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Investigating Barriers to Early Cancer Detection for Rural Indian Women: A Qualitative Analysis of Cancer Outreach in Dehradun, Uttarakhand

Blair Burnett

SIT Study Abroad, beburnet@live.unc.edu

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**INVESTIGATING BARRIERS TO EARLY CANCER DETECTION FOR RURAL
INDIAN WOMEN: A QUALITATIVE ANALYSIS OF CANCER OUTREACH IN
DEHRADUN, UTTARAKHAND**

Blair Burnett

Dr. Azim Khan, SIT Academic Director

Dr. Rajeev Prasad Bijalwan, ISP Advisor, Rural Development Institute

SIT Study Abroad

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Abstract

This study examines barriers to early detection for women's specific cancers in rural India in and around Dehradun, Uttarakhand, within the framework of existing health outreach programs from tertiary hospitals in the state. The burden of cancer mortality within India is disproportionately affecting women living in rural populations considering the current health education and health care infrastructure in place. Barriers of knowledge, access to knowledge, economic condition, geography, and cultural norms are all examined within this study in the context of early cancer detection. National Indian health policy is currently framed to address the burden of cancer within India; however, early cancer detection for rural Indian women has not been adequately addressed with various policy changes over the last few decades considered continually increasing incidence and mortality rates. Therefore, this study, in examination of these barriers to early detection, seeks to provide a framework for future health policy in adequately addressing and successfully reducing cancer mortality rates for rural women within India.

Keywords: cancer, women's cancers, early cancer detection, cancer screening, Uttarakhand

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IMPORTANT ABBREVIATIONS AND TERMS

ASHA – Accredited Social Health Activist

BSE – breast self examination

CHC – Community Health Center

CRI – Cancer Research Institute

DCCP – District Cancer Control Programme

ECDC – Early Cancer Detection Centers

FNAC – fine needle aspiration cytology

HIHT – Himalayan Institute Hospital Trust

ICMR – Indian Council of Medical Research

MDCCP – Modified District Cancer Control Programme

MOHFW – Ministry of Health & Family Welfare

NCCP – National Cancer Control Programme

NPCDCS (first reference) – National Program for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke

NPCDCS (second reference) – National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS)

NGO – non-governmental organizations

PHC – Primary Health Center

RCC – Regional Cancer Centers

RDI – Rural Development Institute

VIA – visual inspection with acetic acid

WHO – World Health Organization

1 – INTRODUCTION

Cancer is a non-communicable disease that is non-discriminatory, affecting both men and women on a global scale. Throughout India at any given time, it is estimated that over 2.5 million individuals are battling cancer. Public health initiatives in India related to non-communicable diseases (NCD) never focus just on cancer, and instead often stress for lifestyle education in eradicating the obesity epidemic, arthritis, or chronic respiratory diseases. However, in India, a country not yet defined as developed nor any longer referred to as developing, cancer incidence has become a growing health concern, with eight million new diagnoses and 5.5 million deaths annually (Das & Patro, 2010). Cancer is now one of the top three causes of death within India, but 30 years ago, cancer was only beginning to be addressed in national health policy (Badwe et al., 2014).

Within India, cancer deaths account for about seven percent of deaths every year (Selvaraj et al., 2014). Dr. Barshi, a physician at the Rural Development Institute, Himalayan Hospital Institute (HIHT), in Dehradun estimates that 70 percent of NCD deaths every year can be attributed to some type of cancer (Dr. Barshi, personal interview, 14 April 2015). The country's national cancer registry program shows that the most prevalent cancers are oral, lung, esophagus and stomach among men, and breast, cervix, and oral cancers among women. Though cancer is non-discriminatory, there exist many disparities within Indian society in cancer incidence mortality rates based on gender and geographic location. Annual death from cancer in India is higher for women than men, at a ratio of 60 percent to 40 percent, respectively (Das & Patro, 2010). Furthermore, 70 percent of India's population resides in a rural setting, far away from the tertiary-level hospitals and institutes providing cancer screening, education, or

treatment. Understanding the geographic and social barriers to cancer detection is the first step in creating effective outreach programs to engage with rural Indian women (Selvaraj et al., 2014).

To address the growing concern of cancer, the Government of India created the National Cancer Control Program (NCCP) in 1971. Following continued increased incidence rates, in 1984, 21 Regional Cancer Centers (RCC) were created to address the issues of cancer prevention and detection for all individuals requiring education and treatment of cancer throughout India. However, with 21 RCCs serving all 676 districts, the undertaking of this government initiative failed to recognize the needs of rural populations when it came to the rising concern of different types of cancer in smaller and more remote communities. The majority of the population in India lives in a rural setting, and each of the 21 RCC established are currently located in large-scale cities throughout the country (Das & Patro, 2010). This study hopes to discuss and investigate known barriers to early detection of women's specific cancers in rural Uttarakhand within the context of current community outreach programs in place working to address the disease burden of cancer for women in India.

1.1 - Rural Indian Women and Cancer

Women are suffering and dying from cancer at a greater rate in India due to social and societal barriers. Both men and women feel the repercussions of lack of effective national preventative health policies for early cancer detection in India. However, the gendered differences in opportunity to leave the home for medical treatment without accompaniment affects the ability to access medical facilities for women seeking cancer education and treatment, especially those from rural populations (Das & Patro, 2010).

Of all women specific cancers, breast, cervical, ovarian and uterine cancers are the ones most affecting the lives of rural Indian women. Those most prevalent in India include breast and cervical cancer, which are reason for approximately 25 percent of the cancer deaths annually (Das & Patro, 2010). Cervical cancer is internationally regarded as one of the most preventable cancers yet; over 1.2 million cases are diagnosed within the country every year, and account for about 15 percent of new cancer diagnoses (Asthana et al., 2014). Incidence of breast cancer is just as high for Indian women as second only to incidence of cervical cancer, where it is estimated that about 800,000 new cases are diagnosed annually (Matthew et al., 2008). However, incidence rates are not as alarming as the breakdown of stage diagnoses for Indian women with cancer. Every year, of the new cancer diagnoses that occur, 50-70 percent of these diagnoses are late stage. As hard as cancer is to manage and beat with an early stage diagnosis, the majority of women throughout India with cancer are being diagnosed in stage III or stage IV when cancer has spread and there is very little to do to eradicate the disease (Das & Patro, 2010).

Acknowledging the geographical barrier of cancer care and detection for rural populations is proof that previous government policy has done little to lessen the burden of cancer for the majority of Indian citizens, females residing in remote communities. Despite the revisions of the country's cancer control program over the last few decades, no organized screening or awareness program for any of the cancers commonly affecting men and women exists throughout India (Das & Patro, 2010).

India's NCCP has undergone three major revisions since the policies inception in 1974. The successes to come from the NCCP have been regarded as successes in "sickness management rather than regular health check up," and the warning signs and symptoms of cancer are not widely discussed at a rural community level. Until significant changes are implemented

to favor early detection in tackling the burden of cancer, external review of the NCCP revisions have stated that prevalence rates for women's specific cancers, specifically in rural populations, will continue to rise (Das & Patro, 2010).

1.2 – Field Study Question & Purpose

Due to the national cancer burden present for rural Indian women, the time for evaluation and analysis of cancer outreach programs to rural communities is imperative. The question that this study seeks to explore is: What are the barriers rural Indian women face in and around Dehradun, Uttarakhand, in early cancer detection? Additionally, what work is the community outreach program through HIHT, Dehradun, doing to address the knowledge gap present for rural populations about cancer as a barrier for early screening and detection?

This study examines barriers in cancer care for rural Indian populations while focusing on understanding the low successes of early cancer detection for rural Indian women despite the development of the NCCP. At its' core, this study investigates the known knowledge gap present for rural Indian populations about cancer, and identifies additional barriers present that outreach programs need to address to successfully implement sustainable initiatives for early cancer detection in the future.

1.3 – Field Study Methodology

This independent study project utilized semi-structured interviews to analyze barriers of early cancer detection for women's specific cancers within rural India. Nine rural Indian women in the village of Patti Misras, 40 kilometers from Dehradun, Uttarakhand, were interviewed for this study. In addition, the second prong of this study sought to analyze these barriers to early

cancer detection for women in rural India through interviews with physicians involved with cancer detection outreach programs and non-governmental organization affiliates as well. This independent study project was conducted in and around Dehradun, the capital city of Uttarakhand and home to one of the best cancer research institutes in India.

The first prong of this study sought to investigate the many cultural, economic, social, and societal barriers present for rural Indian women in accessing early cancer detection. To examine these barriers, interviews were conducted in a village not currently being served by an outreach health program with any type of women's health or cancer focus. Patti Misras and surrounding villages do not have access to a nearby CHC, PHC, or district hospital. In 2000, the Indian Global Health & Education Society worked to fund the running of a health clinic, open 5 days a week, located in Patti village. This clinic employs one doctor, one pharmacist, and eight rotating female health volunteers.

To obtain the most accurate depiction of barriers to cancer detection for women in rural India, a wide-ranging group of women within Patti Misras village were interviewed, varying in age, marital status, geographic origin, socioeconomic status, and occupations. Women were asked to be interviewed individually to ensure control and reduce any confounding factors on their responses. However, with five of the nine interviews of women in Patti Misras village, the women had someone in their family present, either a mother-in-law, husband, sister, or child. In these situations, the relative of the woman being interviewed served as a bystander during the interview process, not answering questions but still present physically. Additionally, healthcare providers at the clinic were also individually interviewed to gain the most comprehensive perspective in the studies' qualitative analysis in barriers to early cancer detection for women.

Four health volunteers and two doctors from Patti were interviewed on behalf of the provider perspective for this qualitative analysis.

Two different questionnaires were developed for this phase of the study: one to analyze the barriers of early cancer detection from the view point of a rural woman living in Patti Misras village and the other for the view point of a seasoned healthcare provider working with the local population. The questionnaires sought to explore the most prevalent barriers women face with early cancer detection: including but not limited to, knowledge, stigma, gender inequality, affordability, and accessibility. In addition, the questionnaire used in interviews with rural women sought to gain an understanding of the knowledge present among women in Patti Misras village about basics of women's specific cancers, such as symptoms, methods of screening, and general cancer knowledge. The questionnaire used for healthcare providers within Patti Misras village still focused on the perceived barriers rural women face with early detection of women's specific cancers. However, this questionnaire sought to also analyze the structure and function of the health clinic within Patti Misras and evaluate the health education currently present surrounding any and all cancers.

The second prong of this study focused on analyzing barriers to early cancer detection for rural Indian women within NGOs, tertiary centers, and cancer institutes located near Dehradun, Uttarakhand. The physicians interviewed were chosen based upon previous work or research they have done with outreach in relation to screening programs for women's specific cancers in rural communities. This background outside of the rural communities sought to inform the study on a broader policy level with the ability to evaluate the government policy in place from revisions of the NCCP as well as the structure of cancer detection programs in rural India. This questionnaire was developed with the audience of healthcare providers in mind to focus on

understanding what certain hospitals and NGOs have done to implement outreach screening in rural India.

To protect the confidentiality of this study's participants, all names and identifying titles of women, health volunteers, and doctors interviewed have been omitted and replaced with pseudonyms throughout the contents of this paper. Verbal consent was taken before beginning any and all interviews conducted. Those interviews conducted in Hindi were translated with help of a healthcare provider within Patti Misras village. The questionnaires developed from both prongs of this study merely served as interview guides to ensure the most comprehensive conversation was achieved with the ability ask follow-up questions for greater clarity. All interview guides for rural women, healthcare providers, and outreach program affiliates are presented in this study in Appendix 1, page 40.

2 – Overview of cancer detection outreach in rural India

2.1 – History of cancer control in India

- ***1974:*** National Cancer Control Programme initiated with specific focus to better equip existing institutes in detecting and treating cancer throughout India.
- ***1984:*** Policy focus within the NCCP was revised to reflect investment in prevention and early detection, rather than simply treatment.
- ***1990:*** District Cancer Control Programme (DCCP) began in specific districts
- ***2001:*** Implementation of Modified District Cancer Control Programme (MDCCP) with rural community focus.
- ***2005:*** MDCCP expanded after external evaluation of NCCP conducted by National Institute of Health & Family Welfare (NIHFW) in 2004

Though the National Cancer Control Program (NCCP) was created in 1974 to address India's growing public health concern of cancer, multiple revisions to the program have yet to address adequate cancer education, detection measures, and treatment throughout each state and district. The latest revisions of the NCCP occurred with the effects of the launch of the Modified

District Cancer Control Programme (MDCCP) in 2001. This policy was altered to focus on cancer detection and care delivery for the rural communities of India to increase services available for cancer detection and care. The goal of this revision sought to equip all levels of primary health care in India for cancer care: from community health centers for early detection or referral all the way to treatment at oncology wings of medical colleges. Though this policy sought to accomplish availability of cancer education and care for the 70 percent of individuals in India residing in rural communities, the MDCCP is strongly linked to the capacity of the regional cancer centers (RCC), government medical colleges (GMC), and tertiary centers already providing cancer education and care located in larger cities. This means that true rural outreach is only occurring in remote areas easily accessible by teams from these tertiary cancer care centers mandated to expand their outreach programs from the revision MDCCP in 2005 (MOHFW, 2014). Also in 2005, HIHT's Department of Community Medicine began to create the infrastructure of their current outreach program discussed in this study. Despite this community-structured revision of national policy, only the state of Kerala has been regarded as successful with implementation of rural community focus for cancer care and detection (Das & Patro, 2010).

To begin to understand the need for NCCP policies, the prevalence of women's specific cancers and their history must first be explored and known. The inception of the NCCP followed a drastic change in life expectancy in India as the country transitioned from a developing nation to a more developed nation. According to the WHO, evolution of a nation when life expectancy is raised dramatically stresses a public health concern for NCDs, such as cancer (Selvaraj et al., 2014).

All current incidence reports are largely estimated through the use of cancer registries throughout the country. These registries are the only widely used tools available to know current women's specific cancer prevalence rates throughout India, but only operate for collection purposes on a voluntary basis. Currently, there are only 21 population-based cancer registries and six hospital-based cancer registries working to analyze cancer prevalence within the entire country of India. It is estimated that with the use of these cancer registries, India is only aware of five percent of cancer cases (Das & Patro, 2010). With so little knowledge of cancer incidence rates, outreach initiatives and larger cancer control policies through the NCCP are only effective in previously defined high-risk regions or populations.

Of the six physicians interviewed for this study throughout Dehradun, Uttarakhand, and surrounding areas, there was no consensus on women's specific cancer prevalence regarding breast, cervical, ovarian or uterine cancers (HIHT physicians, personal communications, 29 April 2015). The outreach programs diagnostic processes used to diagnose cancers described by each physician were similar, where diagnoses are confirmed either through processes done at tertiary centers or through the outreach programs in rural communities offered by these same tertiary centers (Dr. Viraj, personal communication, 29 April 2015). According to Dr. Reddy, an HIHT physician from the Department for Community Medicine, diagnoses are confirmed at the organization of a community-screening program when you go to the patient to run simple diagnostic tests, or when a patient comes to you at the tertiary center.

“Diagnoses are confirmed on two basis: one is when a person, himself or herself, comes for a check up. The thing is, when the community screening programs are organized, when the patients are found positive on screening tests, [and] then they are subjected to

the confirmative test further. There are two ways of identifying the patient: either patient comes to you or we go and screen the patients,” (Dr. Reddy, personal communication, 29 April 2015).

The philosophy described above, where diagnoses only happen when you go to the patient or the patient comes to you, exemplifies the gap in knowledge of true cancer incidence throughout India. Through the diagnostic processes performed either at the clinical center or within the context of outreach “health camps,” cancer diagnoses are confirmed and then volunteered for reporting to a population or hospital-based cancer registry within the state of Uttarakhand. However, considering the lack of cancer registries throughout the country, not every tertiary center has a registry where cancer diagnoses are mandated for reporting. Therefore, a lack of reporting and gap in cancer detection has the potential to incorrectly inform future cancer control policies. Dr. Viraj, HIHT, is confident that accuracy in reporting and detecting cancer has increased over the last few decades, but true cancer incidence for all cancer’s, especially those diagnosed in rural settings is only still recognized on a limited scale (Dr. Viraj, personal communication, 29 April 2015).

The gap among the various steps to cancer detection is lost in that many of the women living with cancer go undiagnosed in a rural community, where there may not be an outreach program present or accessibility to a tertiary center for diagnostic processes to detect cancer is unfeasible (Dr. Reddy, personal communication, 29 April 2015). Various revisions to India’s NCCP has worked to include preventive care and treatment for all Indian citizens, regardless of geographic proximity to the nearest Community Health Center (CHC), yet without an accurate estimate of cancer prevalence in the country, no policy revision will adequately address the health concerns of those most in need.

2.2 – Analysis of Himalayan Institute Hospital Trust (HIHT) rural outreach

Within Dehradun, the capital city of Uttarakhand, HIHT serves as a comprehensive health care system with a burgeoning Cancer Research Institute (CRI), one of most highly regarded tertiary cancer care centers in the country. According to Dr. Patel, an HIHT physician with the Department of Community Medicine, until 2005, the trust, and more specifically CRI, was not required by the state government of Uttarakhand to participate in any rural outreach in relation to cancer mortality or to report cancer cases to any of the 21 population-based registries or 6 hospital-based registries throughout India (Dr. Patel, personal communication, 29 April 2015).

The outreach program from the Department of Community Medicine currently services 38 of over 15,000 villages and rural communities in Uttarakhand. The focus of these programs serve as “women’s health camps,” but are widely used for diagnostic processes in detection of gynecological malignancies and women’s specific cancers in and around the rural communities of Dehradun (Dr. Viraj, personal communication, 29 April 2015). Due to the small scope of HIHT’s outreach program related to women’s health and cancer detection, each rural community was chosen as an outreach site through the use of HIHT medical social workers to identify high-risk sites or through populations strategy, (Dr. Reddy, personal communication, 29 April 2015).

The development of the Department of Community Medicine’s outreach program centered on women’s health can be attributed to a revision to the NCCP in 1990 and 1991. This most recent overhaul of the NCCP aimed for the implementation and education of diagnostic processes to detect cancer outside of high-level tertiary centers in more remote communities. The revision of this policy was created with the intent to equip every CHC and PHC throughout the

state with the staff, technology, and education to facilitate basic diagnostic processes for early cancer detection, such as in-person breast examination, pap smears, ultrasounds, x-rays etc., (Das & Patro, 2010).

Despite this revision, the state of Uttarakhand did not institute any rural outreach programs with any component of cancer education, detection, or care, until 2005. Only then were private tertiary institutes throughout the state encouraged to include cancer as a disease in the function of their outreach programs (Dr. Viraj, personal communication, 29 April 2015).

According to a physician with the Rural Development Institute within HIHT:

“We do not have right now the government health screening program for cancer. In our primary health center, in our secondary health center, in our tertiary health centers, we do not have any system, any processes, any diagnostic methods related to the cancer... We have the state hospital here at Doon Hospital, but we do not have a cancer department. So, the cancer is completely separate, like at CRI. In Uttarakhand, there is one hospital, Cancer Research Institute,” (Dr. Barshi, personal communication, 14 April 2015).

The HIHT outreach program evaluated in this study, according to Dr. Reddy, is more broadly based to cover all women’s health concerns but is still equipped to screen, educate, and advise women in rural Indian communities on cancer care and prevention. The diagnostic processes within HIHT outreach are present to advise rural Indian women on any and all gynecological malignancies (Dr. Reddy, personal communication, 29 April 2015).

However, according to all three HIHT physicians interviewed for this study, the effort of this particular outreach program could do more to completely address the growing cancer burden for women throughout the country (HIHT physicians, personal communications, 29 April 2015). Dr. Reddy acknowledges the presence of a gap in reported prevalence rates for women’s specific

cancers considering the unfeasibility for rural women in accessing a health camp or traveling to a tertiary care center when noticing symptoms of cancer. According to her, the scope of HIHT outreach is so limited; therefore, where there are rural communities far from health centers and no community outreach from a tertiary institution, the prevalence is not reported because “nobody knows in the community; she doesn’t even know because she has never approached a doctor.” Due to lack of access, many women are dying of women’s specific cancers such as breast, cervical, ovarian, and uterine cancers, but are never diagnosed, (Dr. Reddy, personal communication, 29 April 2015). Dr. Patel, HIHT, stated that preventive programs are in place within HIHT and the outreach program; however, “there is limited scope right now within the institute.” He says the institutes’ main focus is “more focused towards treating patients,” rather than extending the support of their outreach program to access more rural communities (Dr. Patel, personal communication, 29 April 2015).

The outreach program of HIHT functions to visit one or two of the 38 previously identified communities every month (Dr. Reddy, personal communication, 29 April 2015). While these communities may not be visited often, literature shows that screening a women once in her lifetime for many gynecological malignancies reduces her chance of contracting women’s specific cancers such as cervical, ovarian, and uterine cancers by 50 percent. Despite past studies, the reduction of cancer prevalence throughout rural India cannot be possible without outreach programs to reach all rural communities lacking healthcare throughout India. However, with the current outreach infrastructure in comparison to the population of the country, there is no way every Indian women could currently be screened in her lifetime to detect for even the most common gynecological malignancies and women’s specific cancers (Das & Patro, 2010).

3 - Investigation of barriers to early cancer detection for rural Indian women

3.1 – Assessment of prior cancer knowledge

Of the nine women from Patti Misras village interviewed, all were asked to define cancer in their own words based upon the experience they have with the disease, either through family, neighbors, or stories from nearby villages. Every woman interviewed either said the word “cyst,” “abscess,” or “boil” to identify cancer in the context of their own health journey and how it has been informed by cancer. Additionally, when probed further about personal definitions of cancer, every woman interviewed thought cancer was simply an external disease. None of the women or healthcare providers interviewed in Patti described cancer as an uncontrolled growth that can occur anywhere in the body, inside or outside (Patti Misras women, personal communications, 21-23 April 2015).

A recent study conducted by the *South Asian Journal for Cancer*, interviewed 281 women in a village in rural India about their general cancer knowledge. Much like this smaller scale study, the women from this 2014 survey all knew what cancer was, but few women were able to correctly identify symptoms, risk factors, or screening tests for women’s specific cancers when asked (Tripathi et al., 2014). All nine of the women interviewed in Patti Misras village were asked about what they think causes cancer, including any risk factors or behaviors. Each woman was aware of cases of throat cancer in the nearby villages that were attributed to the individual smoking or chewing tobacco. However, five of the nine women in Patti Misras village interviewed said the only behaviors that cause cancer are smoking, chewing tobacco, and drinking alcohol. When further questioned about women’s specific cancers such as breast, cervical, ovarian, and uterine cancers, there was no mention of hygiene or sexual health practices

that could prevent some of the women's specific cancers that burden many women in rural India (Patti Misras women, personal communications, 21-23 April 2015).

In regards to early cancer detection, Dr. Reddy was adamant that the most important health education that needs to be disseminated about women's specific cancers were easy ways to detect symptoms and warning signs of cervical, ovarian, and uterine cancers. In regards to her work at health camps, she said "a lot of the time with these women's specific cancers we see many stage III and stage IV diagnoses. With stage III, people will be coming to the camp and it is often their first time to the camp, because they must be having visible complaints and symptoms." With knowledge of basic symptoms, such as excessive bleeding in regards to cervical and uterine cancer, or small lumps for breast cancer, she said women could have a greater impact on their own health outcomes for early cancer detection (Dr. Reddy, personal communication, 29 April 2015).

In the 2014 study from the *South Asian Journal for Cancer*, mentioned above, only 16 percent of the 281 respondents were aware of warning signs of cervical cancer such as vaginal bleeding, blood-stained vaginal discharge, and bleeding after intercourse. When the respondents were asked about "the possibility of early detection of precancerous lesions and early cancer," 49 percent answered negatively. When questioned further, most women in this group answered negatively in regards to early detection for themselves due to lack of knowledge about symptoms and what to look for. This study's interviews with 281 rural Indian women concluded that in terms of barriers to early cancer detection, the "cognitive barrier" was the most important to be addressed in looking towards shifts in adequate health education for women's specific cancers (Tripathi et al., 2014). The conclusions from this survey mirror much of the findings from this current study of general cancer knowledge among women in Patti Misras village.

One woman from nearby village to Patti Misras, Darshni, said that she was unaware of any symptoms or signs of cancer because she had never heard anything about any cancers from the health volunteers or doctors in the clinic (Darshni, personal communication, 22 April 2015). Darshni is not the only woman in Patti Misras or surrounding villages that feels this way. Knowledge of symptoms of cancer varied in this studies interviews; however, of all nine women interviewed, none could name one diagnostic test used in rural community health centers or tertiary care hospitals for early cancer detection and diagnoses, such as mammography, fine needle aspiration cytology (FNAC), pap smears, or visual pelvic examination (VIA). When asked about cancer detection processes, Darshni adamantly spoke for the importance of availability of x-rays and ultrasounds due to information she said she had heard from a local health volunteer (Darshni, personal communication, 22 April 2015).

Within the health education infrastructure of Patti Misras village, without an outreach women's health camp from HIHT, the health clinic depends on eight female health volunteers in the area to disseminate knowledge about importance aspects of healthcare. Dr. Barshi, Rural Development Institute, however, says rural communities cannot depend on local health care workers for dissemination of adequate health education for early detection of women's specific cancers. "The primary workers, they do not know anything about the cancers. They have to educate about everything in rural communities and cancer is not something they are trained about, nor is it something they are really prepared to discuss for the benefit of the local women they work with in rural areas," Dr. Barshi said (personal communication, 14 April 2015).

Rani, a local health volunteer living in Patti Misras, spoke of the training she received on best practices in sharing health education with local women. She has been a health volunteer for the past eight years and said she has received trainings from HIHT, Jolly Grant, the Indian

Society for Global Health & Education, as well as education from Dr. Barshi. When asked about any training on cancer, she said she has never had a specific training on cancer and that any information she has learned to share with her community has been in trainings about women's health on a broad scale (Rani, personal communication, 22 April 2015). Another Patti health volunteer for the past four years, Manita, said training she has received about cancer has never included information about testing, so when women come to her with symptoms that could be possible symptoms of women's specific cancers, she immediately advises women to go to the doctor because that is all she or others at the clinic can do at that point. Currently working in the health clinic, she says she sees more possible cases of cervical cancer than any other cancer, but is unaware of what a pap smear is or how to conduct one (Manita, personal communication, 21 April 2015).

A 2014 study from the *Indian Journal of Community Health* created a two-day educational training on cervical cancer warning signs and screening programs for rural healthcare providers in Southern India using low-cost diagnostic tests, such as pap smear and VIA. At the conclusion of the two-day educational program, all of the 20 healthcare providers were interviewed about their experience as well as the local women who had participated in the screening camp. Overwhelmingly, the difference in pre-test versus post-test scores for providers and women in regards to their knowledge about cervical cancer increased by at least 50 percent in regards to knowledge of basic symptoms and risk factors as well as diagnostic tests for cervical cancer detection. The study said that it "met its objective of improving knowledge and skills among primary care providers," (Isaac et al., 2014). With knowledge available with local health workers, correct dissemination about risk factors, warning signs and symptoms of women's specific cancers is possible for wide spread dissemination within rural areas. However,

the women in Patti Misras village currently do not have the common knowledge about women's specific cancers from the health education infrastructure that is currently available.

3.2 – Assessment of health education accessibility

The clinic in Patti Misras village and those working at it are familiar with HIHT, as many health education trainings the health workers receive are deployed by this tertiary center in Dehradun. However, Patti Misras village is not currently one of the 38 villages benefiting from the outreach programs for women's health under HIHT's Department of Community Medicine. With one doctor, one pharmacist, and 8 health volunteers creating the healthcare infrastructure for this area and surrounding villages, the clinic in Patti Misras village is the only point of contact for healthcare that many in the area use, rather than going down the tough mountain terrain to far away CHCs or PHCs.

Dr. Reddy, HIHT, regarded education and health literacy as one of the great barriers rural Indian women face in early cancer detection. "It is not illiteracy in education, it is illiteracy about what important aspects of women's health and cancer they need to know about themselves," Dr. Reddy said. In reference to breast cancer incidence, she says many rural women ignore common symptoms of cancer, such as small noticeable lumps, and they say "...it's okay, it's fine, it will go and be better with time." Dr. Reddy regards knowing what to look for with women's specific cancers and taking action to go to a doctor when something is wrong as the most important thing a woman in rural India can do for her health, especially when it comes to early cancer detection (Dr. Reddy, personal communication, 29 April 2015).

Another HIHT physician, Dr. Viraj, agrees that without adequate health education for a community, cancer and other non-communicable diseases like it will continue to create a great

health burden for all areas of rural India. She said she blames the social issue of seeing women's health as a taboo subject in India as to why so many rural Indian women do not have adequate knowledge about women's specific cancers and other gynecological malignancies. "Basically, the health issues of women, they are not being addressed in India...People are not even aware of the warning signs of cancer, less the social stigma and taboos there, and, we, females, are not even the breadwinners of the family a lot of the time in the rural area...If a male gets sick, people will take care of him, but, at the same time, if a female gets sick, nobody will take care of her," Dr. Viraj said (Dr. Viraj, personal communication, 29 April 2015).

In spite of this insight, in communities with little health education infrastructure about cancer and other non-communicable diseases, the onus falls on the community members to inform themselves about health concerns instead of third-party tertiary centers or NGOs working towards goals for health education. Dr. Patel, HIHT, acknowledges the onus of the physician to disseminate health information when outreach programs are present, but believes the goal of early cancer detection lies with potential cancer patients:

"[It's] the responsibility of the individual if they are having any kind of symptoms pertaining to some kind of suspicion of having cancer. They should come forward and get themselves screen rather than wait a long time and be busy...But that becomes a real challenges because if we are losing that window period where we can really help, so then the things are out of control of the physician," Dr. Patel said (personal communication, 29 April 2015).

A 2007 study from the *Indian Journal of Medical Sciences* regards the primary health care system in India itself as responsible for disseminating proper health education about any and all non-communicable diseases, especially cancer. In reference to early detection methods for

cervical cancer with rural Indian women, this study concluded that until organized screening methods for cancers have been successfully implemented, a “nationwide educational program for women regarding early warning symptoms” is the best way to tackle the increased burden of women’s specific cancers in rural India (Juneja et al., 2007). Unfortunately, the reach of government services in relation to healthcare and health education does not extend far beyond the geographic boundaries of CHCs, PHCs, district hospitals, or tertiary centers. Patti Misras Village is located at the foot of the Himalayas, at least 30 kilometers from the nearest government run health care facility.

Assessment of available health education for individuals living in Patti Misras and surrounding villages has relied solely on a woman health volunteer or the doctor at the clinic since its’ creation fifteen years prior. Four of the nine Patti village women interviewed first heard about cancer through one of these individuals disseminating health education within the area (Patti Misras women, personal communications, 22 & 23 April 2015). However, every healthcare provider interviewed within the infrastructure of the health clinic in Patti had not received specific training in regards to disseminating information about cancer, specifically (Patti Misras health volunteers, personal communications, 21 & 22 April 2015). The pharmacist at the Patti Misras clinic, funded by the Indian Global Health & Education Society, recalled his training from the Jolly Grant hospital system as focused mostly on pregnancy and early maternal/child health (Vijay, personal communication, 29 April 2015). Dr. Parker, the doctor responsible for running the health clinic in Patti Misras, said no training is ever disseminated on just cancer, and if people want to know about a specific health concern they ask. “They will ask and we will tell. If they do not ask, we do not know whether to tell or not,” Dr. Parker said (Dr. Parker, personal communication, 23 April 2015).

Every woman interviewed had some experience in knowing about cancer whether through diagnosis of a family member in the past or through stories from nearby villages (Patti Misras women, personal communications). One Patti woman, Geeta, was adamant about the lack of health education she was receiving from any one in her community, doctor or health volunteer, and how she relied on stories to learn about different diseases. In an interview conducted in Hindi, Geeta said she was not receiving the health education about things that she was supposed to know, like cancer, from healthcare providers in Patti, ASHAs or Anganwadis. When questioned further about the trust in those relationships, she said that there is no trust because they are not there when needed (Geeta, personal communication, 22 April 2015).

Another woman living in Patti Misras village, Kajiri, spoke of the lack of health education as well as lack of access, considering the health clinic for the area is only open 5 days a week. She praised the work of the current health clinic since she was living in Patti when there was no health clinic nearby, yet she said lack of resources hinder her ability to learn about diseases she should know about, such as cancer. She explained that the clinic has been great in treating minor injuries or illnesses, but any big disease requires a trip down the mountain. She describes herself and her family as in poor economic condition, and said knowing symptoms of cancer is something she wants to learn about because if it happened to her now she probably would not know she had early signs of cancer or what to do (Kajiri, personal communication, 23 April 2015). Jayna, from a nearby village also echoed this sentiment. She said she would have no idea what to do or where to go if she had symptoms of cancer like bleeding or “lumps.” When asked further, she attributed her lack of knowledge to the lack of resources in the area and how she cannot do anything for her health in this area; the doctor does everything (Jayna, personal communication, 23 April 2015).

The women in Patti are not alone. A needs assessment of a population of women in rural India described as at “high risk” for breast cancer showed conclusions where 100 percent of the women interviewed “felt they wanted to have more information about their disease [breast cancer], their chance of cure and life expectancy, possibility of disease affecting other family members, the duration of treatment, the expenses involved etc., so that they could plan for the future,” (Kaur et al., 2014).

Dr. Reddy, HIHT, said willingness to be subjected to health education is imperative with rural populations in the country considering the taboos of women’s specific cancers in regards to overall female health. “The most important is that the community people should be willing...Most important is motivation,” Dr. Reddy said (personal communication, 29 April 2015). From the same department within HIHT, Dr. Viraj agreed with motivation of females to attend outreach camps, but said females should not be the only ones receiving health education about women’s specific cancers and other gynecological malignancies. “If she suffers from a particular cancer, it will be [a] blunt to the entire family, not only to her, not only to her husband, not only to her kids, but a blunt to the entire family. So, it’s better to get her screened; it’s better to address her issues, the health related issues,” (Dr. Viraj, personal communication, 29 April 2015).

3.3 – Cultural barriers to early detection

The structure of Indian society is inherently conservative, and this social construct affects healthcare outcomes for men differently than for women. “Female health issues are basically a taboo for the society [to discuss],” said Dr. Viraj, Department of Community Medicine, HIHT. While acknowledging the strides India has made in reducing gender inequality throughout the

country, Dr. Viraj is adamant that gender inequality is still very apparent in more rural communities, affecting women with potential health issues not being treated because of the inability to leave the house for the doctor unsupervised, or hesitancy to go to a doctor in regards to female specific health issues, including women's specific cancers (Dr. Viraj, personal communication, 29 April 2015).

This studies' interaction with women from Patti Misras village proved Dr. Viraj's assertions were not wrong. All nine women from Patti Misras village were asked about who they felt most comfortable sharing health information with and if they would go to the doctor alone. While almost all said they would go to the doctor unaccompanied because the clinic is so close, each said if they were going to a larger facility in Dehradun, Chandigarh or Delhi for a disease like cancer, they would require someone to come with them. Only one woman from Patti Misras village, Geeta, said she felt comfortable discussing female-specific health issues with her husband and mother-in-law (Geeta, personal communication, 22 April 2015). All other women responded they would feel most comfortable discussing issues such as breast, cervical, ovarian, uterine cancers, and other gynecological malignancies with a doctor only (Patti Misras women, personal communications, 21-23 April 2015). A 2014 study from the *South Asian Journal for Cancer* found with their survey that health of a rural Indian woman, especially when it comes to early cancer detection, is compromised due to sociocultural barriers in relation to society's notion of gender roles (Tripathi et al., 2014).

In response to the perpetuation of India as a conservative society regarding gender, many health outreach programs in rural India are taking note and revising their tactics to increase comfort ability of rural populations pushed towards health education or screening programs in regards to women's specific cancers. A breast health awareness campaign was conducted in 2005

in a rural village in South India where female health workers rather than on-site male doctors were trained to teach breast self examinations to local populations, ensuring that local women were most comfortable when learning about methods of early detection for breast cancer. The study concluded that this training “help[ed] women to know the structure and composition of their normal breasts thereby enhancing their sensitivity to any abnormality for the earliest detection of cancer possible,” (Rao et al., 2005).

Dr. Reddy says that motivating participation of outreach programs for women’s health in regards to women’s specific cancers and gynecological malignancies is difficult due to the taboo nature of discussion surrounding women’s health (Dr. Reddy, personal communication, 29 April 2015). Her goal is of the utmost importance considering the social stigma attached to various diseases, including women’s specific cancers related to gynecological malignancies. Health education programs exist throughout India to combat stigma of tuberculosis and leprosy, yet women’s specific cancers and the conversation about the female body that is required to have when discussing breast, cervical, ovarian, or uterine cancer is nowhere to be seen. According to a 2010 study from the *South Asian Journal for Cancer*, “in the rural areas, many people consider cancer as a communicable infectious disease and consider it a taboo for the family which leads to isolation,” (Das & Patro, 2010). To avoid this isolation, many women in rural areas will avoid telling their husbands or families about very serious symptoms of women’s specific cancers such as breast lumps and excessive vaginal bleeding due to the taboo in Indian society that results when women speak openly about issues of sexual or menstrual hygiene, (Dr. Viraj, personal communication, 29 April 2015). If women are unwilling to speak about health issues related to their bodies, the burden of women’s specific cancers will continue to increase until health

education initiatives for rural outreach do something to directly address the societal taboo in conversations surrounding female health.

3.4 – Economic and geographic barriers to detection

Patti Misras village is located at least 30 kilometers from the nearest government-run healthcare facility. The clinic that is now located at the center of Patti village was funded and has been sustained by financial and resource donations from the Indian Global Society for Health & Education. Before this clinic was built in 2000, any health concern, major or minor, required a visit to the nearest CHC or PHC, down the mountain in Dehradun. With the current health infrastructure of the clinic, residents of Patti Misras and neighboring villages have a local health and pharmacological resource close to their home, not requiring any extensive travel (Mr. Malta, personal communication, 15 April 2015). However, for large health issues, such as cancer, facilities used by a technician, like x-rays, ultrasound, and availability of basic diagnostic tests requires another trip to a government or private hospital at least 30 kilometers from their home. A 2010 study of cancer control in rural India concluded that a major reason for the poor mortality rates in regards to cancer in rural Indian women is due to the geographic distance many outlying rural patients have to travel to receive adequate cancer education, diagnosis, and treatment (Das & Patro, 2010).

Dr. Parker, one of the physicians responsible for care and referrals within the clinic in Patti Misras village, said since his clinic is only equipped to do so much, he refers anyone he thinks may have symptoms of cancer immediately to a government or private hospital in Dehradun (Dr. Parker, personal communication, 23 April 2015). Mr. Malta, an employee of the organization financially responsible for the building of the clinic in Patti Misras village, stated

that the clinic would never be equipped to handle diagnosis or treatment of women's specific cancers. Instead, he says "we are able to give them some direction, a recommendation of a place or hospital in Dehradun to get their treatment done, that is it," (Mr. Malta, personal communication, 15 April 2015).

Because facilities for cancer detection, diagnosis, and treatment are so far away and transportation is limited with no ambulance availability to come to Patti Misras village, many women are not undergoing the screening measures they need in early detection of cancer. In a 2014 survey conducted with women in rural India regarding cancer knowledge and access to care, about 20 percent of women responded their reason for not accessing screening measures at cancer care facilities were due to distance from health center and cost (Tripathi et al., 2014).

All women interviewed from Patti Misras village were asked what barriers, if any, affected them from getting screened or treated for cancer. Every woman knew of at least one government hospital where many treatments and diagnostic tests such as pap smears or mammograms were free of cost, yet many still answered that the far distance from Patti to a nearby PHC, CHC, or district hospital affects their availability to access healthcare in relation to cancer (Patti Misras women, personal communications, 21-23 April 2015). Sunita, from nearby Misras village, said she and her family are only able to go to the doctor in Dehradun when they have money available. If they do not have money available, they are not able to go, and this has affected the health of her family in the past (Sunita, personal communication, 21 April 2015). Another woman from Misras village, Kajiri, said that without money, accessing a hospital is not possible, because you have to take a Jeep or a bus to get there. When asked about her personal economic condition and how this impacts her access to healthcare from facilities in Dehradun or other cities, she said that if we have money we go in a Jeep, but if we don't have money and

someone is really sick, we will sell part of our land so we can go to the hospital (Kajiri, personal communication, 23 April 2015). Currently, financial assistance programs for healthcare are vast in India, but treatment for cancer is still very expensive. According to Dr. Barshi from the Rural Development Institute, “the government is not providing any cancer medicines or treatments free of cost. They provide medicines for HIV/AIDS, everything, but there is not a cancer program incorporated within the government, so, all cancer medicines or treatments are purchased and paid for by patients completely,” (Dr. Barshi, personal communication, 14 April 2015). Until cancer care for men and women has some assistance under the branch of aid from the federal or state governments within India, rural populations able to overcome sociocultural, societal and geographical barriers will still suffer from cancer as much, if not more, as current incidence rates project due to the overwhelming barrier of cost of detection and care.

4 - Landscape for future of cancer detection in India

4.1 – Opportunistic focus of outreach

The function of the rural healthcare outreach program within the Department of Community Medicine at HIHT, Jolly Grant, Dehradun, operates under the broad focus of women’s health overall. Included in this are maternal and child health care, gynecological malignancies, and women’s specific cancers. However, screening and diagnostic processes used in this outreach program to detect and diagnosis women’s specific cancers within rural populations exist only because of opportunistic testing. Within the framework and structure of this particular outreach program, women’s specific cancers may be detected if and only if a woman voluntarily coming to the health camp complains of symptoms the HIHT doctor recognizes as symptoms of a women’s specific cancer (Dr. Viraj, personal communication, 29

April 2015). “When we go into the community, there is not screening for a single disease...[The camp], it includes sexually transmitted infections, reproductive infections, anything in gynecological care. Anything, and then cancer as well,” (Dr. Reddy, personal communication).

All doctors from the Department of Community Medicine within HIHT, Jolly Grant, were aware of constraints of their outreach program for women’s health, but felt the needs of rural women for early cancer detection were being met within the villages they were serving (HIHT physician, personal communications, 29 April 2015). Dr. Barshi from the Rural Development Institute, HIHT, Jolly Grant is critical of the countries’ past cancer control screening methods, but believes inter-sectoral cooperation with opportunistic testing, like outreach being conducted currently at the Cancer Research Institute is the future of government policy for early cancer detection for rural populations. “And why is India not properly screening their patients? The countries’ cancer screening method is not currently linked with the maternal and child health program,” he said (Dr. Barshi, personal communication, 14 April 2015). CRI and HIHT overall with the limited scope of their outreach programs is working to converge women’s and maternal health to create a policy space for the need of early cancer detection for women’s specific cancers.

Smaller scale health camps with a single focus of cancer detection for one cancer has been used as a control method for various decades, yet according to a report from *the Indian Journal for Community Health*, it will never be possible to ensure these screening camps provide coverage to every locale throughout India. In a 2014 study about cervical cancer incidence throughout India, a group of researchers concluded the impossibility “in India to have a country wide Pap smear screening for the known reasons including resources, manpower and quality control,” (Satyanarayana & Smita, 2014).

The government of India, as life expectancy and population continue to increase, has a public health burden to eradicate the communicable diseases that have affected the country for so long, while addressing the newer effect non-communicable diseases are having on the health of the country. Cancer, specifically for women's specific cancers, has become one of the four main NCD concerns in India, along with heart diseases, obesity, and chronic respiratory illnesses. The federal government of India has begun this policy change to tackle NCDs with the convergence of the NCCP and National Program for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) to create the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS). This convergence is only in the first of twelve five year plans, and only promises to cover care under this federal policy for all districts of the country by the end of the twelfth five-year plan, 60 years from now (Chakma & Gupta, 2014).

To combat cancer incidence at a rural level for women "inter-sectoral cooperation and coordination along with inter-sectoral convergence with various departments like education, women and child development, science and technology, environment, etc." is the future of policy and the NCCP to tackle the countries cancer burden for women in rural India. However, this sectoral convergence does not just apply to a disciplinary level. For opportunistic testing within tertiary center sponsored health outreach camps to be truly successful, the support of a wide variety of stakeholders is also imperative. The development and expansion of health outreach camps based in opportunistic testing to target women's specific cancers in rural India relies on the support of civil society, the private sector, NGOs, academia, and the federal and state governments is necessary for successful policy development (Joy & Sanjay, 2014). Time is of vital concern though. Women living in rural India unknowingly suffering from late stage

women's specific cancers due to barriers of access, knowledge gaps, sociocultural and societal concerns, as well as geographic and economic concerns are doing so now. Small-scale outreach, like that discussed from the Department of Community Medicine within HIHT, Jolly Grant, can only do so much to tackle the larger issue.

4.2 – Prevention focus, not treatment focus

According to Dr. Patel, HIHT, success in the institutions outreach programs “counts when you screen a person, if diagnosed, can provide the treatment,” (Dr. Patel, personal communication, 29 April 2015). This focus of his, as a physician, mirrors the development of NCCP policy since 1971, treatment rather than prevention. However, considering the alarming level to which many women's specific cancers are preventable with the right health education and curable if caught early, NCCP policy should actually be focusing on prevention rather than treatment. Even when speaking of the outreach program in which he works with at HIHT's Department of Community medicine, Dr. Patel says, “it becomes familiar that late state disease is what is being screened rather than early symptoms that can be taken care of with the screening program,” (Dr. Patel, personal communication, 29 April 2015). In response to the desire for a rural community focus to early cancer detection among rural Indian women, a possible evolution of the regional cancer centers may be in the works to create Early Cancer Detection Centers (ECDC) with the support of governments and NGOs. With the creation of this policy, these ECDCs could be located in remote locations, more convenient to the most rural communities in India than even the infrastructure of CHCs and PHCs. As per this expansion, this district focus plan is expected to reach all districts throughout India in some capacity by 2017 (Das & Patro, 2010).

A 2012 study concluded that India's cancer burden for rural populations has taken such a significant toll because reporting of incidence rates is and has never been mandatory. In 1981, the Indian Council for Medical Research created the National Cancer Registry Programme, where reporting of cancer prevalence and diagnoses is voluntary, meaning India has never had "clear data on the magnitude of disease [cancer]," and assumptions of cancer prevalence rely on gross estimations and trends (Chatterjee, 2012). While states such as Uttarakhand and Kerala have institutes and population-based registries to report to based upon the infrastructure of certain cancer institutes within these states, not all states within the country have this available health infrastructure (Dr. Patel, personal communication, 29 April 2015).

Dr. Viraj, HIHT, said that change of policy for increased cancer notification and reporting to improve early detection measures relies on national policy, but initiatives of prevention rather than treatment can start at a community level (Dr. Viraj, personal communication, 29 April 2015). One 2005 study of educational techniques within rural communities about cervical cancer showed that "a community oriented education intervention programme emphasizing proper techniques for early cancer detection can bring about the desirable behavioral change among women," (Rao et al., 2005). According to Dr. Viraj, HIHT, the outreach program and its' cancer education component is looking to expand as the need for proper educational materials for the most successful preventive focus is requested.

5 – Conclusion

5.1 – Statement of Findings

Examining barriers to early cancer detection for women in remote communities within the context of an existing rural outreach program allowed the researcher to see the evolution of

policy and policy goals first hand. However, this study examined barriers to cancer detection in a community still untouched by health care outreach from a large tertiary center with cancer care. Therefore, the findings of this study aligned with literature concluding knowledge of women's specific cancers among women in rural communities in India is small. This study concludes that this knowledge gap is present due to the lack of accessibility to adequate health education. The women interviewed about the basics of women's specific cancers were largely unaware of risk factors, warning signs, symptoms, or diagnostic processes used for early detection of cancer. The significance of this knowledge means that outreach programs within existing tertiary centers need drastic policy improvement to even begin to address rural cancer outreach in a successful way.

Assessment of infrastructure of a women's health outreach program from the Department of Community Medicine within HIHT, Jolly Grant, Dehradun, showcased the limited scope tertiary centers currently have in their outreach programs. Physicians herald this program as an answer to issues with early detection of women's specific cancers in rural India, but with a focus of opportunistic testing in very few communities, barriers to early cancer detection have yet to be adequately addressed. For these outreach programs to improve in detecting more women's specific cancers earlier means national health policy in India needs to reform and recognize the importance in developing mandatory reporting to cancer registries. Until prevalence of women's specific cancers is largely known throughout India, outreach programs and the work of tertiary centers to tackle early cancer detection and its' barriers through opportunistic testing of rural Indian women will only go so far in reducing cancer mortality rates.

5.2 – Limitations of Research

The information gained from interviews with all participants in this study was invaluable in engaging a qualitative analysis to discover barriers to early cancer detection for women in rural India. However, barriers to early detection for women's specific cancers still are a very real reality to many women throughout rural India living in areas so remote, that adequate healthcare or outreach programs are not present in their community. Due to the debate surrounding incidence rates of women's specific cancers among the academic, professional, and medical communities throughout the country, none of the prevalence rates found could truly be reported within this study, due to how little the country of India knows about the disease burden of cancer for women throughout the country. The sample size of each stakeholder group interviewed for this study was small, so statistical significance of responses cannot be obtained or verified, and conclusions from this study should be viewed as qualified.

The study faced the most difficult limitation with language barrier. Due to the fact that many of the interviews for this study were conducted in a remote setting in a village in Uttarakhand, there were very few people around available for translation speaking fluent Hindi and English. Both translators used for interviews conducted in Hindi worked within the healthcare infrastructure of Patti Misras village; therefore, there is an obvious bias present given this studies topic in investigating the health education infrastructure available for early cancer detection for women within this community. All interviews were recorded and any unknown phrasing or possible discrepancies were checked and verified by a second translator when necessary. Both translators were male, and the focus of my study was in interviewing women; therefore, the translator's presence may have had an influence in the way some women from Patti Misras village answered the questions asked in this study. In addition, all women were

asked to be interviewed individually, but some women were in the presence of family or interrupted by family during the interview; therefore, answers may have been influenced due to this external factor as well. Also, the researcher, not from India, was often perceived as a foreigner and conducted all research for this study, so the answers could be influenced in this respect as well.

5.3 – Suggestions for Further Research

It is imperative to continue research on early cancer detection policies for women's specific cancers in rural India given the true evolution currently happening in national policy. The burden women's specific cancers is having on rural Indian women is largely preventative and, therefore, further research is vital to future policy change. A major trend in this study was a discussion regarding the knowledge of health, and specifically cancer, among rural Indian women. Barriers of social and societal pressures, geographic distance from healthcare facilities, and economic hindrances to care were mostly known; therefore, a study of just knowledge and accessibility gap could prove more useful to informed policymaking. A future study of this perceived knowledge gap as a single barrier, instead of an overall focus on multiple barriers to early cancer detection might produce results that could have the potential to affect policies on future health education for rural Indian women.

In addition, this study focused on barriers to detection for women's specific cancers under a rural focus only. Future studies should study the barriers women in urban areas face as well considering many women's specific cancers are not just burdening the health of rural Indian women, but those in urban populaces as well. Future studies could also explore barriers to women's specific cancers from a male perspective as well. Considering the extensive discussion

in this study of sociocultural barriers in relation to discussion of women's health and gynecological malignancies as taboo, a men's perspective on this issue is lacking in this study, and could be explored in further research.

Completion of these research projects and many more has the great potential to reform policies on cancer control in India. Despite the work and major revisions of the NCCP since 1971, this national policy has done little to address the cancer burden of women's specific cancers throughout the country when it comes to mortality rates. Further research of barriers to early cancer detection could be aggregated as a vast body of knowledge capable of informing larger changes to health education policy on a rural level as well as changes to sociocultural norms in development of more outreach programs for women's health with a focus on educating everyone in the community on women's specific cancers and gynecological malignancies, not just the women that may be experiencing symptoms.

6 – Appendices

6.1 – Appendix 1: Interview Guides

Physician Questionnaire

- (1) What is your position? How long have you been at this job?
- (2) Could you take a moment to discuss the prevalence of women's specific cancers in India and Uttarakhand? (i.e. breast, cervical, ovarian, and uterine cancers)
- (3) In comparison to the prevalence rates now, what did these look like in the past?
- (4) How did you get these prevalence rates? Is there the use of a cancer registry to record all cancer diagnoses?
- (5) What diagnostic processes are you using to detect and diagnose cancer? Do these processes differ in rural communities? If yes, how so?
- (6) What do you think is the main cause of the current prevalence rates for women's specific cancers in India/Uttarakhand?
- (7) Could you please take a moment to discuss the structure and function of the outreach program that you are a part of?
- (8) How are you measuring successes within the outreach program?
- (9) Within rural communities, how are you working to motivate participation in the outreach program?
- (10) What are barriers you see for rural Indian women in early cancer detection?
- (11) For individuals in poor economic condition from rural areas, what are their options once noticing a possible symptom of cancer?
- (12) How do you think health education should evolve in rural communities to address knowledge gaps in relation to women's specific cancers?
- (13) Can you please take a moment to explain morbidity patterns of cancer from a cultural, medical, and social perspective?
- (14) How do you see the outreach program evolving to address the growing public health concern throughout Uttarakhand and India regarding cancer? Are there any needs that have yet to be met?

Rural Woman Questionnaire – English translation

- (1) What is your name?
- (2) Where are you from?
- (3) How old are you?
- (4) Who do you share information about health concerns with? Do you feel comfortable sharing health information with these people? Why or why not?
- (5) What does cancer mean to you?
- (6) What kinds of cancer do you see in women in your community?
- (7) What do you know about the following cancers: breast, cervical, ovarian, and uterine?
- (8) What has your local health worker or doctor shared with you regarding information about cancer?

- (9) What other individuals outside of your community come to speak with you about health? What have they told you about cancer?
- (10) What do you think causes cancer?
- (11) Is cancer a concern to you? Why or why not?
- (12) What are some symptoms of different types of cancers?
- (13) What are some different tests to detect types of cancer?
- (14) Have you ever been tested for any cancer? Which type of cancer?
- (15) If you or a family member had symptoms of cancer, what would you do?
- (16) In what ways would it be hard or easy to access health care for you and your family if there were a big health problem?
- (17) What more do you want to know about cancer?

Rural healthcare provider questionnaire – English translation

- (1) What is your name?
- (2) Where are you from?
- (3) How old are you?
- (4) How do you work in your community to share health education and information? Do you think women feel comfortable talking with you about their health?
- (5) What does cancer mean to you?
- (6) What does cancer mean to those you work with as a local health care provider?
- (7) How have you been trained to share information about cancer?
- (8) What kinds of cancer do you see in women in your community?
- (9) What do you think causes cancer?
- (10) Are there specific behaviors that you think cause cancer?
- (11) What symptoms of cancer do you see most often from women in your community?
- (12) What are some tests done to help detect cancer?
- (13) If a woman in your community had symptoms of cancer, what would you do?
- (14) How is cancer a concern to women you work with in your community?
- (15) What more do you wish you knew about cancer?
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7 - Bibliography

7.1 – Primary Sources

Dr. Barshi, Rural Development Institute. (14 April 2015). Personal Interview.

Mr. Malta, Indian Global Health & Education Society. (15 April 2015). Personal Interview.

Manita, Patti Health Volunteer. (21 April 2015). Personal Interview.

Sunita. (21 April 2015). Personal Interview.

Archika. (21 April 2015). Personal Interview.

Ramila. (21 April 2015). Personal Interview.

Preeti. (22 April 2015). Personal Interview.

Hemal. (22 April 2015). Personal Interview.

Darshni. (22 April 2015). Personal Interview.

Geeta. (22 April 2015). Personal Interview.

Navdha, Patti Health Volunteer. (22 April 2015). Personal Interview.

Rani, Patti Health Volunteer. (22 April 2015). Personal Interview.

Neha, Patti Health Volunteer. (23 April 2015). Personal Interview.

Jayna. (23 April 2015). Personal Interview.

Kajiri. (23 April 2015). Personal Interview.

Anaisha, Patti Health Volunteer. (23 April 2015). Personal Interview.

Dr. Parker, Patti Doctor. (23 April 2015). Personal Interview.

Vijay, Patti Doctor. (23 April 2015). Personal Interview.

Dr. Reddy, HIHT. (29 April 2015). Personal Interview.

Dr. Patel, HIHT. (29 April 2015). Personal Interview.

Dr. Viraj, HIHT. (29 April 2015). Personal Interview.

7.2 – Secondary Sources

- Asthana S., Chauhan S., & Labani S. Breast and cervical cancer risk in India: An update. *Indian Journal of Public Health*. Vol. 58, No. 1, 2014, pp. 5-10
- Badwe R.A., Dikshit R., Laversanne M., & Bray F. Cancer Incidence Trends in India. *Japanese Journal of Clinical Oncology*. Vol. 44, No. 5, 2014, pp. 401-407
- Chakma J.K., Gupta S. Lifestyle and Non-communicable Diseases: A double-edged sword for future India. *Indian Journal of Community Health*. 2014;26(4):325-332.
- Das, S., Patro, KC. Cancer care in the rural areas of India: A firsthand experience of a clinical oncologist and review of literatures. *Journal of Cancer Research and Therapeutics*. Vol. 6, No. 3, July-September, 2010, pp. 299-303
- Isaac R.C., Ramamurthy P., Finkel M., Kunjuvareed A.I., Trevena L. An Educational Training on Cervical Cancer Screening Program for Rural Healthcare Providers in India. *Indian Journal for Community Health*. Vol. 26, No. 1, January-March, 2014, pp. 115-118
- Juneja, A; Sehgal, A; Sharma, S; Pandey, A. Cervical Cancer Screening in India: Strategies Revisted. *Indian Journal of Medical Sciences* 61.1 (Jan 2007): 34-47.
- Kaur N., Miglani R., Grover R.K. Information and Rehabilitation needs of Indian breast cancer patients: Report of a cross-sectional study. *Indian Journal of Cancer*. Vol. 51, No. 3, July-September, 2014, pp. 262-266
- Mathew A., Gajalakshmi V., Rajan B., Kanimozhi V., Brennan P., Mathew B.S., Boffetta P. Anthropometric factors and breast cancer risk among urban and rural women in South India: a multicentric case – control study. *British Journal of Cancer*. Vol, 99, 2008, pp. 207-213
- Ministry of Health and Family Welfare. (2014). *Overview of National Cancer Control Programme*. MOHFW Publication. Department of Health & Family Welfare, Ministry of Health & Family Welfare, Government of India.
- Rao R.S.P., Nair S., Nair N.S., Kamath V.G. Acceptability and effectiveness of a breast health awareness programme for rural women in India. *Indian Journal of Medical Sciences*. Vol. 59, No. 9, 2005, pp. 398-402
- Satyanarayana L., Asthana S. Cervical cancer screening trials in India and ethical issues. *Indian Journal of Community Health*. Vol. 26, No. 3, July-September, 2014, pp. 211-212
- Satyanarayana L., Asthana S, Bhambani S, Sodhani P, Gupta S. A comparative study of cancer screening methods in a rural community setting of North India. *Indian Journal of Cancer*. 2014 Apr-Jun; 51(2): 124-8. doi: 10.4103/0019-509X.138172.

Selvaraj J., Marimuthu P.D., Babu H.P. Evaluation of age-standardized cancer burden in western Tamil Nadu, India. *Indian Journal for Community Health*. Vol. 26, No. 3, July-September, 2014, pp. 222-229

Tripathi N, Kadam YR, Dhobale RV, Gore AD. Barriers for early detection of cancer amongst Indian rural women. *South Asian J Cancer* [serial online] 2014
<<http://journal.sajc.org.libproxy.lib.unc.edu/text.asp?2014/3/2/120449>>