that are both educational and are in line with women’s conceptualization of the disease. Further, by pinpointing women’s motivation for ICC screening, understanding their screening preferences, and gauging the extent to which social networks influence women’s decision to be screened, care providers can formulate tailored messages that highlight women’s preferences while also clarifying screening objectives, risks, and benefits. As ICC screening coverage expands in developing countries, a systematic effort will need to be undertaken to understand the specific needs and concerns of local populations. Formal attempts to engage influential members of women’s social networks into the screening process, including spouses and peer ‘role models’, are areas of research to be explored.
GENERAL LIST OF REFERENCES


78
APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL FORM
Protection of Human Subjects
Assurance Identification/IRB Certification/Declaration of Exemption
(Common Rule)

Policy: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (56 FR 28003, June 16, 1991) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate institutional review board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.

1. Request Type
   [ ] ORIGINAL
   [ ] GRANT
   [ ] CONTRACT
   [ ] FELLOWSHIP
   [ ] CONTINUATION
   [ ] COOPERATIVE AGREEMENT
   [ ] EXEMPTION
   [ ] OTHER

3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.

4. Title of Application or Activity

5. Name of Principal Investigator, Program Director, Fellow, or Other

6. Assurance Status of this Project
   [ ] This Assurance, on file with Department of Health and Human Services, covers this activity:
     Assurance Identification No. FWA00005960, the expiration date 09/29/2013

   [ ] This Assurance, on file with [agency/dept], covers this activity:
     Assurance No. ______, the expiration date ______

   [ ] No assurance has been filed for this institution. This institution declares that ______

7. Certification of IRB Review
   [ ] This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations.

   b. Expedited Review on (date) ______

   [ ] This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

   Protocol subject to Annual continuing review. Patient Reported Outcomes of Cervical Cancer Screening in HIV+ Women in Zambia

   IRS Approval Issued: 12/2011

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.

10. Name and Address of Institution

11. Phone No. (with area code) (205) 934-3789

12. Fax No. (with area code) (205) 934-1301

13. Email smoore@uab.edu

14. Name of Official

15. Title

16. Signature:

17. Date

OMB No. 0990-0263
Approved for use through 1/31/2012

Public reporting burden for this collection of information is estimated to average less than an hour per response. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Transmittal of this burden statement or any other aspect of this collection of information, including suggestions for reducing this burden to OS Reports Clearance Officer, Office of Information and Regulatory Affairs, U.S. Department of Health and Human Services, 200 Independence Ave. SW, Washington, DC 20201. Do not return the completed form to this address.
Project Revision/Amendment Form

(Please Type: In MS Word, highlight the shaded, underlined box and replace with your text; double-click checkboxes to check/uncheck.)

- Federal regulations require IRB approval before implementing proposed changes.
- Change means any change, in content or form, to the protocol, consent form, or any supportive materials (such as the Investigator's Brochure, questionnaires, surveys, advertisements, etc.).
- Complete this form and attach the changed research documents.

Today's Date: 8/3/09

1. Contact Information

Principal Investigator's Name: Eric Chamot BlazerID: echamot E-mail: echamot@uab.edu
Contact Person's Name: Rachelle Mainard BlazerID: rmainard E-mail: rmainard@uab.edu
Telephone: 4-7155 Fax: 6-6746
Campus Address: RPHB 533B

2. Protocol Identification

Protocol Title: Patient-Reported Outcomes of Cervical Cancer Screening in HIV+ Women
IRB Protocol Number: F080311008

Current Status of Project (check only one):

- Study has not yet begun (No participants entered)
- Closed to participant enrollment (remains active)
- Number of participants on therapy/intervention: __
- Number of participants in long-term follow-up only: __
- Total number of participants enrolled: __

This submission changes the status of this study in the following manner (check all that apply):

- Protocol Revision
- Protocol Amendment
- Study Closed to participant entry
- Study Closure
- Enrolment temporarily suspended by sponsor
- Change in protocol personnel
- Other, (specify) We are adding Heather White to the list of personnel on this study. Ms. White is currently pursuing a DrPH degree in the department of Epidemiology and will be working on this study for her dissertation. She will be engaged in study-related training, data management, data analysis, and manuscript writing for this protocol. Please attach human subjects training requirements for Ms. White.

3. Reason for change

Briefly describe, and explain the reason for, the change. If normal, healthy controls are included, describe in detail how this change will affect those participants.
Include a copy of the protocol and any other documents affected by this change (e.g., consent form, questionnaire) with all the changes highlighted.

4. Does this change revise or add a genetic or storage of samples component?

- Yes [x] No

If yes, please see the Guidebook to assist you in revising or preparing your submission, or call the IRB office at 934-3789.

5. Does the change affect subject participation (e.g., procedures, risks, costs, location of services, etc.)?

- Yes [x] No

If yes, Fiscal Approval Process (FAP)-designated units complete a FAP submission and send to fap@uab.edu. For more on the UAB FAP, see www.uab.edu/ohr.

6. Does the change affect the consent document(s)?

- Yes [x] No

If yes, briefly discuss the changes.
Include the revised consent document with the changes highlighted.
Will any participants need to be reconsented as a result of the changes?
- Yes [x] No
If yes, when will participants be reconsented? __

Signature of Principal Investigator ___________ Date 08/13/2003

☐ Approved Expedited ☐ To Convened IRB ______

Chair or Vice-Chair Date Aug 10, 2003

224 - project-revision-amendment
10/15/08