

CERVICAL CANCER SCREENING BEHAVIOR AMONG NEPALESE WOMEN

by

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DEDICATION

Dad, I have seen you live a courageous life just to create a future for me!
Mommy, I have seen you live a faithful life with obstacles, just to raise me right!
Courage and Faith were my greatest strengths during this journey! Thank you!!

Bua, I was blessed to have your peaceful presence and moral support throughout this time! Ama, I was fortunate for your prayers for me, especially during my illness!
I know your blessings and prayers opened my path to guide my way!

Basu, thank you for giving me the freedom to raise my wings as high as I can and fly away as far as I needed to, to reach my dream!

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Medha, You are the epitome of responsibility! Thank you for keeping the fort down and handling the household when I had to collect data in Nepal. Only you would be this responsible enough at your age. *I love you!*

Bikalp, Thank you for keeping your smile and calming my soul whenever I needed it the most. *I love you!*

Sapana, Thank you for showing me your support in every loving way and keeping your interest in completion of this work ASAP! You are smart and sweet! Thank you for everything! And thank you for your poem you wrote for me! *I love you!*

Poem by Sapana Satyal (Age:10)

*May is almost here, graduation time is near
You're going to get your PhD, as far as I can see
You're gonna do this right, and the future will be bright
You're gonna have some energy, and know that you can be free
You'll have some spare time to realize, that all you need to be free is your PhD
You're going to get some time, with me once you get your PhD and*

I WILL BE HAPPY

Special dedication to TAKAM (Myagdi, Nepal), a village where my education began! Takam was as far as three days of walk from the bus stop but remains closest to my heart and still is the origin of my spirit, and my soul that I know today! And my special gratitude to my Madhav mama for taking me there, carrying me on his back – and for his unconditional love!!

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LIST OF ABBREVIATIONS

Cervical Cancer Screening.....	CCS
Cervical Cancer.....	CC
Dependent Variable	DV
Gross Domestic Product	GDP
Health Belief Model Scale	HBMS
Health Belief Model.....	HBM
Human Immunodeficiency Virus.....	HIV
Human Papilloma Virus.....	HPV
Independent Variable	IV
International Network for Cancer Treatment and Research	INCTR
Nepal Network for Cancer Treatment and Research	NNCTR
Nepalese Health Belief Model Scale	NHBMS
Nepalese Health Belief Model.....	NHBM
Papanicolaou Test	Pap-test
Sample size	N
Visual Inspection with Acetic Acid	VIA
Visual Inspection with Lugol's Iodine	VILI
World Health Organization.....	WHO

ABSTRACT

CERVICAL CANCER SCREENING BEHAVIOR AMONG NEPALESE WOMEN

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George Mason University, 2013

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Even-though Nepal has the highest age-standardized incidence and mortality rates of cervical cancer (CC) in the world, no universal coverage is available for cervical cancer screening (CCS) despite its known effectiveness in preventing and detecting CC. Although availability, accessibility, affordability and awareness are identified in literature as common barriers for women to undergo CCS in low-resource countries, there are new programs emerging in Nepal that provide services eliminating these barriers. Even then, the utilization of these services are reported to be sub-optimal. Sub-optimal utilization of CCS when the services are available, accessible and free indicate the need for further examination of the belief factors associated with CCS behavior, especially considering the major crisis of CC and low resources to provide CCS in Nepal.

The conceptual model for this study was Health Belief Model (HBM), which suggests that the belief factors explain health behavior. This study examined the CCS behavior (difference between the women who underwent CCS and who did not) in relation to the Health Belief Model (HBM) constructs: perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers using independent t-tests. Additionally, the association between the "Cue to Action" and screening status was assessed using Chi-Square. Further, the extent to which each of

the HBM constructs, age, and education predicted CCS behavior was investigated using the Logistic regression.

HBM scale was used as a foundational document to develop Nepalese Health Belief Model (NHBM) scale. The validation evidence was achieved by successful translation of the instrument using back-translation method and a pilot study with 20 Nepalese women from target population. Internal consistency was assessed using Cronbachs' Alpha, as a measure of reliability. The Cronbach's alpha range for NHBM scale was adequate, between .70-.88, except for one construct, "perceived benefits," at alpha= .64. The NHBM scale, developed using a rigorous research process as explained above, may contribute to research in Nepal by potentially serving as a valid and reliable data collection tool not just to study the CCS behavior to prevent CC but also to study other health behavior to prevent other conditions, such as breast cancer.

No significant difference was found in CCS behavior based on their perception of susceptibility of CC or their perception of seriousness of CC. However, the findings indicated that the women's CCS behavior was significantly different based on their perceptions of benefits of CCS ($p<.05$) as well as perceptions of barriers ($p<.01$) to CCS. Contrary to current literature, this study found that women with the education level of Nursery to 10th grade were almost three times as likely to undergo screening as women with college to higher level education.

This study provides another implication that increasing the focus of awareness on benefits of CCS and barriers to CCS may enhance the CCS behavior by influencing their perceptions. Incorporating these findings and supporting them in program development, research, and policy may be of value to increase utilization rates, thus reducing the incidence rates. Further, researching the Nepalese women's belief system pertaining to CCS, with a qualitative method, may allow us to gain more insight about the belief factors that are specific to Nepalese culture, which may or may not have been captured by the HBM.

CHAPTER I: BACKGROUND AND SIGNIFICANCE

Cancer is a leading cause of death worldwide, accounting for 7.9 million deaths in 2007 (World Health Organization [WHO], 2008). Globally, an estimated 274,883 women die annually as a result of cervical cancer (CC), the second most common cancer among women. About 86% of these cases occur in low-resource countries. The Asia Pacific region accounts for more than half of the world's cervical cancer burden. Current incidence rates suggest that the projected burden for the Asia Pacific region in 2025 will reach 62% (Parkin, Louie, & Clifford, 2008). Nepal, a developing country in the Asia-Pacific region, has the highest age-standardized CC incidence rate (32.4 per 100,000 women per year and a mortality rate 17.6 per 100,000 per year), compared to the rates estimated for Southern Asia and the world (See Figure 1).

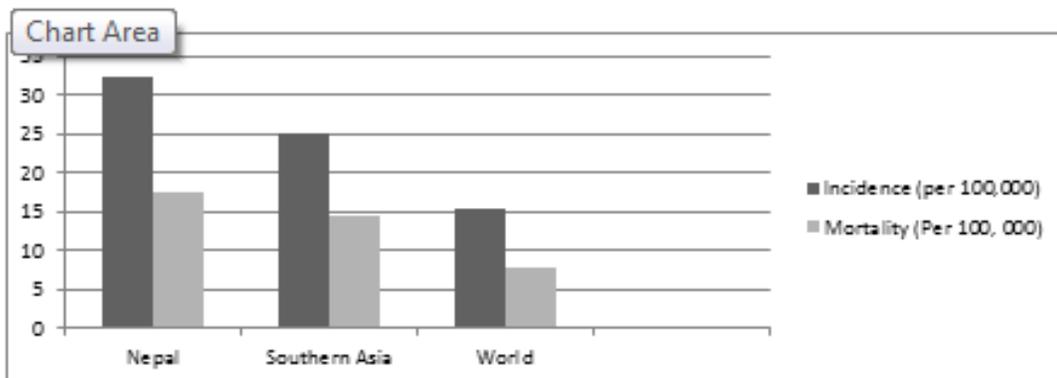


Figure 1 Age-Standardized Incidence and Mortality Rates of CC (adopted from WHO/ICO, 2010, p. 6 & p.12).

Nepal is a landlocked country between China and India in the Southern Asia region, which is composed of Afghanistan, Bangladesh, Bhutan, India, Iran, Maldives, Pakistan, and Sri Lanka (WHO/ICO, 2010). Nepal also belongs to the Asia-Pacific region, which is the part of the world around the Western Pacific Ocean that includes East-Asia, South-East Asia, and Oceania (World Atlas, 2012). See Figure 2.



Figure 2 Map of Nepal in South-Asia, accessed 02Apr2013 from World Atlas (<http://www.worldatlas.com/webimage/countrys/asia/np.htm>)

Nepal has a population of 8.53 million women age 15 years and above who are at risk for developing CC. Among those women, 3,504 are diagnosed with and 1,872 die from CC every year. According to WHO/ICO, CC ranks as the most frequent cancer in Nepal and the most frequent cancer among Nepalese women between 15 and 44 years of age (2010).

Additionally, among women in Nepal, CC has the highest mortality rate when compared to other cancers (WHO/ICO, 2010). CC is the most common malignancy and is often diagnosed at Stage II or higher. Stage II refers to the stage of tumor cells that are more likely to grow and multiply faster than Stage I (National Cancer Institute, 2012). Detecting CC in an advanced stage and/or when it is invasive reduces the chance of survival, thus increasing the mortality rate.

CC is a squamous cell carcinoma which affects the cervix, uterus, and pelvis (Bedford, 2009). Although CC is a major health concern, it can be easily detected via cervical cancer screening and has a high potential for prevention and cure (WHO, n.d.). A study conducted in 22 countries using 32 hospitals found that the central etiological factor in CC is genital Human Papillomavirus (HPV), consistently independent of other risk factors (Bosch et al., 1995). Furthermore, another study reported that 93% of CC is related to HPV (Bosch et al., 1995), a sexually transmitted (STD) virus. Although HPV rates in Nepal are not documented or reported, Nepal has the highest prevalence rates of HIV/AIDS, as compared to other countries in South Asia (CIA, 2011). See Figure 3.

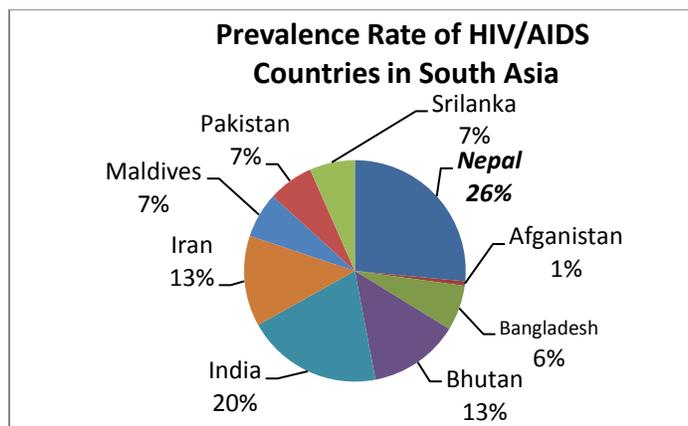


Figure 3: HIV/AIDS prevalence rate of Nepal among other countries in South Asia (CIA, 2011)

Other risk factors that may contribute to CC and lack of cervical cancer screening (CCS) in Nepal include a lack of screening availability and awareness. There are only 0.21 medical doctors per 1,000 people in Nepal and no healthcare workers in many rural regions (CIA, 2011). Moreover, the low literacy rate of 34.9% among women may impact their ability to comprehend the benefits of screening even if it were available.

Because of the fatal nature of CC, HPV vaccination and CCS are recommended by the WHO as effective methods for prevention and early detection of CC (2008). Although HPV is known to be a primary cause of CC and HPV vaccination is established to be one of the primary prevention methods, awareness and knowledge of the vaccination's potential for prevention is lacking among lower socio-economic status groups who are at the greatest risk for cervical cancer, even in a high-resource country such as the United Kingdom (Marlow, Waller, & Wardle, 2007). In the case of Nepal, HPV vaccine is too costly and rarely available. A feasibility study of HPV vaccination, conducted in Nepal (N=1096), concluded that the HPV vaccine is safe and has a high rate of acceptability (Singh et al., 2010). However, high cost and low awareness were found to be the primary barriers to HPV vaccination. Due to the limited resources, HPV vaccine is not yet easily available in Nepal. Although few small programs, offering HPV vaccination, are reported to have started (Nepal Natural and Human Resource Development Association [NAHUDA] and Nepal Fertility Care Center [NFCC], n.d.), the 2010 "Nepal Summary," an official publication of the WHO, did not report any introduction of HPV vaccine in Nepal (WHO/ICO, 2010), indicating the absence of a formal HPV vaccination program.

Nepal is among the poorest and least developed countries in the world, with almost one-quarter of its population living below the poverty line (CIA, 2011). Nepal's gross domestic product (GDP) per capita is only \$1,200 (CIA, 2011). GDP per capita refers to the dollar value of Nepal's GDP exchanged at market currency rates and divided by the average population of Nepal within that year (CIA, 2011). Developing the vaccination program in developing countries costs much more than is estimated by cost per dose. Countries, like Nepal, have to endure additional costs related to vaccine wastage, insurance, UNICEF's 6% procurement fee, programmatic and delivery costs, labor, education and access (International AIDS Vaccine Initiative/Program for Appropriate Technology in Health [IAVI/PATH], 2007). Considering the above issue, the lowest cost per fully immunized girl is estimated to be \$13 (IAVI/PATH, 2007, p.11).

Until recently, services for screening has not existed in Nepal's cities and is still not available in the rural areas. Therefore, Nepalese people feel closer and more comfortable with traditional methods, such as herbs, folk remedies, and spiritual healers (Wasti, Randall, Simkhada, & Teijingen, 2011). Seeking preventive services that have recently been introduced in Nepal (i.e. CCS) requires both trust and belief in CCS; aspects that require women to be strong enough to step out of their cultural boundaries, physically, socially and spiritually (Subedi, 1989). Furthermore, the Nepalese culture is based on curative and not preventive practices, and the population uses home remedies before seeking medical care even with obvious symptoms. Although not seeking medicine and preventive care is concerning, they also seek the traditional methods of care only when they are noticeably ill. This practice indicates that their focus for health is not

likely to be preventive, but curative in nature. Although medical care and preventive measures are available in many areas now, the practice to seek healthcare when disease or symptoms of disease are already apparent, continues within the Nepali culture (Wasti et al., 2011). This unique cultural practice is likely to impact Nepalese women's decision to undergo CCS. The findings of this study of belief factors and perceptions of Nepalese women may add value to improve education and/or intervention programs.

Cervical cancer screening (CCS) services are available in some areas of Nepal, but screening is mostly conducted only when a woman seeks medical care for other reasons. Sometimes, screening is offered only if the woman presents with symptoms. Despite the evidence that universal screening is important, women without symptoms are not routinely screened in many locations in Nepal (Pradhan, Giri, & Rana, 2007).

Methods for screening are different in Nepal compared to high-resource countries. Visual Inspection with Acetic acid (VIA) or Lugol's iodine (VILI) is the method used in Nepal, whereas the Papanicolaou test (Pap test) is used for CCS in high-resource countries. VIA, also referred to as direct visual inspection, cervicoscopy, or the acetic acid test, or the vinegar test, is conducted by passing the speculum to visualize the cervix as the cervix is washed with a dilute solution of acetic acid (or Lugol's iodine, in case of VILI). Then, the cervix is examined with a naked eye or handheld 4X magnification device and adequate light to identify the changes of appearance in the cervix. This approach allows the examiner to assess the results of the test as positive or negative (Lynette, 2005).

Prior to WHO's recommendation to use VIA/VILI as screening methods in low-resource countries, multiple research studies examined VIA and VILI for their accuracy and sensitivity in detecting CC. Both tests were found to be convenient, affordable, and accurate (Khan, Jha, & Pant, 2007; Dhaubhadel, Vaidya, & Choudhary, 2008). A descriptive study found that VIA and VILI have a higher accuracy than Pap test for detection of precancerous lesions of the cervix, and affirmed that these tests are adequate and cost-effective (Khan et al., 2007). VIA screening also has been found to be as sensitive and accurate in detecting any precancerous cells, which are identified by the Pap test and confirmed by cervical biopsy (Dhaubhadel et al., 2008).

Accessible, accurate, and affordable CCS services are available in some areas of Nepal. They are offered by a few non-governmental organizations (NGO), as well as private and governmental organizations (GO). Although universal screening is not yet available for women, the services that are available may not be utilized to their full potential. While women may not have a choice of screening if the services are not available, high cost and poor access are contributing factors in reducing the number of CCS and increasing the incidence of CC (Parkin et al., 2008). One of the most comprehensive CCS programs in Nepal is offered by NNCTR, which provides awareness, is accessible, and free of cost. Despite CCS's high potential for prevention and cure of CC, CCS is not always being utilized even when it is available, accessible and affordable according to Dr. Shrestha, S. (President-Nepal Network for Cancer Treatment and Research, personal communication, March 22, 2011). Thus, examining the belief factors that influence women's CCS behavior may identify the specific barriers and

predictive factors for CCS. The findings may inform future education and intervention programs, potentially increasing the utilization of CCS.

The high prevalence of morbidity and mortality associated with CC among Nepalese women underscores the importance of identifying the factors that contribute to the current low utilization of available screening services. WHO identifies CCS as an effective strategy to prevent and cure CC for women in low-resource countries. Three general categories of barriers to CCS have been identified in literature. The first category includes the structural barriers, some of which include availability, accessibility, and affordability. The second category includes the demographic attributes, and the third category includes the belief factors. The belief factors in this study are based on the Health Belief Model (HBM) constructs and are represented by perceived susceptibility, seriousness, benefits, and barriers (Glanz, Rimer, & Viswanath, 2008). To prevent suffering, death, and other consequences that can result from CC, effective education and intervention programs to increase CCS are essential. If education and intervention are to be effective, it is essential to investigate, identify, and incorporate the predictive belief factors of Nepalese women that impact CCS implementation.

While it is understandable that women may not undergo CCS when there are structural barriers, it is imperative to investigate the belief factors that may contribute to their behavior when the structural barriers are mitigated. The findings of the present study will help reveal the belief factors that predict or influence the utilization of CCS, potentially increasing the effectiveness of current education and intervention efforts.

The association between belief factors and CCS acceptance has been studied with various populations in different countries (Chavez, McMullin, Mishra, & Hubbell, 2001; Chigbu & Aniebue, 2011; Markovic, Kesic, Topic, & Matejic, 2000). However, there have not been any published studies in Nepal investigating whether Nepalese women's belief factors may predict or influence their CCS behavior. It is anticipated that findings of this study will begin the development of evidence needed to improve the utilization of CCS and thereby decrease CC incidence among women in Nepal.

Purpose Statement

The purpose of this study was to examine the role of belief factors on Nepalese women's CCS behavior. Specifically, the aim of this study was to examine the extent to which perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, cue to action, age, and education predict CCS behavior among Nepalese women.

Research Questions

1. What are the psychometric properties (i.e. validity evidence and reliability) of Nepalese Health Belief Model (NHBM) scale and its' domains: perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers?
2. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived susceptibility?
3. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived seriousness?
4. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived benefits?

5. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived barriers?
6. Is CCS behavior associated with cues to action?
7. To what extent do the combination of perceived susceptibility, perceived seriousness, cue to action, perceived benefits, perceived barriers, age and education predict CCS behavior?

Conceptual Framework

The Health Belief Model (HBM) was selected as a conceptual foundation for this study. The constructs of this model served as the reflection for independent variables in this study. The constructs within the model are the key concepts that represent the theory. The HBM is a psychological model developed in the 1950s to explain the lack of public participation in health screening and prevention programs, such as tuberculosis screening (Rosenstock, as cited in Tanner-Smith & Brown, 2010). By focusing on perceptions of individuals, the HBM attempts to explain and predict health behaviors. Since the early work in the 1950s, the HBM has been adapted to other health behaviors, for example sexual risk behaviors on the transmission of HIV (Family Health International, 2002). The HBM has also been tailored for use in breast cancer screening (Champion, 1999) and recently for use in cervical cancer screening (Byrd, Person, Chavez, & Heckert, 2004; Guvenc, Akyuz, & Acikel, 2010; Esin, Buiduk, & Ardic, 2011). Most commonly, it is used as a framework to study the screening behaviors that may result in prevention or early detection of a disease. Hence, for the purpose of this study, the HBM served as the framework to identify the correlates and predictors of screening behavior for CC.

The key concepts of the HBM include women's perception of susceptibility, seriousness, benefits, barriers, and cues to action (Glanz et al., 2008). In this study, these concepts were considered as potential predictors of CCS. The HBM constructs can be explained, as described below, using the concepts from Glanz et al. (2008):

- Perceived susceptibility represents one's subjective perception of the risk of contracting CC.

- Perceived severity represents the feelings concerning the seriousness of contracting CC or of leaving it untreated.
- Cues to action are prompting experiences, such as having a loved one who died from CC, or events that motivate individuals to take preventive action. These experiences may prompt a woman to undergo CCS by influencing her perceptions.
- Perceived threat is a conceptual construct not measured, but informed by perceived susceptibility, perceived severity, mediator variables and cues to action. Since this is not an independent measurable construct, this construct is not further explained in this study.
- Perceived benefits represent the perception of benefits in undergoing CCS.
- Perceived barriers represent the perceptions of certain factors being the obstacles in taking the action.

Using the HBM as a theoretical foundation for the study, the following factors were anticipated to relate to the behavior of obtaining CCS. First, a woman may perceive that she is at risk for acquiring CC if CCS is not obtained (perceived susceptibility). Further, a woman's likelihood of taking the action of obtaining the screening is associated with her perception of the seriousness of a CC diagnosis (perceived severity). Together, perceived susceptibility and perceived severity are expected to predict her perceived threat and the likelihood of taking action, i.e., completing CCS. The HBM also identifies perceived benefits and barriers to taking positive action as factors associated with completing the health promotion behavior (See Figure 4 for a modified Health Belief Model).

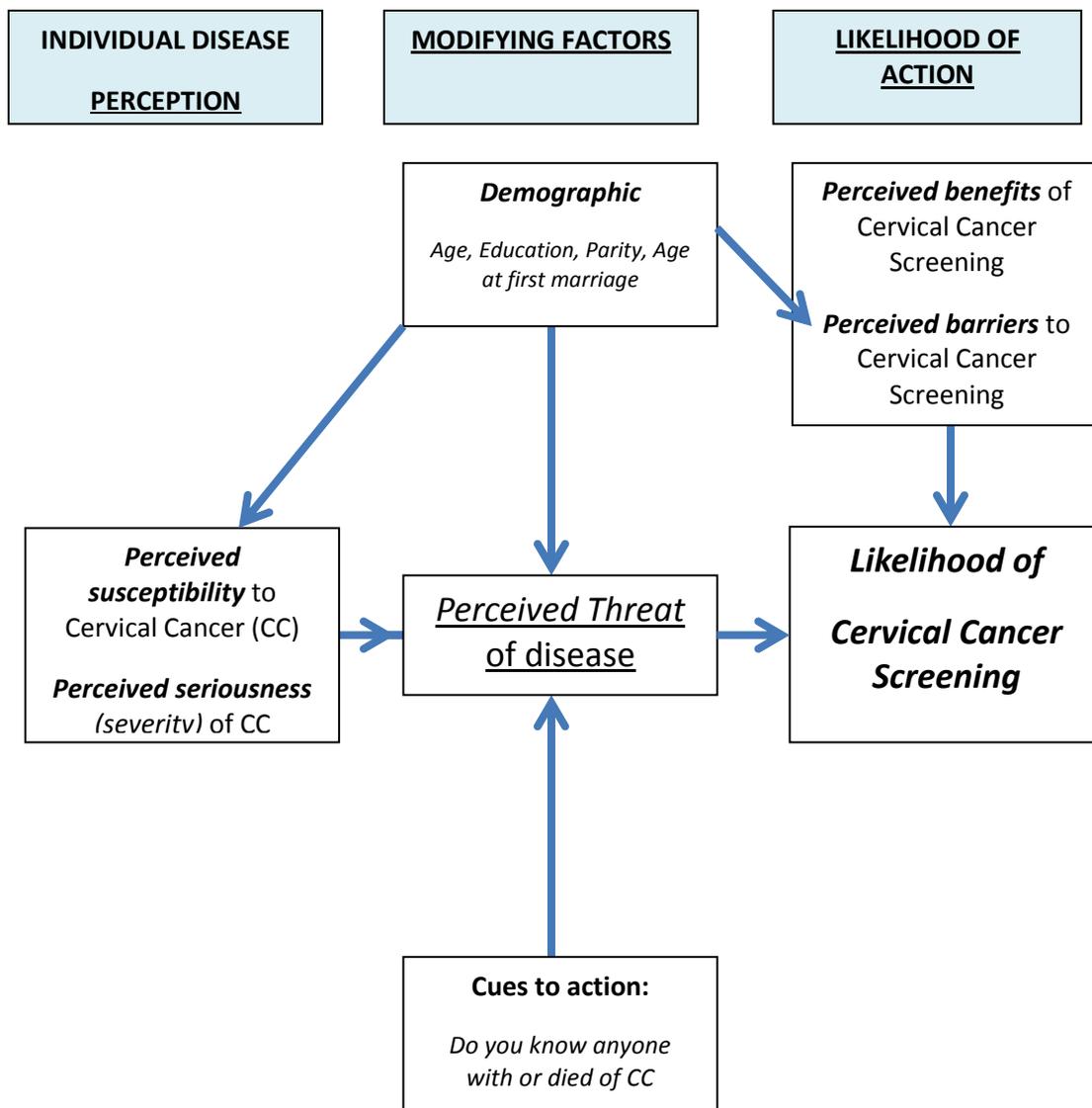


Figure 4: Health Belief Model-Adapted and modified from:Historical origins of the Health Belief Model, In M.H. Becker (ed.); *The Health Belief Model and Personal Health Behavior* , p.7.” by Rosenstock, 1974.

Study variables have been selected based on the constructs in the Health Belief Model and the outcome variable, CCS behavior. The conceptual and operational definitions of study variables are presented in Table 1. The survey items that are incorporated as operational definitions for each variable are the items from Champion's HBM scale that were modified for cervical cancer with permission for the purpose of this study.

Table 1 Conceptual and Operational definitions (Sources are in Parenthesis)

<u>Study Variables</u>	<u>Conceptual Definitions:</u> (Glanz et al., 2008)	<u>Operational Definitions:</u> (Guvenc, Akyuz & Acikel, 2010; Esin, Buiduk & Ardic 2011 & Champion, 1999)
Perceived susceptibility	Belief about the chances of experiencing a risk of getting a condition or disease	Subscale items for NHBM: <ol style="list-style-type: none"> 1. It is extremely likely I will get cervical cancer in the future. 2. I feel I will get cervical cancer in the future. 3. There is a good possibility I will get cervical cancer in the next 10 years. 4. My chances of getting cervical cancer are great. 5. I am more likely than the average woman to get cervical cancer.
Perceived severity	Belief about how serious a condition and its consequences are	Subscale items for NHBM: <ol style="list-style-type: none"> 1. The thought of cervical cancer scares me. 2. When I think about cervical cancer, my heart beats faster. 3. I am afraid to think about cervical cancer. 4. Problems I would experience with cervical cancer would last a long time. 5. Cervical cancer would threaten a relationship with my boyfriend, husband or partner. 6. If I had cervical cancer my whole life would change. 7. If I developed cervical cancer, I would not live longer than 5 years.
Perceived threat	The combination of perceived susceptibility and severity	A construct within HBM that is a concept that is informed based on measuring perceived susceptibility, seriousness, demographics and cues to action. This concept is not measured independently with any items.
Perceived benefits	Belief in efficacy of the advised action to reduce risk of seriousness of impact	Subscale items for NHBM: <ol style="list-style-type: none"> 1. When I undergo cervical cancer screening I feel good about myself.

<u>Study Variables</u>	<u>Conceptual Definitions:</u> (Glanz et al., 2008)	<u>Operational Definitions:</u> (Guvenc, Akyuz & Acikel, 2010; Esin, Buiduk & Ardic 2011 & Champion, 1999)
		<ol style="list-style-type: none"> 2. When I complete cervical cancer screening I don't worry as much about cervical cancer. 3. Completing cervical cancer screening will allow me to find out if there are early signs of cervical cancer. 4. If I complete cervical cancer screening, I will decrease my chances of dying from cervical cancer. 5. If I complete cervical cancer screening, I will decrease my chance of pain and surgery related to cervical cancer. 6. If I complete cervical cancer screening, it will help me find abnormality in my cervix which might be cancer before it becomes an invasive cancer.
Perceived barriers	Belief about the tangible and psychological costs of the advised action	Subscale items for NHBM: <ol style="list-style-type: none"> 1. I feel awkward going to get cervical cancer screening. 2. Undergoing cervical cancer screening will make me worry about cervical cancer. 3. Cervical cancer screening will be embarrassing to me. 4. Undergoing cervical cancer screening will take too much time. 5. Cervical Cancer Screening procedure will be painful. 6. Cervical Cancer Screening will interfere with my family obligations.
Cues to action	Strategies to activate "readiness"	Measure of other related exposure of information or experience that cues one to get CCS: Do you have a friend or a family member with CC or died from CC?
Status of screening	Membership into either "screened" or "not screened" group among Nepalese women who were exposed to the CCS awareness program.	Status of screening measured by "Yes" or "screened" AND "No" or "not screened."

Note. The conceptual definitions above were synthesized from Guvenc et al., 2010; Esin et al., 2011; Glanz et al., 2008 & Champion, 1999. The operational definitions illustrated are the instrument items of HBM based scale, which will be used in this study, adapted from Champion, V.L. (1999), Revised susceptibility, benefits and barriers scale for mammography screening. *Research in Nursing & Health* 22, p. 341-348.

Summary

Despite the evidence that CCS can play a major role in the prevention and early detection of CC for curative treatment, it is not available in some low-resource countries due to common structural factors, such as availability, awareness, accessibility, and affordability. Lack of screening among women may lead to an unfortunate outcome if the structural barriers are making it difficult or impossible for them to undergo screening. When those barriers are removed and the utilization of screening remains sub-optimal, further examinations are warranted to identify factors that hinder CCS.

Although the structural barriers in relation to many health conditions are identified to be common in low-resource countries, other barriers include belief factors that are associated with CCS behavior. While some published studies have investigated the belief factors as predictors of screening behavior across cultures, no published studies regarding belief factors and CCS behavior in Nepal were found. With the high incidence and mortality rates of CC and low CCS in Nepal, a research study examining belief factors that CCS usage is essential. This study investigates those belief factors to inform future education and intervention programs.

CHAPTER II: LITERATURE REVIEW

Introduction

Nepal, a low-resource country within the Asia-Pacific region, has one of the highest incidence and mortality rates of cervical cancer (CC) compared to South Asia and the World (WHO/ICO, 2010). CC is the most common, most frequent and most fatal cancer among Nepalese women (Dhakal & Pradhan, 2009; WHO, 2010). CC is also the only gynecological cancer that can be prevented with screening (Center for Disease Control [CDC] and Prevention, 2010). Additionally, routine screening can also detect early stage CC and early treatment is likely to be curative.

Despite the potential to be prevented and cured, CC is often detected only after the cancer is in the invasive phase. Routine screening could minimize the consequences; however resource scarcity plays a significant role in late stage CC in low-resource countries. Adequate screening for CC in Nepal is suboptimal due to the lack of national standards and restricted government support. World Health Organization (WHO) recommends Cervical Cancer Screening (CCS) as an effective strategy for prevention and early detection of CC. Another evidence-based strategy for prevention, HPV vaccination, may not be the best option for Nepalese women due to its high cost and poor access. Along with the recommendation to use CCS as the primary strategy for prevention, WHO has recommendations to use CCS for certain age groups, certain frequency, and the type

of test for CCS, with considerations for the priorities for the high risk groups within a low-resource country (WHO, 2006 & Goldie et al, 2005). The screening rate is very low in Nepal, 2.4% among all women between ages 18-69 (WHO/ICO, 2010). Lack of screening in this low-resource country could be related to structural factors, such as affordability, accessibility, and availability (Lynette, 2005; Agurto, Bishop, Sanchez, Betancourt & Robles, 2004; Chavez et al., 2001; Esin et al., 2011 & Rama et al, 2010). However, there are new CCS programs that overcome the structural barriers in Nepal and have increased women's awareness of the consequences of CC (Jhpiego, 2008).

Currently, only selective facilities and programs in Nepal are providing the services for CCS. Most of the services that are available, especially in hospital settings, are opportunistic at best. Opportunistic screening refers to services provided, such as CCS, only when a woman presents to seek medical care for other reasons. Among the five regions that make up Nepal, CCS is not available in Far-western and Midwestern regions. The Eastern region has only one hospital that offers CCS. The Western region has one public hospital and one private facility offering CCS as an opportunistic service. The Central region has the most facilities, four private and four public hospitals, which offer CCS which is only offered opportunistically (Jhpiego, 2008).

While there are CC prevention programs in Nepal, CC services that are coordinated nationally to screen for CC were not identified in research by Jhpiego (2008). The foremost cancer hospital in Nepal, BP Koirala Memorial Cancer Hospital (BPKMCH), is reported to have screened 5,000 women in 2008 (Jhpiego). Other screening efforts include screening initiatives of Nepal Network Cancer Treatment

Research (NNCTR), which screens the most women and has continued the services using donations, such as the current funding from the Australian Embassy (Jhpiego, 2008).

NNCTR, a Nepal branch of the International Network of Cancer Treatment and Research, has a cervical cancer screening camp program (CCSP) that incorporates the following structural factors within its program design: awareness, accessible CCS service for free. CCSP is a method to offer CCS by bringing the services to a location accessible to the women in their community. Even with such accommodations, the services are not utilized to their full potential (Dr. Surendra Shrestha, President-Nepal Network for Cancer Treatment and Research, personal communication, March 22, 2011).

While structural barriers can contribute to a low-screening rate, underutilization of services when those barriers are removed warrants further examination. Furthermore, if the awareness about CC and the CCS availability, affordability, and accessibility is ensured, the basic attributes for CCS behavior may be related to women's belief systems and investigating those factors may be essential (Lazcano-Ponce et al., 2002). Identifying those underlying factors may add value to education or intervention programs in order to increase the utilization of services, enabling CCS programs to reach more women to prevent or detect CC.

The purpose of this review is to explore the literature in order to identify the significant factors that pertain to CC and CCS, including consequences of CC, underlying attributes, the CC situation in Nepal, prevention strategies, CCS as an effective prevention method, CCS testing methods, as well as structural and belief barriers preventing women from undergoing CCS. Further, this literature review incorporates an

analysis of general factors that contribute to CCS behavior and specifically analyzes the belief constructs, based on the Health Belief Model, as predictive factors of CCS behavior.

The literature search was conducted electronically using CINAHL, PsychInfo, Medline and the Cochrane Library databases. Search words included the following words and their combinations: cervical, cancer, screening, behavior, belief, structural barriers, recommendation, health, belief, model, susceptibility, perception, seriousness, perceived, benefits, cues to action, perceptions, Pap test, Pap smear, VIA, VILI. Additionally, the bibliography of seminal works and citations was used to access academic articles that were pertinent to the subject area of this research in English. Timeframe was not a vital criteria in this search because the recent literature was limited in the topic area. Articles dated up to ten years were reviewed except for the subject matter of theory and statistics had no specific time limits. Websites of the following key stakeholders were navigated: the World Health Organization (WHO), Centers for Disease Control and Prevention (CDC), the Alliance for Cervical Cancer Prevention (AACP), the International Network of Cancer Treatment and Research (INCTR), Nepal Network of Cancer Treatment and Research (NNCTR), and the National Cancer Institute (NCI).

Cervical Cancer

CC is a cancer that starts in the cervix, which is located between the birth canal and the uterus (CDC, 2010). It is identified as a squamous cell carcinoma which affects the cervix, uterus, and pelvis (Bedford, 2009). Although it is the easiest cancer to prevent,

it is also the cancer that remains asymptomatic until it is in the invasive phase, which is only evident by vaginal bleeding or abnormal discharge (CDC, 2010). These facts heighten the importance of CCS's role in detecting the cancer at a precancerous stage or before cancer become invasive.

Underlying attributes. There are many sources that report a strong association between Human Papillomavirus (HPV) and CC. The central etiological factor in CC is reported to be genital HPV, consistently independent of other risk factors (Bosch et al., 1995; Clifford, Goncalves, & Franceschi, 2006). The International Biological Study Group conducted a study in 22 countries using 32 hospitals and found that 93% of CC is related to HPV, although a positive HPV does not imply CC (Bosch et al., 1995). Other co-factors that have been associated with CC include smoking, multiple sexual partners, high parity, age at first intercourse, age at first marriage, immune-suppression, and long-term use of contraceptives (WHO, 2010; HPV/ICO, 2010; Pradhan et al., 2007; Dhakal & Pradhan, 2009). Since CCS is reported to be preventive of CC, a lack of screening or delayed screening would hinder the possibility to detect the precancerous cells, resulting in increased cases of CC. Additionally, the consequence may include detecting CC at a stage when it is difficult or impossible to treat. Thus, a lack of screening can also be considered an underlying attribute contributing to the diagnosis of CC.

CC in Nepal. Nepal has the highest age-standardized incidence and mortality rate of CC compared to the rates estimated for Southern Asia and the world (WHO, 2008), as illustrated in Figure 1 in the "Background" section of this dissertation. Because Nepal's CC incidence and mortality rate is one of the highest in the world, there should be a high

priority to develop effective screening programs. However, in Nepal, the low percentage of cost coverage by the government, in addition to a lack of necessary resources, contributes to the lack of screening. According to the most recent WHO data, only 4.7% of women had cost coverage for CCS in urban areas and 2.0% in rural areas, averaging an 2.4% in the country (WHO/ICO, 2010). However, there were no reported data on the percentage of women actually screened.

Exacerbating the above situation, Nepalese persons' practice is reported to be curative rather than preventive, where individuals present to a medical institution only after the symptoms are noticeable and painful (Jhpiego, 2008). As a result, CC among Nepalese women is normally not diagnosed until it is at an invasive stage, when it is already too late to treat the disease. A study conducted with Serbian women reported that health care services that are poorly developed, with a focus on curative rather than preventive approach, is a significant factor in detecting cancer at a more invasive phase (Lynette, 2005).

In addition to the rising rates of CC and its prevention challenges, the economic impact of cancer and its consequences continue to increase the cancer burden in Nepal. In 2008, the total economic impact of premature deaths and disability from cancer worldwide was \$895 billion, representing 1.5% of the world's gross domestic product (GDP) (American Cancer Society [ACS] & Livestrong, 2011). The World Bank classifies Nepal as a low-income or low-resource country, as determined by calculating the economies, based on the gross national income (GNI) per capita, using the World Bank Atlas method to divide economies (WHO, 2010, p. 50). The economic impact of CC is

reported to be largely disproportionate in low- resource countries, such as Nepal, due to a lack of access and limited use of preventive services. It is reported that a lack of screening contributes to the continued disproportionate burden of CC (ACS & Livestrong, 2011). The high economic impact in a low-resource country is like a revolving door, because the economic burden is increased due to a lack of screening, and the lack of screening may result from a lack of resources (ACS & Livestrong, 2011). Because the already increased economic burden is attributed to a lack of screening, the utilization of available screening services is paramount to galvanize the resources needed, in order to expand services to prevent and cure more women.

The suffering and pain that women have to endure at an individual and family level with their sickness and death is yet another negative outcome of CC. The experience of women, families, and the children may be a consequence that is not reflected in numerical data. The pain and death that women with CC encounter, the abandonment that the children endure, and the economic loss that has to be tolerated at all levels are worth considering when calculating the CC impact (ACS & Livestrong, 2011). Additionally, the effect of maternal death on child survival is reported to be significant. A study on child survival after maternal death in Bangladesh revealed that the cumulative probability of survival to age 10 years was 24% in children whose mothers died (N=1,385) before their tenth birthday, compared with 89% in those whose mothers remained alive (N=143,473) (Ronsmary, Chowdhry, Dasgupta, Anisuddin, & Koblinsky, 2010). Anderson, Morton, Naik, & Gebrian (2007) found that if a family experiences a maternal death, the family has a 55.0% increased odds of experiencing the loss of a child

less than 12 years, whereas when a no maternal death occurs there are no increased odds. As evidenced by these studies, the consequences of CC do not stop with the death of the woman.

According to a retrospective study, the CC incidence and mortality rates has markedly risen over the last ten years, which concluded that routine cytological screening is urgently needed to ensure early detection and treatment (Jha et al., 2009). Because most CC is in the invasive stage on detection in Nepal, it continues to negatively impact the lives of women, increasing the rates of incidence and mortality. Although CC is one of the cancers that has the most potential for prevention and cure among all cancers of Nepalese women, it continues to negatively impact the women and drain the country's resources (WHO, 2008; Dhakal & Pradhan, 2009). If CCS services are available, affordable, and accessible, low utilization of those services is a lost opportunity that is invaluable at an individual and community level.

Prevention and early detection. CC is the only gynecological cancer that can be prevented. Furthermore, it is the easiest cancer to prevent because of the ability to detect precancerous cells during screening. When identified, the treatment would eradicate the precancerous cells before they become cancerous (CDC, 2010). CCS is essential especially because CC is the only gynecological cancer that is asymptomatic and presents itself only when a woman has vaginal bleeding or abnormal discharge (CDC, 2010).

CCS can help find cancer cells at a stage before the cancer is symptomatic. The earlier the CC is detected, the earlier it can be treated, avoiding complex consequences related to a more advanced cancer. Therefore, a woman has to seek CCS when she is

healthy and asymptomatic. If the pre-cancerous cells are treated, then the CC may be prevented (WHO, 2010). Moreover, the National Cancer Institute (NCI, 2010) report that CCS decreases the incidence and mortality of CC.

With the finding that HPV is associated with CC, preventing transmission of the HPV virus is one of the strategies to avoid cancer. Although research has established that HPV vaccine is one of the most effective measures in preventing CC, its use in Nepal is challenging due to low public awareness and high cost (Singh et al., 2010; WHO/ICO, 2010). In other words, even though there may be occasional vaccination programs, HPV vaccination is reported to be impractical for Nepal due to resource scarcity (Singh et al., 2010; Jhpiego, 2008, p.3). CCS is another method recommended for prevention and early detection of CC. Because the study purpose was related to CCS and screening behaviors, the remaining review focus is related to CCS.

Cervical Cancer Screening (CCS)

Standards for high-resource and low-resource settings are different for CCS due to the variation in available resources. The lack of resources contributes to lower screening rates in low-resource countries, such as Nepal, which may also lack a national guideline for screening and following the WHO guidelines (Baral, 2009). There are marked differences in guidelines for coverage of CCS between high-resource and low-resource settings. For example, the United States' standards recommend that women must have CCS by 21 years of age and be screened at least every two years (ACS, 2011). However, low-resource countries, such as Nepal, follow the WHO guidelines, which

indicate that new CCS programs should start screening at age 30 or older and include younger women only when the high-risk group has been covered (WHO, 2006, p.11). The differences in these guidelines may account for the difference in the incidence and mortality rates attributed to CC.

Screening methods - VIA and Pap-test. One of the reasons that low-resource countries were unable to provide screening before new methods were available was the cost, manpower, and medical resources needed to conduct the Pap smear test (WHO, 2002). In recent years, new tests have shown to be sensitive, accurate, and cost-effective (WHO, n.d.; Ngelangel et al., 2003; Ngoma et al., 2010; Bhatia et al., 2009). While the WHO recommendation for screening according to age group and frequency remains the same as in 2002, the recommendation for methodology, Pap test versus VIA/VILI, has changed to VIA/VILI (WHO, 2002; WHO, 2006). In recent years, most low-resource countries have been using VIA (visual inspection with acetic acid) or VILI (visual inspection with Lugol's iodine).

Sensitivity and specificity of VIA. With any screening test, it is important to determine whether it detects what is being measured and whether it detects it accurately. Current evidence indicates that the effectiveness, accuracy, acceptance, and cost-effectiveness of VIA/VILI have been studied extensively as described below. To compare the validity and acceptability of VIA (inspection-based) versus Pap test (cytology-based), in Phillipines, Ngelangel et al. (2003) reviewed 12,992 women's biopsy samples that indicated positive or suspicious cases. They found VIA to be valid and reported that women who were screened preferred VIA.

To inspect the accuracy of VIA, a meta-analysis of 26 studies reported that VIA has 80% sensitivity and 92% specificity, deeming it highly accurate (Sauvaget, Fayette, Muwonge, Wesley, & Sankarnarayanan, 2011). Additionally, the researchers concluded that the capacity of the screener or the size of the study population did not modify the test's accuracy. In Tanzania, Ngoma et al. (2010) evaluated the feasibility and performance of screening for CC using VIA or VILI with a sample size of 10,378 and found that both screening tests were accurate. In North India, 3,000 women participated in a cross-sectional study, designed to evaluate the detection rates of different stages of cancer, aimed to assess the accuracy of VIA and cure rate after treatment. Bhatia et al. (2009) found that both VIA and VILI were accurate screening tests and the cure rates were satisfactory. Similarly, in Colombia, researchers assessed the accuracy of VIA/VILI and concluded that VIA/VILI are a “good alternative” for screening (Murillo et al., 2010). A review of the literature clearly indicates that VIA/VILI are cost-effective, accurate, and valid tests. Even with the accurate and cost-effective method for screening and established guidelines, however, the utilization of services that are available is not nearly optimal.

Additionally, in an International Agency for Research on Cancer (IARC) handbook, the sensitivity and specificity VIA and cytology in screening CC was compared based on a review of available literature (WHO/IARC, 2005). Out of 16 studies, 12 studies found VIA to have a higher sensitivity rate and 13 studies found cytology to have a higher specificity rate. VIA had an average sensitivity rate of 70.8%, and cytology had average sensitivity rate of 53.5 %, whereas cytology had average

specificity rate of 85.5 % as compared to VIA, which had a specificity rate of 79.3% (WHO/IARC, 2005, p. 82). Overall, VIA had a higher sensitivity rate and cytology had a higher specificity rate, indicating that VIA was sensitive in detecting precancerous and cancerous cells adequately.

Cost effectiveness. Using computer-based models, Goldie et al. (2005) assessed the cost-effectiveness of CC strategies in five countries. They found that the VIA screening method was more cost-effective than Pap test and HPV screen. The cost attribute included the cost of travel, time, equipment, laboratory, supplies, and staff (See Figure 5).

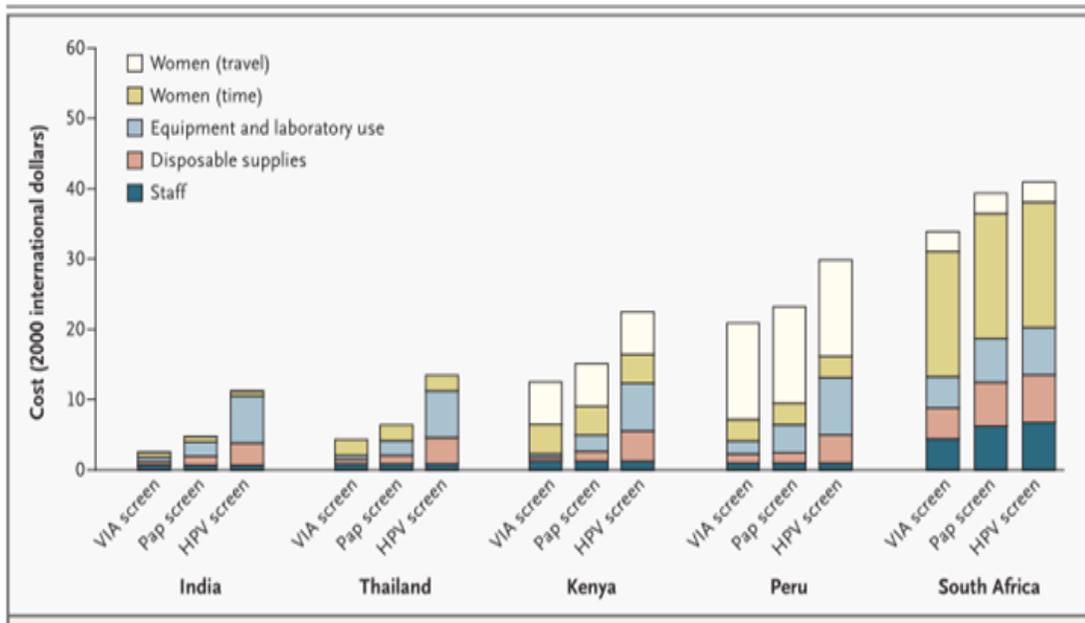


Figure 5: Costs associated with VIA as compared to Pap-Screen-Copied with permission from “Cost-Effectiveness of Cervical-Cancer Screening in Five Developing Countries” by Goldie et al., 2005, New England Journal of Medicine, 353(20), 2162.

Barriers and Predictors

It is well established in research that screening reduces mortality caused by CC (Baron et al., 2008). According to the National Cancer Institute's report, estimates from population studies suggest that screening may decrease cancer incidence and mortality by more than 80% (2010). VIA is an accurate and cost-effective screening method used to detect pre-cancerous or cancerous cells. Even with the awareness that CCS can prevent and detect cancer in early stages, there are many barriers. These barriers involve structural, demographic, and belief factors. These predictable factors overlap in influencing CCS participation. The literature suggests there is a pattern of structural and demographic factors influencing the CCS participation or behavior, by first influencing women's perceptions and beliefs.

General overview. Cost coverage for CCS is a major structural challenge in low-resource countries. The significantly lower levels of coverage of CCS for low-resource countries as compared to high-resource countries are validated in the analysis of the 57 countries as illustrated in Figure 6 (Gakidou, Nordhagen, & Obermeyer, 2008).

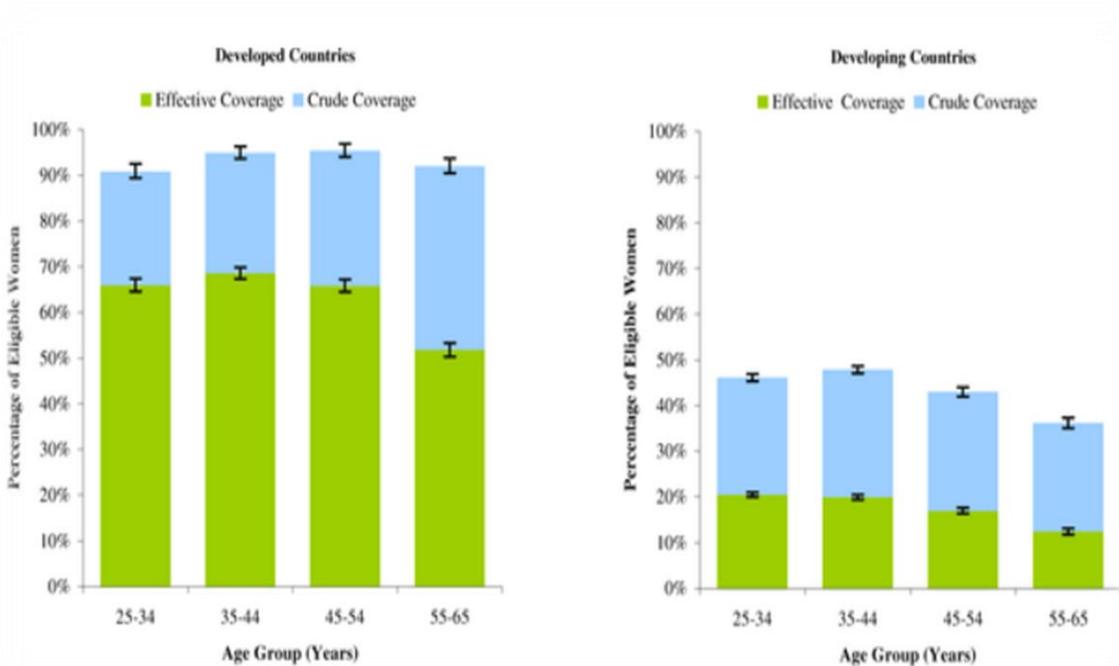


Figure 6: Cost coverage for CCS in Developed Countries as compared to Developing Countries-Copied with permission from “Coverage of CCS in 57 countries: Low average levels and large inequalities” by Gakidou E., Nordhagen S., & Obermeyer Z. (2008.) PLoS Medicine, 5(6), e132.

With the aim to investigate factors contributing to Chinese women’s attendance of CCS, Holroyd, Twinn, and Adab found that cost was a significant factor in addition to education, knowledge of risk, and cultural issues (2004). In this study, modesty and embarrassment (perceived barriers) were identified as significant factors for CCS.

Another study reported that age, insurance status, smoking status, and education were significant predictors of adherence to CCS (Nelson, Moser, Gaffney, & Waldo, 2009).

A study exploring the main factors associated with increased utilization of CCS programs in a population with a high mortality rate due to CC (N=2,094), revealed that educational level and low-cost coverage for CCS were significant (Lozano-Ponce et al., 2002). The authors concluded that “it is of particular importance to take into account and

satisfy the perceptions and expectations of women at risk (Lozcano-Ponce et al., 2002, p. 186).”

The general obstacles for CC prevention and undertaking CCS in low-resource countries include limited public awareness of CC as a health problem, cultural barriers, limited screening service availability, and high cost of services (Markovic et al., 2000). This study reflected the presence of structural barriers of availability, affordability, and accessibility that negatively impact CCS uptake. In a qualitative study, exploring the barriers to CCS among women in Serbia, Markovic et al. identified education, socio-cultural health beliefs, and gender roles as some of the most salient barriers to screening (2005). Further, while investigating women’s knowledge of the perceived barriers to CCS, the thematic analysis identified that interplay of social and personal barriers influenced women’s poor presentation for CCS. In another quantitative study conducted in Nigerian women aware of CCS (N=3,712) to evaluate reasons behind failure to participate in CCS, researchers found that knowledge of CC, education, and age made a significant impact on CCS (Chigbu & Aniebue, 2011). Further, they report that fear of violation of privacy (a perceived barrier) is the major reason for non-participation in CCS (Chigbu & Aniebue, 2011).

An ethnographic qualitative study in California with a multi-ethnic sample found that socioeconomic factors, such as insurance, age, marital status, education, and language acculturation, may predict CCS behavior more than beliefs; however, the authors also report that those women whose belief was similar to the Latina group were significantly more likely to have had a Pap test (Chavez et al., 2001). Although

socioeconomic factors may predict CCS behavior, this study indicated that change in perception plays a role for women to take action and undergo CCS.

There are structural and demographic barriers to CCS that are evident in the literature as presented above, including cost, access, availability, education, age, insurance status, and more. However, it is noted that socio-economic and structural factors influence CCS by first influencing the women's beliefs and perceptions. This finding, as discussed in the above literature review, is congruent with the HBM model (see Figure 4) and analytic framework (see Figure 7). An analytic framework was used by Baron et al. (2008) to present the results of systematic reviews of effectiveness, applicability, economic efficiency, and other barriers to implementation designed to increase screening for breast, cervical, and colorectal cancers. This framework suggests that reducing the barriers and increasing the access changes clients' attitude, perception, and intent, which, in turn, influence the increase the rates in completed screening. Additionally, the study illustrates that reducing the structural barriers also influences other positive or negative effects on client behavior or preventive services received (see Figure 7).

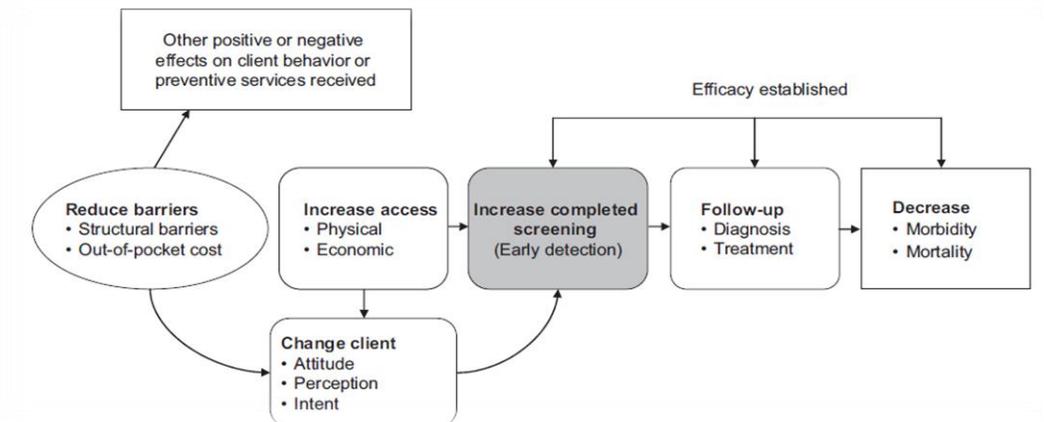


Figure 7: Analytic framework by Baron et al (2008)-Copied with permission from “Client-Directed Interventions to Increase Community Access to Breast, Cervical, and Colorectal Cancer Screening: A Systematic Review,” by Baron et al. (2008). *American Journal of Preventive Medicine*, 35(1S), S58. Copied with permission from Elsevier’s copyright center.

Note. This framework illustrates that a change in client perception *directly* influences the increase in completed screening. Reducing the structural barriers *indirectly* influences the number of completed CCS by *first* influencing the perceptions. Structural barriers also directly influence the change in client behavior, which is likely to increase completed screening. The importance of screening is illustrated in terms of its role in early diagnosis and follow-up with treatment, which leads to reduction of morbidity and mortality.

HBM constructs and CCS

The factors that contribute to preventive behavior such as CCS have been studied by many researchers using many different theoretical frameworks. Among those theories, the HBM was selected as a guiding framework for this study. The HBM attempts to explain and predict health behaviors by focusing on the perceptions of individuals. Most

commonly, it is used as a framework to study the screening behaviors that may result in prevention or early detection of a disease (Glanz et al., 2008). More details regarding the selection of HBM as a guiding theory are presented in the “conceptual framework” section of this dissertation. For this review, studies using HBM as a theoretical model in the published literature were examined, exploring the association between CCS behavior and the following HBM constructs: perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, and cues to action.

When a woman does not undergo CCS, she risks CC being detected at an invasive phase, when it is too late to cure the disease, leading to the woman risking pain, suffering, and even death (*perceived seriousness*). If the woman does not believe herself at risk (*perceived susceptibility*), even if the structural barriers are removed, she is less likely to utilize the preventive services (Montgomery & Bloch, 2010). After her awareness of susceptibility, fear of CC (*perceived barrier*) is reported to have a significant association with CCS behavior (Grange, Malvy, Lancon, Gaudin, & Hasnoui, 2008). When a woman perceives that there are benefits, she is more likely to undergo CCS. Barriers are reported by several studies as a negative factor associated with CCS behavior (Esin et al., 2011; Simkhada, Porter, & Teijling, 2010).

Belief factors contributing to screening behavior have been studied with various populations in various countries in an attempt to improve utilization rates. The role of Nepalese women’s belief factors in preventing CCS has not been studied in Nepal, despite the fact that Nepal is one of the countries with highest incidence and mortality rate of CC in the world. For this study, the participants were recruited from a CCS

program at NNCTR, which provides women with CC awareness and CCS accessibility free of cost. Because this CCS program already mitigates the structural barriers (awareness, availability, accessibility (screening camp), and affordability (free)), confounding variables related to those issues were minimized among the study participants. A woman's decision to undergo CCS may depend on those structural factors more so than on her beliefs; however, the structural barriers were removed from our study participants by design, as NNCTR removed all of them. The study population included the women who attended the awareness program of NNCTR, so they also had awareness before we selected the sample, increasing the clarity between our predictors and dependent variable.

Unavailability of CCS services is the reality in many low-resource settings. In those settings where the CCS programs are available, structural factors such as awareness, accessibility, and affordability are reported to be the major barriers to screening uptake (Agurto et al., 2004; Chavez et al., 2001; Esin et al., 2011; Tebeu et al., 2008; Ogunbowale & Laoyin, 2008; Rama et al., 2010). When the services do surpass the much-needed structural barriers of availability, awareness, accessibility, and affordability, under-utilization of those life-saving services becomes highly concerning. Since the resources are in place and the consequences of CC continue, despite a potential for CC prevention and cure, an investigation of potential factors contributing to CC may reveal attributes that could inform education and interventions designed to impact increase in CCS utilization. When structural factors are managed, belief factors may be the culprit related to the lack of screening (Tacken et al., 2006).

The trend in the literature is that structural and demographic factors are associated with CCS behavior; however, they do so by first influencing the woman's perception (McMullin, Alba, Chavez, & Hubbell, 2005; Chavez et al., 2001). In a qualitative study that attempted to assess the impact of beliefs on Pap smear participation, the researchers indicated that a low level of knowledge led to inaccurate beliefs, which affected women's preventive behavior (McMullin, Alba, Chavez, & Hubbell, 2005). There is some evidence that a woman's belief system may be the final determinant to preventive action and the combined demographic factors may influence her belief system. The literature suggests that demographic variables such as age, knowledge, socioeconomic status, and education may have an impact on preventive behavior by affecting the woman's belief system (Chavez et al., 2001; McMullin et al., 2005). Informed by demographic variables or mediators, it seems logical to study belief factors as the direct predictive attributes of CCS behavior. Byrd, Person, Chavez, & Heckert (2004) demonstrated that although women understood susceptibility, seriousness, and benefits of CCS, their perceived barriers (such as pain or embarrassment) ultimately played a role in whether they undertook the screening. Beliefs may be more influential than knowledge, as demonstrated by this study, which is also congruent with the analytic framework and the HBM.

In the literature, there are many overlaps among the HBM constructs as they relate to CCS behavior. For example, Burak & Meyer (1997) found that the HBM factors that were significant in predicting gynecological screening were susceptibility, benefits-barriers, and cues to action. Perceived seriousness was not a significant predictor in their

study. The variations in the relationships between the constructs and the dependent variable are different among populations and cultures, as evidenced by the literature.

Perceived susceptibility. When a woman perceives she is immune to illness, she is likely to neglect preventive care. If one does not believe that something would be detected, it can be expected that preventive screening may not take place. This phenomenon is referred to as *perceived susceptibility* in the Health Belief Model. If women hold such fatalistic beliefs about cancer prevention, they may be at a greater risk of developing cancer because they are less likely to engage in preventive behaviors (Niederdeppe & Levy, 2011). In a study conducted in Korea, findings suggested that a belief that screening was not necessary was the most frequent reason for a lack of screening (Juon, Seung, & Klassen, 2003). Similarly, a study in New Zealand found that one of the most predictive factors affecting CCS participation was women's beliefs that CCS was not necessary for asymptomatic women (Gao, Desouza, Paterson, & Tongjin, 2008). The perceived susceptibility among various populations carried a similar theme. A qualitative study among Latina immigrants reported the emerging theme that they only needed CCS if they had symptoms (McMullin et al., 2005). Similarly, one of the reasons for a lack of CCS among minority women in Canada included believing it was not necessary (Amankwah, Ngwakongnwi, & Quan, 2009).

Perceived seriousness. It is reported in some studies that fear of cancer, indicative of *perceived seriousness*, is associated with CCS behavior (Agurto et al., 2004; Grange et al., 2008). However, a study involving five Latin American countries reported: "Fear of cancer and death: Most women would rather not know about diseases which

have no treatment that they know of and which might lead to death” (Agurto et al., 2004, p. 94). Researchers also reported that this barrier was found most strongly in Mexico, among women who had never had a Pap smear. For these five Latin American countries, perceived seriousness was negatively related to CCS behavior. Although this attribute of *perceived seriousness* was associated with CCS behavior in both studies, the direction of the relationship is not clear. In the study by Grange et al. (2008), fear of cancer was positively related to CCS behavior, while in the study by Agurto et al. (2004), fear of cancer was negatively associated with CCS behavior. Nevertheless, *perceived seriousness* was a predictive factor of CCS behavior.

Perceived benefits. Perceived benefit refers to the women’s views that there is or will be a benefit as a result of undergoing screening. When they foresee such benefits, this may increase the probability that they will undergo CCS. Perception of benefit can change under certain conditions, as could other perceptions. A study that examined knowledge and health beliefs associated with CCS among Korean American women found that those who had more knowledge also perceived more benefits of having CCS and was more likely to have CCS (Lee et al., 2008). This indicates that *perceived benefits* may be predictive of CCS.

Perceived barriers. Although structural barriers are removed and there are no barriers seen by others, women’s perceptions can themselves be barriers. This phenomenon is another construct called *perceived barriers* in the HBM. This factor appeared most often in the literature as being the predictive or associative factor with CCS behavior and uptake. For example, “I don’t know where I could go” and “the test

would be painful” are the items in a survey representing this construct that were negatively associated with CCS (Byrd et al., 2004). Similarly, “I don’t know where I could go if I wanted CCS” was four times more decisive as a factor for not having a Pap test than having a pap test (Esin et al., 2011). In the same study, other items within this construct that were also significant factors in the decision as to whether to have a Pap test included “Pap test is painful” and “Having a Pap test makes me worry.” In another study conducted among women of Ghana examining the knowledge and health beliefs of CCS, Abotchie and Shokar (2009) found that concern about what others may think (*perceived barrier*) was a significant factor. Additionally, only half of the women perceived themselves at risk (*perceived seriousness*) and other perceived barriers were indicated by their responses that the test is painful and the belief that the test will take away their virginity. In another study examining the barriers to CCS attendance in England, researchers found that the most commonly endorsed barriers were embarrassment, fear of pain, and worry about what the test might find (Waller, Bartosz, Marlow, & Wardle, 2009).

Cues to action. Cues to action, one of the constructs of the HBM, is a “prompt” to a CCS decision influenced by the condition or experience that a person has encountered, such as a TV advertisement, media, or having a mother die from CC. Although perceptions as represented by HBM constructs may play a primary role in CCS behavior, an external factor, such as their friend dying of CC, also influences the woman’s decision to undergo CCS. Research has found that one of the strongest correlates of regular Pap smears was having friends or family attending screening (Juon

et al., 2003). While factors such as the media or newspaper advertisements could be included as items in the *cues to action* construct, the significant association was reported between CCS behavior and “knowing someone who had the diagnosis of CC” (Levy et al., 2006, p. 17).

Measurement: Cervical Cancer Screening Behavior

The Health Belief Model (HBM), the most commonly applied theoretical concept for health behavior research, is measured by numerous instruments to capture its constructs in the context of disease prevention behaviors (Glanz et al., 2008). Among the instruments that measure the HBM constructs is Champion’s tool, the HBM scale. The HBM-based scale is utilized most commonly in the literature for its validity, reliability, and success in its adoption in relation to health behavioral studies, such as HIV/AIDS, colon cancer, and CC prevention. Additionally, it has been successfully adapted by researchers for target populations with different languages and/or cultures. Champion’s HBM scales were assessed for content validity, revised based on analysis for content validity, and administered to a probability sample of 581 women who participated in a large intervention study (Champion, 1999). All HBM scales were measured using a 5-point Likert scale. Internal consistency and test/retest reliability for each of the constructs are presented in Table 2.

Table 2 Psychometrics of Champion's HBM scales

Subscales of HBM in Champion's HBM Scales	Psychometrics of Champion's HBM scales	
	Alpha	Test/Retest Reliability
Susceptibility	0.93	0.70
Seriousness	0.80	0.45
Benefits	0.80	0.45
Barriers	0.80	0.65

Note. Champions HBM scales for all four subscales indicate good validity and fair test/retest reliability for subscales *seriousness* and *benefits*. Adapted with permission from “Revised susceptibility, benefits and barriers scale for mammography screening,” by Champion, V.L, 1999, *Research in Nursing & Health* 22, p.349.

Glanz et al. reported that Champion's HBM scales have been translated into at least four languages. The internal consistencies of those translated instruments are presented in Table 3(2008, p.52). The table indicates that the reliability of the instruments in those cultures/languages is good as indicated by Cronbach Alpha ≥ 0.70 .

Table 3 Internal consistencies after translation of HBM into other cultures

Subscales of HBM in Champion's HBM Scales	Internal Consistencies after Translation into Other Cultures			
	Turkish	Arabic	Chinese	Korean
Susceptibility	0.82	0.85	0.92	0.78
Seriousness	0.83	0.81	0.85	0.75
Benefits	0.82	0.79	0.79	0.87
Barriers	0.75	0.77	0.74	0.90

There are more translations of Champion's instrument in the literature than those listed above. For example, Parsa, Kandiah, Mohd, Hejar, & Afiah (2008) translated Champion's HBM scale into the Malaysian context and validated the scale among Malaysian women. They found that the Cronbach's alpha reliability coefficients ranged from 0.77 to 0.94 for the subscales of HBM. The translated version was found to be valid and reliable for use with Malaysian women. The use of the tool reaches across countries throughout the world and, after translation, is used not only to measure breast cancer prevention behavior, but other disease prevention behaviors such as CCS.

To measure the concepts of the HBM, Guvenc et al. (2010) developed an instrument, the Health Belief Model Scale for CC and Pap Smear Test based on Champion Health Belief Model scales (Champion, 1993; Champion, 1999), for breast cancer screening (Champion, 1993; Champion, 1999; Guvenc et al., 2010). The HBM scale for CCS and Pap smear test was reported to follow the translation process consistent with the research methodology for translation. For the final instrument, with 35 items, the Cronbach's alpha reliability coefficient for the five subscales (perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, and health motivation) was reported to range from 0.62 to 0.86; a test/retest reliability coefficient was reported to range from 0.79 to 0.87 for the subscales (Guvenc et al., 2010).

Another example of Champion's HBM scale, for breast cancer prevention behavior, serving as a foundation for a CC prevention behavior study, is reflected in research by Allahverdipour & Emami (2008), who used this scale to study the association between HBM variables and the Iranian women's participation in CCS. They adapted the

original instrument to measure CCS behavior, translated and adapted it to Iranian language and culture, and utilized it for the study about CCS behavior.

Translation

Considering the international nature of this study and a target population of different languages and cultures, a translation method that is effective and sensitive to linguistic and cultural differences is essential in developing an instrument that is valid and reliable. While some studies fail to report the method of translation, many studies are noted to utilize back-translation and incorporate expert review and pilot testing as a part of the procedure (Medina-Shepherd, 2010; Beaton, Bombardier, Guillemin, & Ferrer, 2000). In the literature review for this dissertation, reference to any standards for the translation process and details of the method in the process was found to be lacking in most of the published research. Forty-seven articles that Maneesriwongul & Dixon (2004) reviewed revealed that information about instrument translation processes provided in the publications was inadequate, and the researchers recommended that all studies involving instrument translation should include information to establish that translation processes were adequate.

Pan and Puente (2005) disseminate the Statistical Research Division (SRD) official guidelines and recommendations, based on the published literature, for translation of data collection instruments. This report clearly describes the approaches that are commonly used to translate surveys and makes recommendations for translation methods. Those described approaches include simple direct translation, modified direct translation,

back-translation, and the committee approach. The committee approach, the recommended technique, is reported to be most comprehensive. The approach includes pretesting of the translated instrument and incorporates the input from team members with skill sets that go beyond the skills of a translator. A brief description of the methods of translation is presented below:

Simple direct translation is conducted in one step only by a single bilingual individual. In this method, only one person is involved and there is no process to ensure that the translated document has the concepts and contents accurately.

Modified direct translation uses added modification, such as an addition of the committee meeting. Although this method would be more preferable than simple direct translation, there are other methods that ensure the accuracy and meaning in target language better.

Back-translation technique includes three basic steps: translation of source language to target language; translation of target language to back-translation into source language; and comparison of original source instrument with back translated source language instruments.

Committee approach entails convening a collaborative group of individuals with complementary skills. In this method, translation is done in a parallel fashion where the experts may independently translate the source instrument to target instrument and then the team meeting is held to reach consensus. Using the final decisions, the instrument is prepared for pilot with target population (Pan & Puente, 2005, p. 4).

Although a committee approach was recommended by Pan and Puente (2005), only one published study was found to report the use of this method. Although the standards and detailed methods of translation are presented using the “state of science,” this publication is not a peer reviewed publication (Pan and Puente, 2005). The most commonly cited method noted in published studies was the back-translation method, which was also reported to have the least limitations. Back-translation methods that were utilized by studies did not only include the three steps mentioned above, but they also involved committee review and pilot testing. This differs from the committee approach, where members of the committee are involved in the actual translation without undergoing the process of translation and back-translation. An example from the literature illustrating the use of the committee approach for translation is presented below.

Lee-Lin et al. (2007) adopted the committee approach, as recommended by SRD, for translation by convening three bilingual translators, all of whom were health care providers or educators with many years of work experience. The authors report that each of the committee members translated one-third of the questionnaire initially. After completing their individual translations, the group met to settle the discrepancies and agreed on translated language that combined the best of their independent translations. Upon review of the cultural and linguistic accuracy of the translation by the author and the committee, only items that reached complete 100% agreements among all reviews were retained. The pretesting of the instruments was conducted with 10 participants;

revisions followed to improve the survey (Lee-Lin et al., 2007). This example reflects the process of the committee approach.

Statistical Research Division's information about producing high-quality translations seemed to be thorough and comprehensive. According to the SRD recommendation, a high-quality translation should have three goals: reliability, fluency, and appropriateness (Pan & Puente, 2005). First, reliability refers to the message in the source text that is accurately transferred into the target text, including semantic equivalence, technical accuracy, the functional equivalence of the source text, and textual completeness. Second, the goal of high-quality translation is fluency, which refers to a tool that reads well and makes sense in the target language. Third, the goal of appropriateness refers to the style, tone, and appropriate transference in the target text (Pan & Puente, 2005).

An example of a back-translation approach that seems to be comprehensive was revealed by Beaton et al. (2002). To apply this method, the authors suggest a six-stage process: 1) translation; 2) synthesis; 3) back-translation; 4) expert committee review; 5) pretesting; and 6) submission and appraisal. Although this method is somewhat similar to the committee approach, the committee approach directly involves the multidisciplinary expert team in translating the instrument themselves without involving formal bilingual translators at the beginning. Although the committee approach is recommended by SRD, involving the bilingual translators first, before reaching the expert committee, may save the time of the experts and remove the extra burden related to translation, allowing the committee to focus on offering their expert opinions. Using the

back-translation method allows for the formal translation process to be completed before involving the experts and includes experts' opinions in the final document. Notably, back-translation using independent bilingual translators could increase validity and reliability.

The back-translation method is a standard procedure for translation of standardized quality of life questionnaires utilized by the European Organization for Research and Treatment of Cancer (EORTC) (Koller et al., 2007). EORTC's quality of life (EORTC QL) questionnaires are used in international trials and one of their "core questionnaires has been translated and validated into more than 60 languages" (Koller et al., 2007, p. 1813). Their published article about their translation process provides a thorough step-by-step procedure (see Figure 8) and recommendations to ensure quality in translating a document.

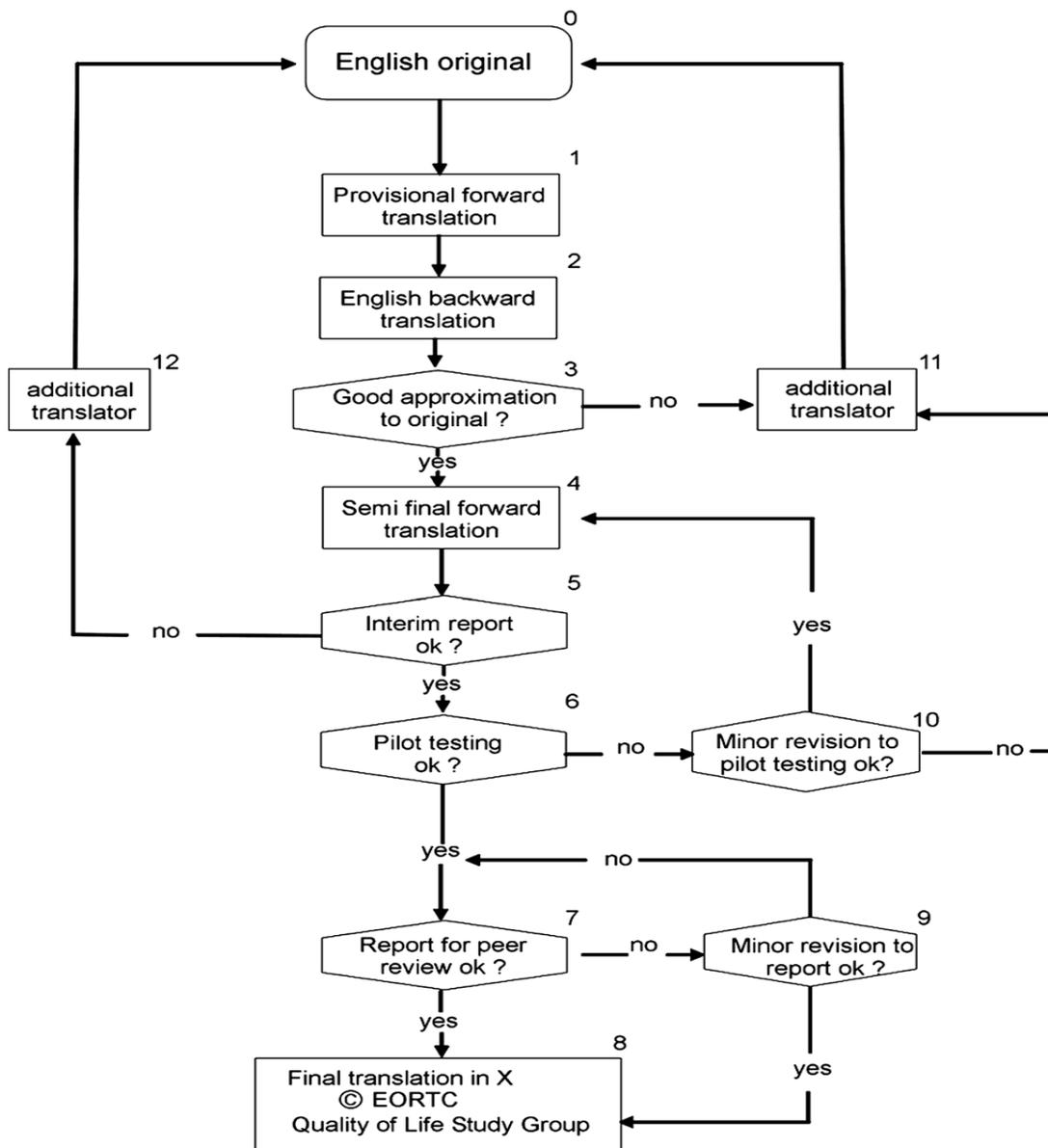


Figure 8: EORTC Standard Translation Procedure-Copied with permission from “Translation procedures for standardized quality of life questionnaires: The European Organization for Research and Treatment of Cancer (EORTC) approach by Koller et al, 2007, *European Journal of Cancer*, 43, 1813.

Note. EORTC uses a back-translation method

Summary

Nepal has one of the highest incidence and mortality rates of CC in the world. Lack of CCS is one of the leading factors in low-resource countries that increase the incidence and mortality rates of CC. CCS is an established method which can prevent CC, detect CC and allow for early treatment. Evidence shows that the structural barriers (awareness, availability, affordability and accessibility) in general limit the women from undergoing CCS in low-resource countries; where as, the belief barriers influence the CCS differently in different countries and cultures. Although Nepal lacks necessary resources to offer universal CCS program at this time, there are new CCS programs which provide for all of the structural barriers, yet without optimal use. There were no studies found, about the belief factors of Nepalese women in relation to their CCS behavior. Using the HBM as a conceptual framework and HBM scale as a foundational instrument, Nepalese Health Belief Model (NHBM) scale was developed after establishing the validity evidence, by back-translation method and pilot study. The aim of this study was to examine the role of Nepalese women's belief factors on their CCS behavior and the extent to which those factors predict CCS behavior.

CHAPTER III: METHODOLOGY

In this section, the study design, sampling, methods, measurement strategies, translation protocol, ethical considerations, data collection, and approach to data analysis are presented. A quantitative cross-sectional descriptive design using a semi-structured survey method, with face-to-face interviewing was used to study the belief factors that may correlate with or predict CCS behavior among Nepalese women.

Research site and subject recruitment

Nepal, one of the low-resource countries, has a branch of the International Network for Cancer Treatment and Research (INCTR). Nepal Network for Cancer Treatment and Research (NNCTR) serves the public in regard to prevention and treatment of cancer. One of the programs that NNCTR coordinates is called the Cervical Cancer Screening Program (CCSP). NNCTR is a not-for-profit organization, which works in collaboration with many reputable organizations including the National Cancer Institute (NCI), the International Atomic Energy Agency: Program of Action for Cancer Treatment, the International Union Against Cancer, the World Health Organization, professional societies, the European School of Oncology, the International Cancer Control Congress, the Tropical Health Education Trust, and others (Jhpiego, 2008). According to the president of NNCTR, the Australian embassy provided the support for

CCSP, and other primary funding sources include donations, grants, and contracts. The women served by NNCTR CCSP were recruited as participants for this study.

Among all organizations reported to provide CCS services in Nepal, NNCTR is reported to be a leader as it reaches out to the community via screening camps and offers CCS that is accessible at free of cost (Jhpiego, 2008). Additionally, this program screens the highest number of women, when compared to other programs (Jhpiego, 2008). NNCTR uses a preventive approach by offering screening to asymptomatic women versus other programs which use an opportunistic approach. The opportunistic approach refers to a way of screening only when the women visit the clinic or healthcare institutions for other purposes, as reported in Cervical Cancer Prevention (CECAP) Situational Analysis (Jhpiego, 2008).

Structural barriers to screening were eliminated by the comprehensive program offered by NNCTR. Despite the availability of screening services, which was brought to their community for free, women were “still not using the program to its full potential” (Dr. Surendra Shrestha, President-Nepal Network for Cancer Treatment and Research, personal communication, March 22, 2011). No written report was available for utilization rates of the CCS program that was published or documented, available reports report the number of women served and not the utilization rate of the services.

For the purpose of this study, to specifically examine the belief factors of women, purposive sampling of women who do not have structural barriers was identified to be a good fit because removing the structural barriers is likely to minimize the variability introduced by the structural barriers in this study with a specific focus on the belief

factors. While the advantage of the purposive sampling is that the selected factors are clearly defined and identified in the sample, the disadvantage is that the more clearly defined the characteristics are, the more limit there is to generalizability (Rebar, Gersch, Macnee, & MacCabe, 2011, pp. 116-117). Although the ability to generalize the findings is limited in this initial study, it is the researcher's sense that the data from a study sample without structural barriers will provide the clarity in analyzing the belief factors related to the CCS behavior among Nepalese women.

The initial plan was to survey the women during the awareness program and follow up later to learn about their screening status one month after the screening program was offered. About five months after the dissertation defense and approval, NNCTR changed the program structure and began to screen the women while they were already on site for the awareness program. While this change in structure increased the utilization of CCS for Cervical Cancer Screening Program (CCSP) of NNCTR, the intent of this study was not to conduct the NNCTR program evaluation. NNCTR was a research site and not a program of study. In order to address the proposed research questions of this dissertation, the subject recruitment method was changed to surveying the past participants of the awareness program in their community and using established data about their screening status (yes/no) was offered two weeks after the screening program was offered.

This purposive sample was an ideal fit to examine the *belief factors* that predict CCS behavior because it allows for separation of the belief factors from structural factors. In order to study the belief factors and their association with the screening status of

Nepalese women, consideration needs to be given to structural factors that can be confounding variables. For the purpose of this study, recruiting participants using only one program without structural barriers may reduce some confounding variables, allowing for clearer analysis of belief factors, as compared to recruiting the participants with varying levels of structural barriers. Additionally, the sample was selected from a population that shared a common factor, attending an awareness program that educates them on CC as well as about a convenient and free CCS service. According to Rebar, Gersch, Macnee, & McCabe (2011), a purposive sampling technique may be used when a sample that is hard to recruit or identify and has factors that are clearly defined. However, the disadvantage of purposive sampling is that more unique characteristics are likely to limit the generalizability (Rebar, Gersch, Macnee, & McCabe, 2011). Because mediating factors, such as education and age may influence the CCS behavior, demographic information was collected to incorporate those variables during analysis.

The inclusion criteria for this study included the women between the ages of 30 to 60 years. This age criteria were established according to the age criteria established by NNCTR for their screening services. Additionally, the women had to have attended the awareness program supported by NNCTR to be included in the study. The exclusion criteria included those who did not participate in the awareness program but underwent screening and women who were less than 30 years and greater than 60 years in age.

Participation in this study was voluntary and confidential. Incentives of 100.00 Rupees were given to participants for their time. Equivalent to about one dollar and fifty

cents in U. S. dollars, this amount allowed the participant to buy a dozen bracelets or about two bead necklaces that married women wear in Nepalese culture.

Sample

The study population for this research included women who participated in the CC and prevention awareness program led by women leaders, all of whom were trained to provide awareness programs by the Nepal Network for Cancer Treatment and Research (NNCTR). In this program, all of the participating women were given similar information and all were offered the program free of cost at a location in or near their community.

Sample Size Determination

Sample size determination included the unique considerations for the purpose of the study, research questions, and statistical analysis plan. Because this study used the logistic regression (LR) as a statistical method for analysis, the literature was reviewed to identify the appropriate technique to calculate the sample size. Research suggested that in using LR, the larger sample size may yield a greater chance to detect a statistically significant difference between the groups (screened/not screened); however, the findings may not have a practical importance (Tabachnick & Fidell, 2007). The literature indicated a number of methods and rules-of-thumb established to guide in identifying the needed sample size for the test to be meaningful, considering desired power, pre-established alpha, and number of IVs and DVs. A simple rule-of-thumb by Green (1991), as cited in Tabachnick & Fedell (2007, p. 123) suggested is that $N \geq 50 + 8m$ (where m is

the number of IVs) is needed for testing multiple correlation and $N \geq 104 + m$ for testing individual predictors. As reported, these rules-of-thumb assume a medium-size relationship between the IVs and the DV, $\alpha = .05$ and $\beta = .20$. Green developed these rules based on Cohen's power analysis approach to sample size selection. After comparing a variety of rules-of-thumb, Green concluded that the rule of thumb of $N \geq 50 + 8P$ (where p is number of predictors) was more accurate than other rules for the case of medium effect with Power = .80 (Brooks & Barcikowski, 1994).

While the formula $N \geq 50 + 8P$ is recommended for multiple correlation, the formula, $N \geq 104 + m$; (m =number of predictors), also allows for studying the individual predictors (Green 1991 as cited in Tabacknick & Fidell, 123) as desired for this study. For this study, there are five predictors. The sample size using Green's formula ($N \geq 104 + m$; m = number of predictors) was determined to be 109. Adding the four modifiers (age, education, age at first marriage, parity) as predictors in the formula, the total sample size was determined to be 113. The estimated participation rate was anticipated to be 75% based on the plan to interview the women at the awareness site. The plan was to approach 171 women. If the participation rate was higher than 75%, the plan was to stop the enrollment once we surveyed 113 participants. If the participation rate was lower, we planned to increase the number of women we approached until we reached the sample size of 113. The participation of 75% was estimated based on the anticipation that the data collection will take place at the awareness site, where women may not have time to stay or they may not be comfortable. However, the data collection occurred in their community and the women agreed and seemed to be at ease with the process.

The participation rate was 100%. We conducted a pilot study with 20 women from the target population to evaluate the Nepalese Health Belief Model (NHBM) scale that was developed after translating Health Belief Model (HBM) scale using specific translation criteria and back-translation method. Because the pilot participants were from the target population and there was no major change in the survey or the data collection process during the pilot study evaluation, those participants' responses were included in the analysis. With 20 women who participated in the pilot study and 110 women who participated in the data collection, the total sample size was 130. Data from nine participants were excluded based on the age criteria and the final sample size was 121.

Ethical Considerations

There are significant ethical considerations in a research topic which is as sensitive as this, in a cultural setting where women are very conservative (Global Partnership for Education, n.d.). Because of this, Human Subjects Review Board (HSRB) at George Mason University (GMU) required a Nepali cultural expert researcher to be involved, according to its protocol for all international studies. In addition to incorporating a cultural expert, a letter of support was obtained from NNCTR, to conduct the study using the data from their CCS program and to obtain their support for subject recruitment and the data collection process (see Appendix B: NNCTR Support Letter).

Because Nepalese women are known to be modest and shy, extra care was taken to provide a private setting, including an interview setting that was far from others' hearing distance. Considering that there was a lack of space in the village, the data

collection site, spaces outside of the temple, an empty room in their house, or an empty room above the shops was used to maintain their privacy. Data were collected via a face-to-face approach. This method was chosen after considering the private nature of questions and the low literacy rate of Nepalese women, average 34.9% (CIA, 2011). Additionally, female Nepalese research assistants, trained by the researcher, administered the survey to provide ease and comfort for participants to answer the questions.

Approval to conduct the study was obtained from the HSRB at GMU, as well as from the Nepal Health Research Council (NHRC). Women were verbally informed about the study in Nepali and a written informed consent was obtained from the women in the Nepalese language prior to their participation in the survey. A copy of the informed consent was given to the participant. Women were assured that refusing to participate in the study would not affect their access to either education, CCS, or other privileges. The risks and benefits of participating in the study were explained, including their rights to decline participation or to withdraw from the study at any time.

Instrument

An instrument developed by Dr. Champion based on HBM, called HBM-based scale, has been successfully adapted to measure the HBM constructs for CC prevention behavior (Glanz, et al., 2008; Guvenc et al., 2010; Allahverdipour & Emami, 2008). Additionally, it has been successfully adapted and translated into other languages and cultures for many studies (Glanz et al., 2008; Esin et al., 2011; Parsa et al., 2008). For the purpose of this study to examine the health belief model constructs (perceived

susceptibility, perceived seriousness, perceived benefits and perceived barriers), Dr. Champion's HBM-based scale was selected and used as a foundation document.

With permission from Dr. Champion, this instrument was adapted to CC prevention behavior for Nepalese women after successful translation into the Nepalese language (See Appendix C: Permission to use the survey). Tests of reliability and validity of the Nepalese Health Belief Model (NHBM) instrument were conducted (See Appendix D for Champion's HBM scale, Appendix E for HBM scale adapted and modified to HBM scale for CC, and Appendix F for Nepalese Health Belief Model scale translated from Champion's HBM scale for CC).

Translation

The back-translation approach and process based on Koller, et al (2007) was adapted and modified for this dissertation. Initially, two bilingual translators were recruited for forward-translation of HBM scale from English to Nepali to prepare the Nepali version for expert review. Because of their limited ability to understand the subject-area and terminology of the instrument as it would translate in Nepali, this process was slightly modified. A bilingual professional with Masters-level education in English served as a translation coordinator. He direct-translated the instrument in Nepali and the two bilingual PhD-level health professionals were requested to complete the translation process until there was a consensus on the translation criteria of the Nepali instrument. The third expert, president of NNCTR with direct knowledge of CCS work, joined the two experts to resolve, review and ensure that the Nepali instrument indeed

meets the translation criteria. The president of NNCTR, PhD-level expert, validated the translation in collaboration with the other two experts. Discrepancies were minor and were only related to a choice of words appropriate for the target population. The translation to NHBM scale was finalized when they had consensus on the elements listed on the consensus form (Appendix G). The translation coordinator updated the document and facilitated the process until the process was complete.

This version was then back-translated into English by two Nepali bilingual translators. According to Koller et al. (2007), using different translators for back-translation can improve validity and reliability of the translated document. English back-translations were compared to the original version to ensure that the meaning of the original questions has been preserved.

The original survey and the English back-translated instrument were submitted to the dissertation committee for approval to go forward with the pilot testing. The surveys did not look exactly the same because the choice of words and the order of words were noted to be vastly different to preserve the meanings of the concept for the target population in the Nepali language. The instrument was approved, via email after email discussion, by all committee members to go forward to the pilot testing phase.

The pilot testing was conducted on the Nepalese Health Belief Model (NHBM) scale in Nepal with 20 women from the target population. Kollar et al. (2007) recommended 10 to 15 persons of the target population to pilot the translated document. In a focus group held following questionnaire completion, they were asked whether the translated questionnaire items were:

- Difficult to answer
- Confusing
- Difficult to understand
- Upsetting/offensive
- Awkwardly worded.

The evaluation of participant focus-group, research assistant (RA) focus group, and a combined focus group with research assistants and participants were used to validate the data collection process and the instrument. Minor changes in the process were made as a result. One of the feedbacks from both the research assistants and participants was that they found the interview to be awkward because some items on the survey were extremely similar. Although it made sense to the researcher that including those similar questions in each construct contributed to the reliability of the instrument, research assistants needed education about the reason why the items were so similar. After the discussion, the research assistants and participants of the focus group agreed that the research assistants would inform the participants, that they “will notice that the questions are similar and they are supposed to be that way to capture all the information needed for the purpose of this study,” before beginning the interview.

Data Collection Plan

The mode of data collection was face to face. Although there are disadvantages of this modality, such as social desirability response bias, cost and time, the benefits include a higher response rate, and accurate responses (Kelly, Clark, Brown, & Sitzia, 2003). For

the purpose of this study, RAs used a structured survey with a list of questions that were the same and in the same order for each respondent. Using a standard NHBM-scale instrument with each participant, they also used a research script when collecting data. A Likert-type scale with visual response options was used with participants for them to record their response. (Appendix H: Answer Handbook)

After the Nepalese Health Belief Model scale (NHBM-scale) was ready and the HSRB approval was obtained from both GMU and NHRC (See Appendix A), the researcher met with the chairperson and program officer of NNCTR to select the RAs for hire, plan the RA training, the pilot study, and the data collection. NNCTR had endorsed a letter of support to allow the researcher to recruit their program participants for this study with the participants' consent. NNCTR representative obtained the permission from the potential participants among the women who attended the awareness program in the past, using a "recruitment script" (See Appendix I) in the Nepali language. The data were collected after obtaining informed consent from the participants who had given the permission to be recruited. The consent was obtained and data were collected by the RAs, who were trained, by using the script in Nepali (See Appendix J for the RA script). Each participant had a consent form and answer handbook that were marked with the same ID number. The data collection handbook only contained the ID number. Both the name and number were documented only on the informed consent form and were stored securely by the researcher, out of reach of the RAs and others. Surveys of those who underwent CCS and those who did not, were divided into two groups for analysis (see Figure 8, p. 28).

RAs were selected from NNCTR's Cervical Cancer Screening Program (CCSP) working group, and they were trained on the process for data collection. The approach to train the RAs included an orientation program which provided a didactic overview of the concepts in administering structured face-to-face surveys, review of the informed consent content and process, review of the script, demonstration, and a role-play activity incorporating the above elements (see Appendix K: RA training). All research assistants were women from Nepal. The researcher was accessible and at the data collection site at all times during the data collection period.

Data Analysis Plan

The data analysis was conducted using the Statistical Package for the Social Sciences (SPSS) version 20 (IBM, 2011). The data were analyzed in several stages. In the first stage, the data were assessed for missing values and outliers. Frequencies were run to detect any other needs to adjust or recode variables and to ensure that the data were clean. When assessing the data, it was found that nine participants did not meet the inclusion criteria of age < 60 and > 30. Because Nepal's calendar years are 57 years ahead of U.S. years, the variable with "year" was adjusted to reflect 2012 in the U.S. for the year 2069 in Nepal. In addition, a new variable, "age," was created and the variable "education" was re-coded to four levels for the purpose of analysis.

The sample description was obtained by running the descriptive frequencies for all of the variables. The validity and reliability of the Nepalese Health Belief Model (NHBM) scale were tested. The evidence of the validity included the factors considered

in translating the HBM scale into the NHBM scale as well as the results of the pilot study evaluation.

Internal consistencies as measured by Cronbach's alpha were calculated for the NHBM scale and each of its domains: perceived susceptibility, seriousness, benefits, and barriers. Internal consistency is the degree to which all of the subparts of an instrument measure the same attribute or dimension, as a test of the instrument's reliability (Polit & Beck, 2008). Cronbach's Alpha also measures the reliability of an instrument (Polit & Beck, 2008). For internal consistency, Nunnally and Bernstein (1994) recommend a threshold of .70. Champion's HBM scales have been translated into at least four languages (Glanz et al., 2008, p.52) and Table 3 indicates that the reliability of the instruments in those languages (Turkish, Arabic, Chinese and Korean) is good, as indicated by Cronbach's $\alpha \geq .7$ (Glanz et al, 2008, p.52). A coefficient alpha, an index of internal consistency, estimates which items of an instrument reliably measure a single construct (Polit & Beck, 2008). For the NHBM scale, Cronbach's alpha was calculated to assess the reliability of the NHBM scale.

Some content validity was obtained by translating the instrument with a research based method, called back-translation, that is considered to be most accurate and effective (Koller et al, 2007) to maintain the concepts of the original tool and yet to fit the target population. Three experts were involved in translating the HBM scale into the NHBM scale and two bilingual individuals were involved in back-translating the NHBM scale into English as a part of the preparation of the pilot study for further validity evaluation.

A pilot study was conducted after the translation process. Ten college-educated research assistants (RAs), with a volunteer experience in health care, were hired and trained on cervical cancer, cervical cancer screening, administration of informed consent, and structured face-to-face survey methodology. Twenty women from the target population were recruited for the pilot study. RAs had the research script available, which allowed for the standardization in the data collection process. Because the structured survey (versus open interview) and standard script (versus no script) were used by RAs, the inter-rater reliability was not tested as suggested by the dissertation committee.

The pilot study was conducted with 20 women from the target population. The women in the pilot study were about 43 years in average and had average of 23 years of age on marriage. All of the pilot study participants were married and about one-third (35%) were with parity three. Among the pilot participants about half of them had some college or higher level of education. One-fifth of the participants knew a friend or family member who had or died of CC.

The purpose of the pilot study was to test whether the proposed NHBM scale was appropriate for the study population. RAs documented the time necessary for the completion of each survey, which was 25-35 minutes. The focus groups with RAs, participants, and both groups provided feedback on the instrument and the process, to finalize the process. Researcher and NNCTR CCS coordinator met with five participants separately followed by group discussion with all ten RAs. Then, the last focus group consisted of ten RAs and six participants.

Independent *t*-tests were used to analyze the significant difference between the means of the two groups, screened and non-screened, pertaining to perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers. Because the scores for the perceived barriers subscale were negative compared to other subscales, the scores were reversed to be consistent and accurate for analysis. The *t*-test analysis examined whether perceived susceptibility to CC, perceived seriousness to CC, perceived benefits of CCS and perceived barriers of CCS differed significantly between the screened group and non-screened group.

According to Munro (2005), three general assumptions should be examined when conducting an independent *t*-test. As required by the first assumption, the two independent variables were categorical and contained two levels of two mutually exclusive groups. Although the “assumption” about the normality of distribution was not met as evidenced by the significance level $<.05$ of the Shapiro-Wilk test for all DVs indicating that the distribution was not normal, the “*t*-test is robust with regard to the assumption of normality (Polit, 1996, p. 130).” Thus the assumption of normality of distribution of DVs was not a concern. The third assumption is the homogeneity of variance did not apply because the SPSS software makes an adjustment while calculating results so that any discrepancies in this assumption are taken into account (Munro, 2005). For the purpose of this study, if there was a significant difference between the means of two groups (screened/not-screened) in relation to any construct, it was inferred that there was a relationship between the DVs and the status of screening.

To examine if there was a relationship between cue to action (Yes/No) and the group membership in the screened or not screened group, a chi-square test of independence was conducted with $\alpha=.05$ as a criterion. The purpose of the chi-square statistical test is to examine the group differences when the dependent variable is nominal, such as “the status of screening” (Polit & Beck, 2008, p.600). A chi-square test of independence is the most common nonparametric statistical test used to infer population differences in proportions between two or more groups (Polit, 1996).

Logistic Regression (LR) was the statistical test used to analyze the extent to which the combination of perceived susceptibility, perceived seriousness, and cue to action, perceived benefits, perceived barriers, age and education predict CCS behavior. LR allows one to predict a binary DV from a set of IVs that may be continuous, categorical or a mix of both. The dependent variable (DV), status of screening has two independent groups (screened and non-screened), which represent the CCS behavior in the context of this study. LR analyzes the relationship between the independent variables and a dichotomous dependent variable. LR calculation yields a predictive equation (Polit & Beck, 2008, p.629), which informs us about the presence and the extent of prediction of DV by IVs. In other words, LR is a statistical test that allows us to look at relationships between more than two factors and test whether those relationships are likely to occur by chance (Rebar, Gersch, Macnee & McCabe, 2011, p.29).

Although there are no assumptions about the distributions of the predictor variables, the data needed to be screened for outliers and multicollinearity (Mertler & Vannatta, 2005, p.328). Before conducting the Logistic Regression, data were screened

for missing data and outliers. A preliminary multiple Linear Regression was conducted to calculate Mahalanobis' Distance to evaluate multicollinearity among the predictors. The findings as presented in the table of Collinearity Statistics (Table 4) indicated that multicollinearity was not a concern since tolerance statistics for all seven IVs were >0.1.

Table 4: Collinearity Statistics

Subscales of HBM	Unstandardize Coefficients				Collinearity Statistics	
	B	SE	T	Sig	Tolerance	VIF
(Constant)	192.645	43.113	4.468	.000		
Perceived Susceptibility	-.913	.898	-	.311	.874	1.144
Perceived Seriousness	.045	.877	.051	.960	.857	1.167
Perceived Benefits	-3.652	1.277	-	.005	.822	1.216
Perceived Barriers	-1.524	.788	-	.056	.921	1.217
Age	.068	.422	.162	.871	.921	1.085

Note: Tolerance level is >.1 indicating that the multicollinearity is not a concern

Binary logistic regression was then conducted using the “Enter” method (Mertler & Vannata, 2005). Age, education, perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers were entered for logistic regression analysis to examine the extent to which the predicting variables predict the cervical cancer screening behavior. The research questions, statistical method, and the variables are listed in Table 5.

Table 5: Data Analysis Plan

Research Questions	Statistical Analysis Plan	
	Test statistic	Variables
1. What are the psychometric properties, validity and reliability evidence of “Nepalese Health Belief Model” (NHBM) scale?	Cronbach’s alpha	Perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, and status of screening
2. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived susceptibility?	Independent <i>t</i> -test	Perceived susceptibility Status of screening
3. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived seriousness?	Independent <i>t</i> -test	Perceived seriousness Status of screening
4. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived benefits?	Independent <i>t</i> -test	Perceived benefits Status of screening
5. Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived barriers?	Independent <i>t</i> -test	Perceived barriers Status of screening
6. Is CCS behavior significantly associated with cue to action?	Chi-square	Cue to action Status of Screening
7. To what extent do the combination of perceived susceptibility, perceived seriousness, benefits, barriers, age and education predict CCS?	Logistic regression	Predictors: perceived susceptibility; perceived seriousness; perceived benefits; perceived barriers, age and education. Outcome variable=status of screening

Summary

With the purpose of examining the predictive factors of cervical cancer screening behavior among the women of Nepal, it was important first to ensure that the instrument is valid and reliable to measure the concepts that it was meant to measure in another culture and language, even after the translation process. In order to use an appropriate instrument for the target population and to uphold the concepts measured by the HBM scale, the back-translation method was utilized. In the back-translation process, the main steps include forward-translation, consensus on the newly developed survey in the target language and back-translation of that survey by two bilingual individuals back into English. The original instrument and the instrument that is translated back into English needed to be conceptually similar.

A pilot study of the instrument was conducted to further validate its use for this purpose. In this study, two doctoral level health care professionals serving in the public health arena and a third doctoral-level leader, an expert in the subject area (cervical cancer screening program), were involved in forward translation. Using a guided worksheet with specific criteria (i.e., instrument is easy to read; grammatically correct, etc.), the two professionals and the expert reviewed and revised the tool until they reached a consensus. After the back-translation and comparison of the two documents (before and after translation), a pilot study was conducted with 20 women prior to the instrument's use with the target population.

The Cronbach's alpha was used as a measure of internal consistency, and the data from the translation process and from the pilot study focus groups were used to analyze

the validation. To investigate the difference between those who are screened and who are not in reference to their HBM constructs (perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers), an independent *t*-test was used as a statistical test. Due to the nominal dichotomous dependent variable in this study, logistic regression was used as a statistical test to detect the belief factors (HBM constructs) which predict the CCS behavior among Nepalese women.

CHAPTER IV: FINDINGS

Introduction

This chapter presents findings of the specific research questions related to the purpose of this study: to examine the role of belief factors on Nepalese women's cervical cancer screening (CCS) behavior and to examine the extent to which perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, education, and age predict CCS behavior among Nepalese women. This chapter is divided into three sections. The first section describes the sample. Then, the second section presents the psychometric properties and validation evidence of the Nepalese Health Belief Model (NHBM) scale. Finally, the last section reports the analysis and findings of the six research questions.

Sample Description

The final sample size was 121 Nepalese women recruited from the NNCTR's cervical cancer (CC) and cervical cancer screening (CCS) awareness program's attendance list. The response rate was 100%. The women were between 30 and 60 years of age, with the mean being 43 years ($SD=9$). In addition to grade level being similar to class level in Nepal, School Leaving Certificate (SLC) is slightly different from GED in the U.S. After 10th grade level education, all students have to take the SLC exam and the results determine whether they move on to college or retake the exam. In Nepal, SLC is

also an important credential for job market. In our sample, almost half (43%) of women never entered school and only 17% of women with college level and higher. Most of those women (91%) had children. About 33% of all women were at parity 2. See Table 6 for characteristics of the Sample.

Table 6: Characteristics of the Sample

Variables	Total (N=121)		Screened (N=76)		NotScreened (N=45)			
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%		
Education								
No schooling	52	43	32	42	20	44		
Nursery to 10 th Grade	33	27	15	20	18	40		
School Leaving Certificate (SLC)	15	12	13	17	2	4		
Some college and higher up to PhD	21	17	16	21	5	11		
Married								
Yes	115	95	76	100	39	87		
No	6	5	0	0	6	13.3		
Children								
Yes	112	93	74	97	38	84		
No	9	7	2	3	7	16		
Miscarriages								
Yes	33	27.3	25	33	8	18		
No	88	72.7	51	67	37	82		
Parity (# of living children + # of miscarriages)								
0	9	7.4	3	3	6	5		
1	10	8	8	7	2	2		
2	40	33	21	17	19	16		
3	27	22	20	17	7	6		
4	17	14	11	9	6	5		
5	11	9	8	7	3	3		
6	3	3	2	2	1	1		
7	3	3	3	3	0	0		
9	1	1	0	0	1	1		
Know a friend or family who has CC or died of CC?								
Yes	35	29	20	26	15	33		
No	86	71	56	74	30	67		
Summary Statistics								
	<i>Min</i>		<i>Max</i>		<i>Mean</i>		<i>SD</i>	
	<i>S</i>	<i>NS</i>	<i>S</i>	<i>NS</i>	<i>S</i>	<i>NS</i>	<i>S</i>	<i>NS</i>
Age at interview (N=121)	30	30	60	60	44	45	8	8
If married, age at marriage (N=115)	12	14	30	32	21	21	4	4

Description of the NHBM scale and Psychometric Properties

Research Question 1: What are the psychometric properties, validity and reliability evidence of “the Nepalese Health Belief Model (NHBM)” scale?

The Nepalese Health Belief Model (NHBM) scale was translated and developed using Dr. Champion’s Health Belief Model (CHBM) scale as a foundation. This tool contains 24 items in four domains: perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers. Just as the CHBM scale, the NHBM scale uses the Likert scale, which consisted of five levels of response (1=strongly agree; 2=agree; 3=neutral; 4=disagree; 5=strongly disagree). Because responses on one of the domains’, perceived barriers, were in a negative direction, the scoring of those item responses was reversed so that the items with positive and negative scores were in the same direction for accuracy.

The composite scores were calculated by summing up the Likert-scale responses of each item for each subscale. A person’s total score was determined by adding individual item scores. The descriptive statistics of composite scores for NHBM subscales are presented in Table 7.

Table 7: Descriptive Statistics of NHBM Subscale Variables (N=121)

NHBM Subscales	Items (Total=24)	Minimum	Maximum	Mean	SD
Perceived susceptibility	5	5	22	13.08	3.98259
Perceived seriousness	7	12	35	25.72	4.07533
Perceived benefits	6	15	30	24.19	2.88298
Perceived barriers	6	10	30	19.91	4.61955

Characteristics of NHBM scale’s individual items and their descriptive characteristics are presented in Appendix L.

Reliability

For the NHBM scale, alpha coefficient was calculated to estimate internal consistency of each subscale. The cronbach's alpha coefficient for each subscale was from .64 to .88: perceived susceptibility ($\alpha=.88$), perceived seriousness ($\alpha=.7$), perceived benefits ($\alpha=.64$), and perceived barriers ($\alpha=.77$). The alpha coefficient was .70 for NHBM scale. Estimates of the internal consistency, reliability of scores, for each subscale were determined using Cronbach's alpha or alpha coefficient (Cronbach, 1951). For internal consistency, Nunnally and Bernstein (1994) recommend a threshold of .70. For the NHBM scale, one of the four subscales measured an Alpha slightly less than .70.

In addition to Cronbach's alpha to evaluate for internal consistency of each subscale, survey items were also evaluated for each subscale using the corrected item-total correlations (D-Index). The discrimination index is the correlation between the score on a given item and the total score on each scale (Baghi & Atherton, 2004). According to Baghi & Atherton:

“The corrected item-total correlation is defined as the correlation between the given item and the total scale score, having removed the given item from the total score. If the D-Index is measured with a negative sign, item is not measuring the same construct as the associated scale or domain, and this item is a candidate for deletion. High positive values for the D-Index indicate that respondents who had high scores on each scale are more likely to get high scores on any particular item than respondents who had low scores (2004, p.25).”

The alpha and the D-Indexes are reported for each subscale and the total scale. As described above, the D-Index that is negative is a candidate for deletion and the higher D-Index result in higher reliability coefficients. The data on Cronbach’s alpha and D-Index range is presented below in Table 8.

Table 8: Internal Consistency Reliability Coefficient and D-Index

Name of Scale	Number of Items	Alpha	D-Index Range
Perceived susceptibility	5	.88	.71-.75
Perceived seriousness	7	.70	.32-.54
Perceived benefits	6	.64	.27-.47
Perceived barriers	6	.77	.44-.66
Total NHBM Scale	24	.70	.10-.42

No negative numbers were measured by the D-Index range in the NHBM scale indicating that none of the items needed to be deleted as the positive and higher D-Index results in higher reliability coefficients (Baghi & Atherton, 2004). A detailed description of each item and their D-Index including the “Cronbach’s alpha if item deleted,” are presented in Appendix L.

Validity Evidence

Two processes in general provided the evidence for validity of NHBM instrument. First was the translation process including the forward-translation to Nepali, review of the experts and consensus on the translation criteria and second was the evaluation of pilot study data, which included individual feedback and focus group results. During and after the translation of CHBM scale to NHBM scale, three experts reviewed the survey individually then together until they came to a consensus that the

survey met the established criteria. Translation Consensus Form (see Appendix G), the form with criteria for review by the translators and experts, was designed to guide them and listed the criteria and their definitions. The criteria for translation were listed on the consensus form with the definitions generated by the principles presented by Koller et al. (2007, p.1815) and Pan & Puente, 2005. Those criteria and the definitions are presented below:

- Reliable: Translated text conveys the intended meaning of original
- Complete: Translations do not add any new information to translated document and do not omit information in source document.
- Accurate: Translated document is free of spelling and grammatical errors
- Culturally appropriate: Messages conveyed in translated text is appropriate for target population
- Clear and easy to read: Content in the translated document is clear and easy to convey for the Research Assistants
- Conceptual equivalent: A given concept is present in both the source and target cultures, regardless of the words used to express the concepts
- Semantic equivalent: The terms and sentence structures that give meaning to the information presented in the source language are maintained in the translated text
- Normative equivalent: The translated text successfully addresses the difficulties created by differences in societal rules between the source and target culture

The feedback from the pilot study suggested that the questions and process were acceptable to participants. The group response indicated that a few questions were difficult to answer because there were many questions asking the same thing and they “felt like it was not necessary.” The subscales of the instrument have very similar questions, which can give that perception. That mix of questions was a part of the original instrument development and that was discussed with the group. After discussion, it was decided that this concern did not require a change in instrument items, but instead the research assistants would inform the participants that “the questions may sound the same but that is how they are designed.” There were no other changes to the tool as a result of the focus group. The RAs reported that the time for administering the survey ranged from 25 to 35 minutes.

Belief factors and Status of screening

Research Question 2: Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived susceptibility?

An independent samples *t*-test was conducted to compare the mean difference between the two independent groups (screened/not screened) pertaining to perceived susceptibility of cervical cancer. In other words, the *t*-test analysis tested whether perceived susceptibility differed significantly between the screened group and not screened group. For perceived susceptibility, there was no significant mean difference between the two groups. Those women who were screened had a mean score of 13.37

(SD=4.34), while the group who were not screened had a mean score of 12.80 (SD=3.26). These results suggest that a woman's status with regard to screening is not associated with her perceived susceptibility. See Table 9.

Research Question 3: Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived seriousness?

There was no significant difference in perceived seriousness between the screened group of women and the not screened group. For perceived seriousness, those who were screened had a mean score of 25.83 (SD=4.46), while those women who were not had a mean score of 25.84 (SD=3.46). See Table 9.

Research Question 4: Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived benefits?

There was a significant difference in the scores for perceived benefits, with women who were screened having a higher mean score ($M=24.83$, $SD=3.08$) than those who were not ($M=23.36$, $SD=2.24$) ($t=3.03$, $p=.003$). See Table 9.

Research Question 5: Is there a difference of means between the two independent groups (screened/not screened) in relation to perceived barriers?

There was a significant difference in the means for perceived barriers, with those women who were screened ($M=20.71$, $SD=4.64$) than those women who were not ($M=18.64$, $SD=4.45$) ($t=2.40$, $p=.018$). See Table 9.

Table 9: Findings of Independent *t*-tests

Outcome Variables	Status of screening (groups)				<i>t</i> test
	Screened (N=76)		Not Screened (N=45)		
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Perceived Susceptibility	13.37	4.34	12.80	3.26	0.82
Perceived Seriousness	25.83	4.46	25.84	3.46	-.02
Perceived Benefits	24.83	3.08	23.36	2.24	3.03**
Perceived Barriers	20.71	4.64	18.64	4.45	2.43*

* $p<0.05$. ** $p<0.01$.

”Cue to action” and status of screening

Research Question 6: Is there a significant association between “cue to action” and status of screening (Screened/Not-screened)?

The variable “cue to action” was operationalized with the question: “Do you know anyone with cervical cancer or who died of cervical cancer?” with Yes/No response. The percentage of participants that had a friend or family member who had CC or died of CC did not differ by status of screening, $\chi^2 (1, N=121) = .68$, $p=.41$. See Table 10.

Table 10: Chi Square- Status of screening and Cue to action

Status of screening	<u>“Cue to action:” Do you have a friend or family member who has CC or died of CC?</u>				Chi-Square
	Yes		No		
	F	%	F	%	
Screened	20	26	56	74	.68
Not screened	15	33	30	67	

**p*<.05

Predicting CCS Behavior among Nepalese Women

Research Question 7: To what extent do perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, education, and age predict CCS behavior among Nepalese women?

The purpose of this research question was to investigate whether perceived susceptibility of cervical cancer, perceived seriousness of cervical cancer, perceived benefits of cervical cancer screening, perceived barriers of cervical cancer screening, education and/or age predict the CCS behavior, among Nepalese women, individually or in combination.

Although there are no assumptions in LR about the distributions of the predictor variables, LR is sensitive to high correlations among predictor variables (Mertler & Vannatta, 2005). Preliminary Linear Regression was conducted to calculate Mahalanobis' Distance and to evaluate multicollinearity among predictor variables. It was found that the multicollinearity was not a concern as indicated by the tolerance statistics of >.1 for all predictors.

Logistic Regression was conducted using the Enter method to determine if and to what extent the independent variables (perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, education and age) were predictors of the women's status of screening. Overall model, goodness-of-fit test, R^2 type indices were assessed. Then, the summary report of model variables was evaluated which presented several statistics: β , $SE\beta$, *Wald's* χ^2 , p , and e^β . β represented the effect the IV has on the DV; *S.E.* was the standard error of β ; *Wald* represented the significance of each variable in its ability to contribute to the model; *df* and p were also reported for the *Wald* statistic in the summary table. The R , partial correlation of each IV with the DV was presented followed by the final value presented in the summary table, $Exp(B)$, which was the calculated odds ratio for each variable. The odds ratio represented the increase or decrease in odds of being classified in a screened or not screened group when the predictor variable increases by 1 (Mertler & Vannatta, 2005).

In the initial SPSS outputs display the LR tests for the overall model. Based on our results, the model seemed to be reliable in distinguishing between screened and not-screened groups (-2 Log Likelihood=142.1; Goodness-of-fit χ^2 (8)= 17.61, $p<.05$). The chi-square value and the significant p value tell us that our model as a whole fits significantly better than an "empty model" (Merler & Vannatta, 2005) or one without our predictors. For screening status, 13.5% of the variance was accounted for by the model as indicated by Cox & Snell- R^2 and Nagelkerke results. The Hosmer and Lemeshow Test, a statistical test for goodness of fit, was not significant (χ^2 (8)= 6.21, $p>.05$), indicating that the model was a good fit. The model correctly classified 65.3% of the cases, which is the

overall percent of cases that are correctly predicted by the model. In other words, 65.3 percent of the time, we could consistently predict who will screen and who won't based on the model equation.

The final output, summary report's regression coefficients are presented in Table 11. Wald statistics indicated that perceived benefits was closest to being significant to predict the woman's status with respect to screening, $p=.05$. The relationships that are identified by LR or the predictive equation are based on the odds ratio, which is the change in odds of being one of the categories (i.e. screened) of outcome when the value of a predictor increases by one unit. According to the prediction equation $ODDS = e^{a+bX}$, the $ODDS = e^{0+.939}$ or about 3 (2.56) is the odds ratio. In other words, the odds ratio for women with education of nursery to 10 class have almost three times as likelihood of being screened for cervical cancer than those who have some college to higher education level according to the findings. Other variables indicate little or no change in the likelihood of being screened or not for cervical cancer.

Table 11: Regression Coefficients-Variables in the equation

	B	Wald	Df	Sig.	Odds Ratio
Some college and higher (Ed)		5.045	3	.469	
No school (Ed-1)	.117	.032	1	.859	1.124
Nursery to 10 class (Ed-2)	.939	1.944	1	.163	2.557
School Leaving Certificate (Ed-3)	-.619	.518	1	.472	.501
Perceived Susceptibility	-.066	1.406	1	.236	.936
Perceived Seriousness	.040	.445	1	.505	1.040
Perceived Benefits	-.164	3.746	1	.053	.849
Perceived Barriers	-.047	.869	1	.351	.954
Age	.015	.292	1	.589	1.015
Constant		1.124	1	.289	25.314

CHAPTER V: DISCUSSION

Because cervical cancer (CC) is a major crisis among Nepalese women and cervical cancer screening (CCS) has shown to be an effective prevention strategy, this research examined the role of perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers, constructs of the Health Belief Model (HBM), on Nepalese women's CCS behavior. CCS behavior, as measured by the status of screening, was found to be significantly different in relation to the perception of benefits of CCS and barriers to CCS; however, CCS behavior was not significantly different in terms of the women's perception of susceptibility to CC and seriousness of CC. In analyzing the extent to which perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, age and education predict CCS behavior, no statistically significant predictors of CCS were noted; however, women with education level of Nursery to 10th grade were almost three times as more likely to be screened than as women with the education level of some college and higher. This finding is at odds with previous studies of service uptake. The literature supports the argument that a higher education level is related to a greater likelihood of preventive behavior in Nepal (Acharya, Bell, Simkhada, Tejjlingen, & Regmi, 2010). No studies were found that explain the finding in this study, that women with lower education level were more likely to have healthy behavior than

women with higher education level. Keeping the education factor neutral, awareness education about CC and CCS was conducted with all of women, to influence them to undergo CCS. While there may be a chance that other unknown factors (not accounted for by this study) may explain this finding, further research is needed to examine what these are. Possible contributing factors may include the fact that the range of education level, Nursery-10th grade, was much more broad and the number of women in that category were considerably higher (N=33, 27%) than the group with education level of some college and higher (N=21, 17%). Although it may be speculated that the difference in beliefs or other factors that are unique to Nepalese women may have contributed to this finding, no reports or studies were found to support this inference. Because demographic information was not collected on all possible influencing factors, such as socio-economic status, additional research with more comprehensive demographic data collection is recommended to clarify this finding, which may have implications for education and further research.

Validity and Reliability

As this study was based on HBM and there were no instruments measuring HBM factors in Nepali, Dr. Champion's (1999) valid and reliable HBM scale was adapted to be used as a foundation document in the development of the Nepalese Health Belief Model (NHBM) scale. Validity of NHBM scale was established by translating the HBM scale to NHBM scale using a research based methodology, back-translation (Koller et al., 2007; Maneesriwonul & Dixon, 2004; Weeks, Swerissen, & Belfrage, 2007). Translated

NHBM scale was further tested and validated by conducting a pilot study and evaluating the instrument and the process. Back-translation process included the revision and consensus by the experts, who came to consensus that the NHBM scale accounts for cultural norms, language, and social rules appropriate for Nepalese culture. Easy to read, accuracy and successful consideration for the difficulties created by differences in societal rules between the source and target culture were also an intricate part of the criteria incorporated in the translation process.

Reliability testing resulted in adequate Cronbach's alphas for the NHBM scale and three of its subscales (Alpha= .70-.88). Additionally the corrected item-total correlation of all items measured positive values, indicating that the scales and subscales measure their domains. These reliability measures were less favorable than other studies based on HBM in other cultures and countries. The basis of this finding may include the lack of flexibility for the experts to add or remove any items of HBM scale and an option to only modify to maintain the concepts. Additionally, the intent of this study was to use the established and extensively researched valid and reliable HBM scale as a basis to develop NHBM scale rather than to create a new one. Even though other studies report higher reliability values, most of their studies' main intent was noted to be solely to develop that instrument and refine it (Parsa, Kandiah, Mohd, Hejar, & Afiah, 2008; Guvenc et al., 2010). However, taking the opportunity to refine the NHBM is likely to improve the internal consistency, reliability.

Health Belief Model (HBM)

Developed in 1950's to explain the lack of public participation in such prevention programs as tuberculosis screening, HBM has become the most frequently used and most researched conceptual model for preventive health behavior research across disciplines and health sectors (Tanner-Smith & Brown, 2010; Family Health International, 2002; and Rosenstock, 1974). With the key concepts of perceived susceptibility, perceived seriousness, perceived benefits, and perceived barriers, HBM is used to explain and predict health-related behaviors. In this study, the concepts of the HBM model were used as variables in relation to CCS behavior. Because HBM is also a psychosocial model which does not account for other forces, such as religion and lived experiences of participant that also explain health behavior, this may have introduced bias impacting the findings in the study considering that the research was conducted in another country with participants of different culture (Janz & Becker, 1984).

Nepalese women's CCS behavior in relation to HBM subscales: perceived susceptibility, perceived seriousness, cue to action, perceived benefits and perceived barriers

The findings related to HBM constructs in this study were as expected, as explained below, although not all hypotheses were statistically supported. To briefly review the study findings, women's perception of susceptibility to CC or the perceived seriousness of CC made no significant difference to their screening behavior, as measured by their status of screening. In contrast, there was a significant difference in CCS behavior in relation to perceived benefits and perceived barriers. No significant

association was found between CCS behavior and cue to action, women's knowing of someone with CC or dying of CC.

Perceived susceptibility, perceived seriousness and cue to action. According to HBM and findings of other researchers (Granze et al., 2008; Juon et al., 2003; Gao et al., 2008; Agurto et al., 2004) perceived susceptibility, perceived seriousness and cue to action are constructs that are related to the likelihood of CCS behavior. The contradiction in our findings as compared to other studies and HBM concepts calls for speculating of other possible underlying factors, unique to Nepalese women.

All of the women, screened and non-screened, participated in a similar awareness program prior to the screening session. As a result, their perceptions could have become similar and influenced the likelihood in screening of all participants to the same extent. The finding that there was no significant difference between those who screened and those who did not in relation to their perception about their risk of getting CC and the seriousness of CC may be a result of this phenomenon.

It is also likely that this finding may be related to Nepalese culture and history of Nepalese people, and not necessarily the reflection of HBM. Research shows that seeking preventive services that have recently been introduced in Nepal (i.e. CCS) requires both trust and belief, aspects that require women to be strong enough to step out of their cultural boundaries, physically, socially, and spiritually (Subedi, 1989). Additionally, Nepalese people have their focus on curative and not preventive practices, where they seek the care only when they are noticeably ill. Although medical care and preventive measures are available in many areas now, the practice to seek healthcare when disease

or symptoms of disease are already apparent, continues within the Nepali culture (Wasti et al., 2011). This unique cultural practice may be likely to impact Nepalese women's decision to undergo CCS. Hence, these factors may or may not be accounted for by the HBM or captured by NHBM scale.

During informal conversations at research sites, women were observed to discuss that they would not get CC because they pray to God and God will protect them. One of them stated, "Bad things are going to happen when its time, no matter what..." While this observation may not be generalized, these statements do resemble the theory of fatalism. Fatalism refers to the belief that all events, actions, incidence are determined by fate, they are meant to happen and with the will of God, they are not going to happen (Akhigbe & Akhigbe, 2012). While the focus of this study was to examine the role of belief factors (as defined by HBM) on CCS behavior, there may be bias introduced by other factors, such as history, culture, lived experience, and fatalism, not accounted for by HBM.

Cue to action, referring to a woman knowing someone with CC or dying of CC, was an attribute that was not significantly associated with CCS behavior in this study. Other research, not conducted in Nepal, indicated that there is a significant relationship between cue to action and CCS behavior (Glanz et al., 2008; Levya et al., 2006; & Juon et al., 2003). However, Nepalese women, living in one of the poorest countries in the world with one of the highest incidence and mortality rates of CC in the world, may not be as prompted for CCS to the same degree by "Cue to Action," to undergo CCS as women in other population. Results may be suggestive that the difference in environment and other factors may explain how much cue to action prompts screening behavior.

Perceived benefits. There was a significant difference in CCS behavior (women who screened and women who did not) in how they perceive the benefits of CCS. The new awareness, allows us an opportunity to change education and intervention to increase utilization by using the finding to integrate into existing programs. If those education and intervention approach is implemented at a large scale and expanded to other programs, the results are likely to decrease the incidence and mortality rates of CC. These findings are consistent with studies which report that CCS behavior is related to perceived benefits as a subscale or to certain items measuring perceived benefits (Lee et al., 2008; Levya et al., 2006). In this study, the specific perceived items that made the most difference, within the “benefits” subscale, between those who were screened and who were not included: “When I undergo CCS, I feel good about myself” AND “Completing CCS will allow me to find out if there are early signs of CC.” Emphasis in these two factors during awareness and education sessions is likely to make a difference in their CCS behavior and utilization of CCS services. Small group discussion including women who have undergone screening, with good experience and positive perceptions may be one approach to influence their perceptions about perceived benefits.

Perceived barriers. The significant difference between those who were screened and those who were not was noted on their perception of barriers to CCS. This finding is consistent with other studies in literature, which report that perceived barriers are predictive of and associated with CCS behavior (Byrd et al., 2004; Esin et al., 2011; Abotchie & Shokar, 2009; Waller et al., 2009). In this study, the items of “perceived barriers” subscale, that were most influential for undergoing CCS were: “I feel awkward

going to get CCS;” “CCS will be embarrassing to me;” “Undergoing CCS will take too much time;” and, “CCS procedure will be painful.” Based on this finding, it can be inferred that the study participants, who were not screened or have not had the awareness regarding CCS, would benefit from education and/or an intervention program that can increase their awareness about these barriers to CCS. Considering the sensitive nature of these barrier items as found and listed above, an education program that incorporates small group discussion facilitated by a female leader, in addition to the current awareness program, may increase effectiveness.

Research Approach

Harzing, Reiche and Pudelko (2007) assert that when conducting international research, the researchers face numerous challenges that reach beyond those encountered in domestic research. This proved to be true in this study. Conducting this international research was more challenging than expected or planned. However, staying fully alert, proactive planning and patience helped to overcome those challenges. Specific challenging steps encountered in conducting this research study included obtaining HSRB approval from Nepal, translating the HBM scale to the NHBM scale, training research assistants, conducting pilot study, and collecting data in another country. The HSRB from the Nepal Health Research Council (NHRC) was obtained in three months. Although less time was initially allocated for the HSRB approval by the researcher in the timeline for this study, Nepali challenges such as a lack of electricity for

three days out of each week is one example of the understandable complexity that affected the study timeline.

A prolonged lack of communication with NHRC, sometimes for as long as two weeks, was a reality that proved to be frustrating, especially when waiting to clarify something minute. However, expecting this and planning to be patient would be the author's recommendation based on this experience. Perhaps because NHRC is the only organization that processes and grants HSRB approval in the country, the requirements were more lengthy and strict compared to the requirements at George Mason University, for example. Again, being prepared to accept the unexpected, especially when not knowing all the particulars of the situation and culture of another country, would make the process less stressful when starting an international research study.

A back-translation method was selected for translating the HBM scale into the NHBM scale, as it was reported to be the most accurate (Koller et al., 2007; Maneesriwonul & Dixon, 2004; Weeks, Swerissen, & Belfrage, 2007) method for translation in cross-cultural research. To conduct this process, two bilingual translators were recruited for a forward translation into Nepali. Those translators were unable to complete the task as they found that they either did not know appropriate words or could not find proper Nepali equivalents for some English words. They were also not familiar with healthcare terminology despite their experience as translators in other disciplines. Still, two of the three experts completed the initial translation. With one additional doctoral-level expert, who specialized in CC and CCS, they reviewed the NHBM scale in accordance with the established translation criteria (See Appendix G: Translation

consensus form), concurring that the instrument was reliable, complete, accurate, culturally appropriate, clear and easy to read, conceptually equivalent, semantically equivalent, and normatively equivalent.

Once the NHBM scale was finalized, two bilingual translators translated the NHBM scale back into English via a blind process, without access to the original English instrument. The original instrument and the instrument that was created appeared to be quite different on the surface. The differences can be attributed to many unique differences between the two languages. Additionally, the difference in the culture changes the way same concepts are communicated. For example saying a same word with different tone can have different meanings as if they were two. During translation, there were times when it was suggested that an item “can be asked better with a different item.” However, the translators and experts were requested to translate the document but not to remove or add items. Not being flexible for them to add, delete, or replace an item may have attributed more to the differences in the appearance of the instruments. However, the concepts of the original document remained the same and met the translation criteria, although the writing seemed very different.

In coordinating the translation process, many challenges were encountered, including recruiting translators and experts; facilitating the translation process despite the local challenges, such as electricity outages and unplanned office closings; coordinating the experts to review the instrument with the translation criteria. It was complex at times to maintain contact with the translators and keep the focus on the translation criteria during the process.

In the future, if the translation process needed to be repeated for another study or project, it would be recommended to use the same methodology; however prepare by interviewing the translators regarding their experience and ability to translate. Even better, requesting the true experts to do the translation from the start may be ideal. Knowing more in advance about the foreign language and how it relates to English and about the level of complication ahead of time would have been less stressful during this process. However, having a contact who could best communicate with all experts and translators in the target country was of great value to complete this process.

Research assistant (RA) training was an important step to ensure appropriate method of data collection and accuracy of the data. Average age of the RAs was 36 with a range from 23-48. The RAs were selected with specific criteria of at least a college degree for education and an experience in healthcare either as an employee or as a volunteer. All of them had completed a college degree, seven had completed Bachelor's degree and three had completed Associate equivalent degrees. Among all of the participants, there were four social workers, a data collector of disabled persons, four volunteers at Nepal Network for Cancer Treatment and Research (NNCTR), and one Registered Nurse who also volunteered at NNCTR.

We had prearranged the training hall, rented an LCD projector, hired 10 research assistants, and obtained support from two organizations to conduct the RA training and the pilot study in one day. When I reached to the location for RA training, it turned out that two of the research assistants could not make it. I expressed that I really need all RAs to be present so I could teach the material the same way to all because it would make a

difference in how they collected data. While we were discussing options to reschedule, the two research assistants were brought by someone. This reflects the culture of Nepal, which, as I experienced, is very genuine and respectful and where people go above and beyond to meet the needs of their guest. Being treated as a guest was a privilege and was one of the key ingredients of success in the process. In summary, it may not always be possible to attain the quality of research as intended based on the circumstances of the population site and sample; however, thorough preplanning and a good network of contacts will always be beneficial.

The pilot study was one of the processes that were successful and rewarding. Partnering with the NNCTR and the Balkumari Savings and Loan Cooperative Organization allowed us to prearrange plenty of space within two floors, to accommodate ten women at a time, and a well planned food, surveying, and focus groups made it a busy but productive day. It was helpful that the role-playing of survey administration using the script was a part of the RA training. Since they had the opportunity to role-play and practice, it was easier to assess issues specific to the actual pilot study instrument and process with more objectivity.

One observation was that the women participating in the pilot were not vocal and said “OK” or “It’s good” to almost everything that was asked of them. They were laughing, talking, and smiling even during the interview, appearing really happy. When they were asked about it, their first responses were, “Oh, just because” or “This is nice.” During the focus group, one woman said, “This is the first time that anyone has ever asked us what we think, feel, or believe; otherwise, they always tell us what to do.”

(Nepali quote translated in English.) The group then nodded and said “Yes, yes,” elaborating about how true that statement was. This was an interesting observation or an effect that was likely therapeutic to them. Perhaps the women may have more follow-through concerning their health if their education or research begins by asking them what they think, feel, or believe.

Recommendations for Future Research

Because the NHBM is developed with valid and fairly reliable measures, researchers can use it with other study populations in research related to preventive health behavior. Adding a scale to measure fatalism coupled with HBM scale may enhance the findings, indicating the role of belief factors and of other factors, not related to HBM, such as fatalism. Because this study was fairly small, a larger-scale study about Nepalese women’s CCS behavior, incorporating more geographical area, women in various caste systems, religions, socioeconomic status, and varying level of coverage for CCS services, is recommended. Since the findings of this study showed that perceived susceptibility, seriousness, and cue to action were not different for women who underwent screening and women who didn’t, follow up with a qualitative study to understand better the underlying factors related to screening, including those not related to HBM, is recommended.

The women’s feedback about “feeling great” when they were asked about their feelings and thoughts about CCS in this study, sparked an interest to conduct or suggest a study comparing two educational approaches as related to their behavior: traditional,

lecture-type education and education with materials created based on the women's feedback and their thoughts. A study conducted in Nepal which hypothesized that community-based participatory intervention could significantly reduce neonatal mortality rates revealed that participatory intervention with women's groups was one of the factors related to greatly improved birth outcomes in poor rural population (Manadhar et al., 2004). This suggests that there may be potential to decrease the incidence and mortality rates if the programs incorporate the women in education and intervention as a part of awareness team. Participating in such a role might have great influence in their behavior or the behavior of other women.

In this study, the participants were asked one open ended question, "What do you think your friends believe are the barriers to cervical cancer screening?" Although their responses were obtained to that question, analyzing them requires a thorough translation process. An attempt was made and translation was started with some of the participant's responses; however, they did not seem to be related to the question. It was then decided that it would be more accurate and appropriate to analyze this data with proper translation process and bilingual expert and a thorough analysis at a later time, with a qualitative approach.

Another important study to research behavior health in Nepal, perhaps with more clarity, is an instrument development of an instrument measuring "fatalism." Although it was not researched directly, there seemed to be components of fatalistic beliefs among Nepalese women in this study. Developing a tool for fatalism using back-translation to combine that with NHBM scale in the future may be ideal for this target population.

Implications

This study has many direct and indirect implications for practical, educational, research, policy, and international policy realms. This is the first study to develop a Nepali version of the HBM scale. To study the role of belief factors of Nepalese women, a well researched conceptual model, the HBM, and a validated research instrument, the HBM scale, were used. A rigorous, research-based translation process, back-translation, was used to develop the NHBM scale from the HBM scale. Development of the NHBM scale was a rigorous process which included considerations regarding the differences in the two cultures, original scale, country, and language including the cultural differences and social norms. Although there were challenges to locate competent translators initially, the experts being involved in translation was found to be more ideal in this case. The lessons learnt and implications for the future include the need to interview and assess the ability of the translators to fulfill this role which makes the process more effective. Also, a communication plan with the translators, experts, back-translators, translation coordinator would have reduced the time needed to complete the process. Overcoming that initial challenge, the efforts of experts, and back-translators to ensure the criteria of validity for NHBM are in consensus of all experts required much time and energy, but with positive outcome.

The pilot study was successful without any major changes. Although it was not part of this research, the response of the women participants that they were happy because they were actually asked about their thoughts and beliefs for the first time, has

implications for practice (how we interact with them), education (create effective teaching material with their opinions added), research (teaching modalities), and policy (provide support for education and research). The message was that the more women believe in what they are taught, the more they are likely to do what we propose. This was discovered through their input and is a valuable finding, even though it was not a response to the study items.

The measure of reliability of NHBM scale was not as high as the researcher would have desired; however, there is an opportunity to refine the scale to improve these measures. The implications of the NHBM scale for future research include the ability of researchers to have access of this instrument to use for other health behavior research in Nepal. An instrument based on Dr. Champion's well established HBM scale, may be of value in future health prevention research for not only CC but also in other preventive health areas in Nepal. Because of the realization in this study that fatalism may play a role in the health behavior, that HBM does not account for, utilizing NHBM scale with fatalism scale, back-translated into Nepali, would be recommended.

Limitations

The first limitation involves the generalizability of the study. There are many women with different social, cultural, and economic characteristics living in Nepal, and this study was carried out with a small group of women. Because the socio-economic status could not be collected, it is also possible that the sample population may not be completely represented as well.

Another limiting factor in generalizability was introduced by the method of participant selection and recruitment. With the intent to study belief factors specifically, the selected participants had to have CCS services available, accessible, and free, in addition to having attended an awareness program about CC and CCS. While this was ideal for the specific purpose of the study, it limited the characteristics of the participating women limiting the generalizability of the findings.

Ten RAs were hired for data collection. Considering that the data were collected with structured face-to-face methodology, RAs could have introduced bias, potentially affecting the reliability of responses. Such bias might have emerged from the way in which the questions were asked or in respondents' wish to give socially desirable responses. To minimize this effect, all RAs were provided with a standard script, questions, and training on structured face-to-face data collection, including didactic and role-play methods. Also, the same RAs were involved in pilot study as well as data collection in an attempt to decrease this bias.

Although HBM was the most researched conceptual model to explain health behavior (Glanz et al., 2008), the model is considered a psychosocial model that does not account for other forces that also explain health behavior (Janz & Becker, 1984). Although the common structural factors were accounted for in this study, the model is predicated on the premise that "health" is a highly valued concern or goal of most individuals (Janz & Becker, 1984). Due to the culture in Nepal, where evidence suggests that they do not prioritize disease prevention and healthy behavior in general, HBM may not explain their attitudes and beliefs as much as in other cultures as indicated by

published research (Janz & Becker, 1984). Since the instrument, HBM scale was based on HBM and its constructs, HBM scale may not completely measure the influential factors on health behavior of Nepalese women as well as it would in cultures that fit the psychosocial profile in developing the HBM model and HBM based instrument.

Conclusion

This study examined the difference in CCS behavior of Nepalese women in relation to perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers and cue to action. There was no significant relationship between cue to action and CCS behavior. While CCS behavior was not found to be significantly different based on perceived susceptibility and perceived seriousness, a significant difference in CCS behavior was noted in relation to perceived benefits and perceived barriers. A Logistic regression analysis examined to what extent perceived susceptibility, perceived seriousness, perceived benefits, perceived barriers, cue to action, age and education predict CCS behavior, and found no statistical significance for their predictability; however, the results indicated that the women with education level of Nursery to 10th grade were almost as 3 times likely to screen as those in college level and higher. This finding will need more evidence and research because it is against currently available evidence and understanding.

The non-significant results regarding perceived susceptibility, perceived seriousness and cue to action suggest further examination by qualitative method to understand other factors that may play a role on CCS behavior of Nepalese women;

Whereas, the significant difference in CCS behavior of Nepalese women in reference to perceived benefits and perceived barriers, indicate the need to add emphasis to influence these perceptions among Nepalese women. While women being exposed to same awareness program may be a factor for the statistically non-significant results, it is also possible that Nepalese women have beliefs or other factors, perhaps not related to HBM, that play a role in their decision to undergo CCS.

With awareness that perceptions of benefits of CCS and barriers to CCS do make a difference in their CCS behavior, tactics to influence their understanding and perception becomes a priority. The approach to do so may need to be planned with care to ensure that they will be effective. During analysis, it was noted that the items that were most different in two groups (screened and not) were very sensitive and private in nature. Small group discussions with a woman leader or utilizing the women in their community to discuss the positive aspects are one of the recommendations. It may even be more effective if the women themselves could be involved in planning the approach to influence the other women to undergo CCS by impacting their understanding and perceptions.

The findings that perceived barriers and perceived benefits were significantly different among the study participants, who had the benefit of availability, accessibility, and free service with an awareness session, were suggestive of the importance to increase focus in awareness of perceptions of benefits and barriers for the women. Those structural benefits were a requirement of the participants to minimize the confounding variables. If the findings for a study sample who already the benefit of the structural

factors indicated a need for increased emphasis on perceived benefits and perceived barriers, it is likely that these findings are applicable and interventions even more important to other women who do not have the benefit of the awareness program and other factors. Therefore, the implications of these findings may extend beyond the target population.

Although it is a reality that there are no universal CCS programs in Nepal, and despite the major CC crisis in Nepal, new programs are emerging. This study was conducted with the women participants who were exposed to an awareness program and who had the CCS services accessible for free with the purpose to focus on belief factors involved. When the programs are not available or accessible, inability to obtain CCS is unfortunate but may be atypical and cannot be labeled as related to their behavior. When comprehensive programs emerge and offer services without structural barriers, not using the screening services is costly in all aspects and it is more of a behavior factor, which is better understood through a concept like HBM. In a low-resource country with one of the highest incidence and mortality rates of CC in the world, findings about certain belief factors influencing CCS behavior, warrants despite the availability of CCS program that is accessible and free, warrants a focus, intervention and support in every aspect, with implications for practice, research, education, policy, and international policy.

**APPENDIX A: HSRB APPROVAL FROM GEORGE MASON UNIVERSITY
(GMU) AND NEPAL HEALTH RESEARCH COUNCIL (NHRC)**



Office of Research Subject Protections

Research Hall
4400 University Drive, MS 6D5, Fairfax, Virginia 22030
Phone: 703-993-4121; Fax: 703-993-9590

TO: Kathleen Gaffney, College of Health and Human Services

FROM: Aurali Dade
Assistant Vice President, Research Compliance 

PROTOCOL NO.: 8094 Research Category: Doctoral Dissertation

PROPOSAL NO.: N/A

TITLE: Cervical Cancer Screening Behavior among Nepalese women

DATE: May 14, 2012

Cc: Kalpana Satyal

On 5/14/2012, the George Mason University Institutional Review Board (GMU IRB) reviewed and approved the above-cited protocol following expedited review procedures.

Please note the following:

1. Copies of the final approved consent documents are attached. You must use these copies with the IRB stamp of approval for your research. Please keep copies of the signed consent forms used for this research for three years after the completion of the research.
2. **Any modification to your research (including the protocol, consent, advertisements, instruments, funding, etc.) must be submitted to the Office of Research Integrity & Assurance (ORIA) for review and approval prior to implementation.**
3. Any adverse events or unanticipated problems involving risks to subjects including problems involving confidentiality of the data identifying the participants must be reported to the ORIA and reviewed by the IRB.

The anniversary date of this study is 5/13/2013. **You may not collect data beyond that date without GMU IRB approval.** A continuing review form must be completed and submitted to the ORIA 30 days prior to the anniversary date or upon completion of the project. In addition, prior to that date, the ORIA will send you a reminder regarding continuing review procedures.

If you have any questions, please do not hesitate to contact me at 703-993-5381.



Nepal Health Research Council

Estd. 1991

NHRC

Ref. No. 36

Executive Committee

Executive Chairman
Prof. Dr. Chop Lal Bhusal

Vice - Chairman
Dr. Rishi Ram Koirala

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Dr. Samjhana Dhakal
Dr. Devi Gurung

Representative
Ministry of Finance
National Planning Commission
Ministry of Health & Population
Chief, Research Committee, IOM
Chairman, Nepal Medical Council

19 July 2012

Dr. Kathleen F Gaffney
Principal Investigator
George Mason University
USA

Ref: Approval of Research Proposal entitled Cervical Cancer Screening Behavior among Nepalese Women

Dear Dr. Gaffney,

It is my pleasure to inform you that the above-mentioned proposal submitted on 8 June 2012 (Reg. no. 72 /2012 please use this Reg. No. during further correspondence) has been approved by NHRC Ethical Review Board on 16 July 2012 (2069-01-01).

As per NHRC rules and regulations, the investigator has to strictly follow the protocol stipulated in the proposal. Any change in objective(s), problem statement, research question or hypothesis, methodology, implementation procedure, data management and budget that may be necessary in course of the implementation of the research proposal can only be made so and implemented after prior approval from this council. Thus, it is compulsory to submit the detail of such changes intended or desired with justification prior to actual change in the protocol.

If the researcher requires transfer of the bio samples to other countries, the investigator should apply to the NHRC for the permission.

Further, the researchers are directed to strictly abide by the National Ethical Guidelines published by NHRC during the implementation of their research proposal and submit progress report and full or summary report upon completion.

As per your research proposal, total research amount is NRs. 80,000.00 and NHRC processing fee is US\$.100.00.

If you have any questions, please contact the research section of NHRC

Thanking you,
Sincerely Yours,

.....
Prof. Dr. Chop Lal Bhusal
Executive Chairman

**APPENDIX B: NEPAL NETWORK FOR CANCER RESEARCH AND
TREATMENT - SUPPORT LETTER**



नेपाल नेटवर्क फॉर क्यान्सर ट्रीटमेन्ट एण्ड रिसर्च
Nepal Network for Cancer Treatment and Research
NNCTR / INCTR Nepal
Banepa, Kavre
2001

**Executive Committee:****Chairman :**

Dr. Surendra B.B. Shrestha
Banepa -5
Tel : 011-661445

Vice Chairman :

Prof. Dr. Manohar Lal Shrestha
Kathmandu
Tel : 01-4221800

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Tel : 011-661206

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Dr. Aarati Shah
Kathmandu

Prof. Dr. Pradip Vaidya
Kathmandu

Dr. Sudip Shrestha
Kathmandu

Dr. Kasturi Malla
Kathmandu

Dr. Sheela Verma
Kathmandu

Dr. Meeta Singh
Banepa

Dr. Achala Vaidya
Banepa

Ms. Praneswori Shrestha
Banepa

Member Secretary :

Ms. Radha Pyari Nakarmi
Banepa -6, Tel : 011- 661195

Ref: 21

Date: 10th Aug 2011

Kalpna Satyal, RN, MS-HSMG, CRRN
PhD Candidate, Nursing
College of Nursing, George Mason University
5505 Tobego Court
Fairfax, VA-22032

Subject : Support letter to conduct research utilizing program and data of Nepal
Network for Cancer Treatment and Research (NNCTR / INCTR Nepal)

Dear Kalpana,

We are delighted to hear that you are interested in conducting research in NEPAL utilizing the information and work of International Network of Cancer Treatment and Research (INCTR), Nepal Branch Office . Findings of your research are likely to be beneficial to the Cervical Cancer Screening (CCS) program according to our detailed discussion in May, 2011 in Kathmandu, Nepal. Our program offers screening services that is free of cost and accessible to the women after providing free awareness about cervical cancer and the service we offer. Despite our efforts, the utilization of our services is not always optimal. With the intended purpose of your study to examine the contributing belief factors of Cervical Cancer Screening behaviors, your research findings may highlight the areas that we need to incorporate in education and intervention to achieve effectiveness, increasing the utilization of screening services and contributing to prevention and early findings of Cervical Cancer.

We will be happy to give you the field support in identifying the participants for your research and provide assistance in coordinating the process to recruit research participants and collect information from them.

If you or George Mason University has any questions, you may reach us at email: nnctr@ntc.net.np, infor@nnctr.org.np or by phone at 977 11 664 524.

Signature
(Dr. Surendra B. Bade Shrestha)
Chairman
NNCTR / INCTR Nepal

Date : 11. August 2011

Signature
(Radha Pyari Nakarmi)
Program Officer
NNCTR / INCTR Nepal

Date : 11. August 2011

**NNCTR/ INCTR Nepal, Branch Office**

Current Office : Ghokechaur Banepa, Ward No. 1. Phone / Fax No. : 977-11-664524,

Email : nnctr@ntc.net.np

APPENDIX C: VICTORIA CHAMPION'S PERMISSION TO USE HBM SCALE



INDIANA UNIVERSITY

SCHOOL OF NURSING
IUPUI

May 2, 2011

Kalpana Satyal
5505 Tobego Court
Fairfax, VA 22032

Dear Ms. Satyal,

Thank you for your interest in my work. You have permission to revise the Health Belief Model tool as long as you cite my work and send me an abstract of your completed project.

Sincerely,

Victoria Champion, PhD, RN, FAAN
Mary Margaret Walther Distinguished Professor
Edward W. and Sara Stam Cullipher Endowed Chair
Executive Associate Dean for Research Affairs

VC:dd

Enclosure

APPENDIX D: HBM SCALE

Original HBM scale utilized for forward-translation to Nepali

Victoria Champion's HBM scale items modified to Cervical Cancer

Adapted with permission from "Revised Susceptibility, Benefits, and Barriers Scale for Mammography Screening," by Champion, V.L (1999), *Research in Nursing & Health*, 22, 341-348.

Susceptibility:

1. It is extremely likely I will get cervical cancer in the future.
2. I feel I will get cervical cancer in the future
3. There is a good possibility I will get cervical cancer in the next 10 years
4. My chances of getting cervical cancer are great
5. I am more likely than the average woman to get cervical cancer

Seriousness:

1. The thought of cervical cancer scares me
2. When I think about cervical cancer, my heart beats faster
3. I am afraid to think about cervical cancer
4. Problems I would experience with cervical cancer would last a long time
5. Cervical cancer would threaten a relationship with my boyfriend, husband or partner
6. If I had cervical cancer my whole life would change
7. If I developed cervical cancer, I would not live longer than 5 years

Benefits :

1. When I undergo cervical cancer screening I feel good about myself
2. When I complete cervical cancer screening I don't worry as much about cervical cancer
3. Completing cervical cancer screening will allow me to find out if there are early signs of cervical cancer
4. If I complete cervical cancer screening, I will decrease my chances of dying from cervical cancer
5. If I complete cervical cancer screening, I will decrease my chance of pain and surgery related to cervical cancer
6. If I complete cervical cancer screening, it will help me find abnormality in my cervix which might be cancer before it becomes an invasive cancer

Barriers:

1. I feel awkward going to get cervical cancer screening
2. Undergoing cervical cancer screening will make me worry about cervical cancer
3. Cervical cancer screening will be embarrassing to me
4. Undergoing cervical cancer screening will take too much time
5. Cervical Cancer Screening procedure will be painful
6. Cervical Cancer Screening will interfere with my family obligations

Cues to Action:

Do you have a friend or family member who has or died of cervical cancer?

APPENDIX E: HBM SCALE MODIFIED AND ADAPTED FOR CC

Victoria Champion's HBM scale items modified to Cervical Cancer
Adapted with permission from "Revised Susceptibility, Benefits, and Barriers Scale for Mammography Screening," by Champion, V.L (1999), *Research in Nursing & Health*, 22, 341-348.
5 Point Likert Scale (Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree)

Susceptibility (+):

1. It is extremely likely I will get cervical cancer in the future.
2. I feel I will get cervical cancer in the future
3. There is a good possibility I will get cervical cancer in the next 10 years
4. My chances of getting cervical cancer are great
5. I am more likely than the average woman to get cervical cancer

Seriousness (+):

1. The thought of cervical cancer scares me
2. When I think about cervical cancer, my heart beats faster
3. I am afraid to think about cervical cancer
4. Problems I would experience with cervical cancer would last a long time
5. Cervical cancer would threaten a relationship with my boyfriend, husband or partner
6. If I had cervical cancer my whole life would change
7. If I developed cervical cancer, I would not live longer than 5 years

Benefits (+):

1. When I undergo cervical cancer screening I feel good about myself
2. When I complete cervical cancer screening I don't worry as much about cervical cancer
3. Completing cervical cancer screening will allow me to find out if there are early signs of cervical cancer
4. If I complete cervical cancer screening, I will decrease my chances of dying from cervical cancer
5. If I complete cervical cancer screening, I will decrease my chance of pain and surgery related to cervical cancer
6. If I complete cervical cancer screening, it will help me find abnormality in my cervix which might be cancer before it becomes an invasive cancer

Barriers (-):

1. I feel awkward going to get cervical cancer screening
2. Undergoing cervical cancer screening will make me worry about cervical cancer
3. Cervical cancer screening will be embarrassing to me
4. Undergoing cervical cancer screening will take too much time
5. Cervical Cancer Screening procedure will be painful
6. Cervical Cancer Screening will interfere with my family obligations

Cues to Action:

Do you have a friend or family member who has or died of cervical cancer?

Tell me what you think your friends may consider as factors that influence their decision to undergo cervical cancer screening.

APPENDIX F: NEPALESE HEALTH BELIEF MODEL (NHBM) SCALE

नेपालीज हेल्थ बिलिफ मोडल स्केल
Nepalese Health Belief Model Scale (NHBMS)

कमजोरी :

१. मलाई भविष्यमा पाठेघरको मुखको क्यान्सर हुने सम्भावना धेरै छ ।
२. मलाई भविष्यमा पाठेघरको मुखको क्यान्सर हुन्छ जस्तो लाग्छ ।
३. मलाई अबको १० वर्षमा पाठेघरको मुखको क्यान्सर हुने सम्भावना धेरै छ ।
४. मलाई पाठेघरको मुखको क्यान्सर हुने सम्भावना एकदम नै धेरै छ ।
५. अरु साधारण आइमाई भन्दा मलाई पाठेघरको मुखको क्यान्सर हुने सम्भावना धेरै छ ।

गम्भिर्यता :

१. पाठेघरको मुखको क्यान्सरको सोचले मलाई डर लाग्छ ।
२. जब म पाठेघरको मुखको क्यान्सरको बारेमा सोच्छु, मेरो मुटु छिटो छिटो धड्किन्छ ।
३. म पाठेघरको मुखको क्यान्सरको बारे सोचन डराउँछु ।
४. मलाई लाग्छ, पाठेघरको मुखको क्यान्सरबाट आउने समस्या धेरै समय सम्म रहिरहन्छ।
५. पाठेघरको मुखको क्यान्सर भएमा मेरो केटा साथी, श्रीमान वा सहकर्मी सगको सम्बन्धलाई विगन सक्छ ।
६. यदि मलाई पाठेघरको मुखको क्यान्सर भएमा मेरो सम्पूर्ण जीवन नै परिवर्तन हुन्छ ।
७. यदि मलाई पाठेघरको मुखको क्यान्सर भएमा म ५ वर्ष भन्दा बढी बाच्ने छैन ।

फाइदाहरु :

१. जब म पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण गराउन जान्छु, तब म राम्रो अनुभव गर्छु ।
२. जब मेरो पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण पूरा हुन्छ, म त्यसको बारे खासै चिन्ता गर्दिन ।
३. पाठेघरको मुखको क्यान्सरको प्रारम्भिक जाँचले मलाई पाठेघरको क्यान्सरको प्रारम्भिक लक्षण थाहा पाउन सहयोग पुग्छ ।
४. यदि मैले पाठेघरको मुखको क्यान्सरको प्रारम्भिक जाँच गराए भने यस रोग बाट मेरो मृत्यु हुने सम्भावना कम हुन्छ ।
५. यदि मैले पाठेघरको मुखको क्यान्सरको जाँच गराए भने मैले यस रोगबाट हुन सक्ने दुःख र चिरफारको सम्भावना कम गर्छु ।
६. यदि मैले पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण गराएँ भने यसले मेरो पाठेघरको मुखमा हुने क्यान्सर पूर्वको असमान्य अवस्था बारे थाहा हुन सक्छ जसले मलाई क्यान्सर हुन बाट जोगाउन मद्दत गर्छ ।

रोकावटहरु :

१. मलाई पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण गराउन जान असजिलो लाग्छ ।

२. पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण गराए पछि मलाई त्यसबारे चिन्ता मात्रै रहिरहन्छ ।
३. पाठेघरको मुखको क्यान्सरको प्रारम्भिक जाँच गराउन मलाई धेरै असजिलो लाग्ने हुन्छ।
४. पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण गराउन धेरै समय लाग्ने हुन्छ ।
५. पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण प्रक्रिया पीडादायक हुनसक्छ ।
६. पाठेघरको मुखको क्यान्सरको प्रारम्भिक परीक्षण बाट मेरो पारिवारिक गोपनियता भङ्ग हुनसक्छ ।

सङ्कार्यको लागि सङ्केत:

के तपाईंले पाठेघरको मुखको क्यान्सर भएको अथवा त्यो रोगले मरेको कोही चिन्नुहुन्छ ?

(यस को उत्तर, उत्तरपुस्तिकाको पछाडिपट्टि रेकर्ड गर्नुहोला)

APPENDIX G: TRANSLATION CONCENSUS FORM

Translation Consensus Form
“Nepalese Health Belief Model Scale”

Health Belief Model(HBM)Scales(Champion,1999)->Nepali Health Belief Model(NHBM) Scales

Date: 22 May 2012

Researcher: Kalpana Satyal, PhD Candidate, George Mason University, United States of America

Translator 1: *Janardhan Lamichhane, PhD*

Signature: _____

Translator 2: *Maya Nath Poudel, PhD*

Signature: _____

Translator 3: *Surendra Shrestha, PhD*

Signature: _____

Coordinator: *Dipesh Parajuli*

Signature: _____

Instrument is:	Yes	No	If discrepancy - how resolved
Reliable: Translated text conveys the intended meaning of original	√		
Complete: Translations that do not add any new info to translated document and do not omit info in source document	√		
Accurate: Translated document is free of spelling and grammatical errors	√		
Culturally appropriate: Messages conveyed in translated text is appropriate for target population	√		
Clear and easy to read: Content in the translated document is clear and easy to convey for the interviewer	√		
Conceptual equivalent: A given concept is present in both the source and target cultures, regardless of the words used to express the concept.	√		
Semantic equivalent: The terms and sentence structures that give meaning to the information presented in the source language are maintained in the translated text	√		
Normative equivalent: The translated text successfully addresses the difficulties created by differences in societal rules between the source and target culture	√		

APPENDIX H: ANSWER HANDBOOK

Do you have friend or family member who has or died of cervical cancer?

Yes



No



Tell me what you think your friends may consider as factors that influence their decision to undergo cervical cancer screening.

**Cervical Cancer Screening Behavior
among Nepalese women
Handbook And Consent #**

In what year were you born?

How old were you on your first marriage?

Education:

- No schooling completed
- Nursery school to 5 Class
- 5-10 Class
- SLC (School Leaving Certificate) Pass
- Some college, no degree
- Intermediate (IA); Equivalent to AD
- Bachelors degree
- Master's degree and higher

Do you have children?

- YES
- NO

If Yes, how many?

Besides those , did you lose any babies?

- YES
- NO

If Yes , how many?

Sample Answer Sheet

Strongly Agree 1



Strongly Agree



Agree 2



Agree



Neutral 3

Neutral

Disagree 4



Disagree



Strongly disagree 5



Strongly disagree



APPENDIX I: RECRUITMENT SCRIPT

Recruitment Script

Script to invite participants for this research (In person recruitment, recruitment by telephone)

If the recruitment is by telephone, researcher will not access the database of awareness attendees herself. The program director, who knows the community and program well, will provide that information.

Good morning/afternoon/evening! My name is Kalpana and I am conducting a research as a part of my PhD research at George Mason University in the United States. I wanted to do this in my home country, Nepal. Nepal has the most cases of cervical cancer per year and most women die every year as compared to the world. Because of that, this research to learn about what belief factors of the Nepali woman predicts their use of the cervical cancer screening. All women between the age of 30-60 are requested to take part. There are no risks or direct benefit to you in participating. However, your participation may help us understand this problem better so that we can use the lessons learned to increase the number of women who undergo the screening services. You will be compensated 100 Rupees for your generous time today. If you have further questions, please call me at _____ .

Script for Research Assistants

Changes are related to the name of PhD candidate as a third person

Good morning/afternoon/evening! My name is _____. I am assisting with data collection in the research about Nepali women's belief factors about cervical cancer screening. Mrs. Kalpana Satyal is studying PhD in the United States at George Mason University. She wanted to conduct her research in Nepal, the homeland, because more women are dying from cervical cancer in Nepal than any other countries in the world. She wants to examine whether our perceptions impact our behavior to get the cervical screening done. If you are between the age of 30-60, you can choose to participate. There are no risks or direct benefits to you in participating. However, your participation may be helpful to better understand what specific belief factors of Nepalese women may if any impact their cervical cancer screening behavior. This will not impact any benefits or services you have now. You will be compensated 100 Rupees for your generous time today. If you have further questions, please call Mrs. Kalpana Satyal at _____

APPENDIX J: RA SCRIPT

Script for Face-to-Face Interview

Cervical Cancer Screening behaviour among Nepalese Women

Instructions for Interviewers:

- *Inform participant about details of the study and obtain their consent*
- *Be sure the consent and answer booklet have exact identifying number (participant's name will be on consent, and only on the answering booklet)*
- *Questions should be read out exactly as written.*
- *If a participant does not understand the question then it should be repeated.*
- *Participant should be informed that there is only one choice for each question before interview and during if needed.*
- *After dictating the question and the choices, use the response card to record their response*
- *You should read out the scripted description of survey questions to participant if clarification is requested*
- *Making and keeping the participant comfortable, you should remain neutral and only interact about survey questions during the interview*
- *Use the last page on answering booklet to ask and record response to the last item*
- *Place the booklet in the Manilla folder.*

Introduction

Hi my name is _____ and I am a research assistant helping to conduct research about Nepalese women's beliefs of cervical cancer screening. Thank you for agreeing to participate in this research. Firstly I will explain what this research is about.

Nepal has the highest incidence and mortality rates of cervical cancer in the world. In other words, more women die from cervical cancer in Nepal than almost anywhere else in the world. This research is about understanding Nepalese women's beliefs about cervical cancer and cervical cancer screening. With your input, our intent is to find out what belief factors influence a Nepali woman to undergo cervical cancer screening. With the findings of this study, we can reach more women by considering their specific beliefs to increase the use of screening incorporating certain belief factors that they might have about cervical cancer.

There are no right or wrong answers. We are just interested in what you think. We are asking these questions to lots and lots of people. There will be only one answer to each question except for the last question. I will read the questions and I will give you this booklet (hand the answer sheets) to record your answers, one question at a time. Please let me know if you either did not hear or did not understand the question, I will be more than happy to repeat.

Your answers will be kept confidential. The booklet is numbered so that the researchers can identify you when needed, but others including I will not know which answer sheet is yours. I will ask you to kindly put the answer booklet in this envelope (Manilla) when we finish.

Answering the questions will not affect your current benefits in any way. You will get 100 Rs for your time. You do not have to answer the questions if you do not want to.

Before we begin, are there any questions you would like to ask me about the survey?

Consent:

Please review the consent or ask any questions you might have.

[Interviewer Instructions – Pass consent form to participant. Allow adequate time and assist the participant with reading and understanding]

If you are willing to take part then please sign and date the form.

Survey:

I will read each question slowly, please mark your response on your booklet. (Pointing to the response graphics on their booklet) The strongly agree means _____ and its indicated by two thumbs up; Agree means _____ and it is indicated by one thumb up; neutral means _____ indicated my neutral face; disagree means _____ indicated by one “X” and strongly disagree means _____ indicated by two “XX”. If you need me to repeat the question or repeat it slowly, please let me know. Ready?

Begin Survey questions...

APPENDIX K: RA TRAINING APPROACH

Approach to train research assistants: Concepts and role play

(Structural Interview Technique)

The concepts:

Structured interview for a face to face survey administration is a data collection method in which the interviewer (research assistant) collects data from the participant. She has the role and responsibilities to ensure that the data is objective and accurate. To ensure that personal differences among the data collector's is minimized the interview has to be as structured as possible. The role of an interviewer is to ask the questions, while that of the interviewee is to respond with answers.

The interviewer is responsible to ensure and carry out the tasks below:

1. Show sensitivity to the interviewee's burden
 - ✓ Before conducting an interview, give the interviewee a general statement of how long it is expected to take.
 - ✓ Keep that time commitment as much as possible to give them respect and to stay in tract of your role
 - ✓ If they share some stories, okay to listen but avoid the emotional involvement and possible introduction of bias.

2. Develop rapport with the interviewee and show interest
 - ✓ Be empathetic, friendly, unbiased, and honest.
 - ✓ Important: appearance, verbal mannerism, body language, calm, no sighs or other signs of emotions, also control positive emotions, and be aware of non-verbal cues as well as tone that may suggest bias.
 - ✓ Casual clothing is appropriate for the field data collection sessions.
 - ✓ Give the interviewee a reason to participate
 - ✓ Explain the consent in a way they see the purpose for the work, as scripted. Let them know their answers will be confidential, means that the evaluator could associate the interviewee's name with specific responses but promises not to do so.
 - ✓ Okay to use verbal cues to acknowledge: pause, restating, repeating, thank you...

3. Ask questions in prescribed order and manner
 - ✓ Exactly as they are worded
 - ✓ In the order in which they are
 - ✓ Ask every question, provide pause to allow them to think
 - ✓ Read questions slowly (two words per second)
 - ✓ Repeat questions that are misunderstood or misinterpreted
 - ✓ Do not let the respondent stray from the questions in the interview

- ✓ Keep non verbal cues as neutral as possible
 - ✓ Keep engaged and focused (non verbally) with the respondent and as neutral as possible
4. Ensure understanding
 - ✓ Repeat the question
 - ✓ Give an expectant pause
 - ✓ Repeat the reply
 5. Ensure non- bias
 - ✓ Being neutral is the most important and sometimes difficult task
 - ✓ Bias can be perceived in the way you ask questions, respond to question, non verbal reactions, verbal comments

Review the consent:

Review the script:

Role-Play (during kickoff or during the data collection process if needed):

1. Two RAs will take turns “playing” interviewer and interviewee using the principles as described.
2. Person playing interviewee is asked to challenge “play real” with the interviewer pertaining to the skills taught.
3. RAs will use the script as practice for role-play

APPENDIX L: NHBM SCALE TABLES

Appendix L: Table 3 - Item characteristics of NHBM scale

NHBM Scale (Total items=24) = Cronbach's Alpha =.70 (N=121)					
	Mean	SD	D-index	Alpha if Item Deleted	Notes
Perceived Susceptibility(5): Alpha = .88					
1. Extremely likely I will get CC in future	2.68	1	.70	.86	
2. Feel I will get CC in future	2.52	.93	.71	.86	
3. A good likely I'll get CC in next 10 yrs	2.73	.89	.75	.85	
4. My chances of getting CC are great	2.59	.98	.72	.85	
5. I am more likely than average to get CC	2.64	.96	.71	.86	
Perceived Seriousness (7): Alpha=.70					
1. Thought of CC scares me	3.93	.88	.39	.67	
2. Thinking about CC, my heart beats faster	3.83	.99	.48	.64	
3. I am afraid to think about CC	3.91	.90	.54	.63	
4. Problems from CC would last a long time	3.41	1	.40	.66	
5. CC would threaten a relationship with my significant other	3.37	1.07	.36	.67	
6. If I had CC, my whole life would change	3.87	.93	.32	.68	
7. If I have CC, I would not live longer than 5 years	3.50	1.02	.35	.68	
Perceived Benefits (6): Alpha=.64					
1. When I have CCS, I feel good about myself	4.15	.68	.39	.61	
2. When I have CCS, I don't worry about CC	3.70	1.02	.27	.66	
3. CCS will help me find out if there are early signs of CC	4.07	.74	.46	.57	
4. If I get CCS, I am less likely to die from CC	4.17	.70	.43	.58	
5. If I get CCS, I decrease my chances of pain and surgery r/t CC	4.13	.68	.51	.57	
6. If I get CCS, It will help me find abnormality in my cervix which might be cancer before it becomes an invasive cancer	4.07	.91	.32	.62	
Perceived Barriers (6): Alpha=.77					
1. I feel awkward going to get CCS	3.30	1.26	.44	.76	
2. Undergoing CCS will make me worry about CC	3.10	1.22	.51	.74	
3. CCS will be embarrassing to me	3.50	1.13	.66	.70	
4. Undergoing CCS will take too much time	3.60	1.00	.49	.74	
5. CCS procedure will be painful	3.04	1.20	.44	.76	
6. CCS will interfere with my family obligations	3.40	1.01	.59	.72	

APPENDIX M: SIGMA THETA TAU GRANT

Sigma Theta Tau Grant Application

Jacqueline Wavelet [jwavelet@gwu.edu]

Sent: Saturday, April 14, 2012 7:13 PM**To:** ksatyal**Categories:** Orange Category**Attachments:** Research Grant Agreement.doc (64 KB)

Kal,

I am pleased to inform you that the research committee of the Epsilon Zeta Chapter of Sigma Theta Tau International has approved \$1000.00 to support your proposed study *Cervical cancer screening behavior among Nepalese women*. The committee is delighted to be able to support you as we feel that your project has merit and relevance to the nursing community.

Please inform me of your acceptance of this grant by completing the attached form (Epsilon Zeta Chapter Research Grant Agreement). A check for the amount will be sent to you upon receipt of the form. The Research Committee will expect a report from you October 1, 2012 and March 1, 2013, and every six months thereafter until completion of the research. This report should include a detailed itemization of your expenditures as well as a summary of your project to date. As the completion of your project, it is expected that you will present at a research venue sponsored by Epsilon Zeta or Sigma Theta Tau.

The grants will be announced the Epsilon Zeta spring meeting this coming Wednesday (April 18), and it would be great if you could attend and be recognized. The general chapter meeting begins at 6pm, and the dinner at 7pm. If you are attending, please let me know.

Congratulations on receiving this grant. The Research Committee looks forward to following your progress.

And on a personal note, I'm so happy that you applied for a grant! Your proposal was one of the highest scoring, and a pleasure to read.

Sincerely,

Jackie

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REFERENCES

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CURRICULUM VITAE

Kalpana Satyal was born on 25 November 1975 in Thamel, Kathmandu, Nepal. She began her education in Takam, Myagdi, Nepal. She received her Bachelor's of Science in Nursing from George Mason University, Fairfax, in 1999; a Masters of Science in Health Systems Management from George Mason University, Fairfax, in 2004; and a Post-Graduate Certificate in Quality Improvement from George Mason University, Fairfax, in 2005.

Kalpana has practiced as a Nurse in various specialty areas. Of all specialty areas, she has concentrated on acute rehabilitation nursing the most in her clinical experiences.

Kalpana has practiced as a Legal Nurse Consultant since 2004.

Kalpana has served in leadership roles most of her Nursing Career. She has served as a Director of Nursing (DON) at a Long-Term-Care facility, Director of spinal cord injury acute rehabilitation unit, and Director of Professional Practice for the system, at Inova Health System.