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# Women's Experiences With the Follow-Up System for Cervical Cancer in a Developing Country

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Abstract

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# Abstract

Although Grenada has an extensive health care infrastructure and cervical cancer screening rates are relatively high, Grenada also has a disproportionate rate of morbidity and mortality from cervical cancer. The aim of this study was to explore factors that contribute to these disproportionate rates in Grenada. Using a phenomenological qualitative approach, Andersen's behavioral model of health care utilization and a systems based model for assessing care were used as a guide to explore Grenadian women's follow-up experiences with Pap test and cervical cancer screening. Purposive sampling was used to recruit 8 women for semi-structured in-depth interviews. Data were collected on enabling, need, process and quality factors and coded using *apriori* and open strategies. Results showed that communication strategies used by private practitioners and good interpersonal relationships with nurses enabled follow-up whereas inadequate treatment services, delays in the receipt of test results, and lack of trust in the government clinics were hindrances. This research identified gaps in the follow-up system and is, therefore, significant for the Grenada Ministry of Health to inform planning and restructuring in order to increase system effectiveness. Implications of positive social change include broadening the knowledge base and skill sets of nurses, highlighting strengths of the public system, and identifying target areas for resource allocation. These changes can result in increased workforce efficiency, improved accessibility and quality, a more user-friendly follow-up process and, thus, reduced morbidity and mortality from cervical cancer.

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# Dedication

This study is dedicated to the women who gave of their time to sit with me and share their experiences. Without them this study would not have been possible.

# Acknowledgments

The following persons have encouraged and supported me throughout this journey, and I wish to express my gratitude to them.

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# Chapter 1: Introduction to the Study

## Background

Cervical cancer disproportionately affects women in developing countries. Among women, globally, it is the third most common cancer and the fourth leading cause of cancer deaths(Ferlay et al., 2013). In 2012, cervical cancer was responsible for approximately 527,000 new cancer cases and over 265,000 deaths with over 84% of the new cases and 86% of the deaths being in the less developed regions(Ferlay et al., 2013). In addition, 11.6% of female cancers in developing countries compared to 2.9% in developed countries have been attributed to cervical cancer(Ferlay et al., 2013). Latin America and the Caribbean (LAC) are among the regions with the highest incidence rates, with an estimated 69,000 new cases in 2012(Ferlay et al., 2013); this number is projected to rise to 126,000 by 2025 (Parkin et al., 2008). In addition, approximately 29,000 women died from this disease in 2012, making it the second leading cause of cancer deaths among women in this region. In the same year, the average incidence rate was 21.2/100,000, almost twice that of the global average of 14.0(Ferlay et al., 2013). Additionally, cervical cancer is the leading cause of years of life lost (YLL) due to cancer among women in the 25–64 year age group in LAC. It accounted for 341,000 YLLs in 2000 compared to approximately 68,000 thousand YLLs in North America (Yang, Bray, Parkin, Sellors, & Zhang, 2004).

Unfortunately, cervical cancer is an unnecessary burden in developing countries because it is a preventable and treatable disease. The Papanicolaou (Pap) test, which is a sensitive, affordable and efficient screening test, has significantly reduced incidence and mortality rates in developed countries. This test, also referred to as a Pap smear or cervical cytology, is a procedure done to identify abnormal cells of the cervix that could lead to cervical cancer formation. A sample of cells are removed from the cervix by a trained health care practitioner and examined in a laboratory for any abnormalities (National Cancer Institute [NCI], 2010). Through early identification of abnormal cells, progression to cervical cancer can be prevented. This test was introduced in the United States in the 1950s, and within 37 years it reduced the incidence of cervical cancer by approximately 75% (NCI, 2006). In developed countries that use organized screening programs, the Pap test has been shown to be more effective in reducing the burden of cervical cancer (Peto, Gilham, Fletcher, & Matthews, 2004).

Organized screening programs use a logical approach to prevention and early detection. Practitioners issue formal invitations to women recommending and advocating their participation in screening at intervals suggested by the screening guidelines (Howard, 2009). However, testing programs, though available in many developing countries, lack the level of organization that is required to reduce incidence and mortality(Sankaranarayanan, Atul,& Rajkumar, 2001; WHO, 2002).In 2012, the age-standardized incidence and mortality rates in Caribbean countries were 21.0/100,000 and 8.6/100,000 compared to 15.7/100,000 and 8.3/100,000 in the less developed regions and 6.6/100,000 and 2.6/100,000, respectively, in North America(Ferlay et al., 2013).The age-standardized incidence rate in Grenada between 1996 and 2000 was 60.7/100,000 women, more thandouble the Caribbean rate while the age-standardized mortality rate was 9.7/100,000/year (Asulin et al., 2004), more than four times the North American rate. Findings from a recently conducted study on cervical cancer and its associated mortality in Grenada from 2000 to 2010 showed a mortality rate of 16.7/100,000(Bahadoor-Yetman et al., 2014) which is higher than the previous estimates. This increasing trend is worrisome especially as this cancer is preventable using low-cost screening tests available country-wide and also because mortality rate from cervical cancer has been decreasing for countries in the Americas(Luciani, Cabanes, Prieto-Lara, & Gawryszewski, 2013).

Although it is important for women to be screened using accurate screening tests, addressing abnormal results through follow-up procedures is crucial to reducing incidence and mortality rates. Follow-up procedures are the monitoring processes that the health care practitioner and patient are required to comply with after receipt of the test results. According to the WHO (2002), successful screening is dependent on high coverage levels, good referral and follow-up systems, and high-quality caring services. Consequently, control and effort at every stage of the screening process are significant for the success of cervical cancer screening programs (Valdespino & Valdespino, 2006). Gakidou, Nordhagen, and Obermeyer (2008) found that screening coverage in developing countries averaged 19% compared to 63% in developed countries. They recommended that individual countries adopt strategies that are tailored to their needs. However, the results of an ecological analysis conducted in Colombia showed that increases in screening coverage do not translate into decreases in mortality. Instead,findings showed that reduction in mortality occurred when follow-up was completed (Chocontá-Piraquive, Alvis-Guzman, & De la Hoz-Restrepo, 2010).

Timely follow-up of abnormal Pap tests results and adherence to physician recommendations are significant in reducing cervical cancer morbidity and mortality as demonstrated by researchers. However, the published literature revealed wide variations worldwide in the rates of loss-to-follow-up. In developed countries, rates ranged from 4% to78%(Coker, Eggleston, Meyer, Luchok, & Das, 2007;Felix et al., 2009;Leyden et al., 2005; & Martin, 2008) compared to 1% to 79% for a few countries in Latin America with available follow-up data (Murillo et al., 2008). In addition, Murillo et al. (2008) noted a lack of data on follow-up of positive screening tests from studies that have evaluated screening systems in LAC countries. This deficiency exists despite this area being identified as a priority area for cervical cancer prevention and control (Pan American Health Organization [PAHO], 2008). Consequently, Murillo et al.(2008) suggested that the lack of progress in cervical cancer mortality reduction in the LAC region could be the result of lack of follow-up in women with abnormal Pap tests results.

## Grenada Health System

Grenada is a 344 square kilometer tri-island nation, located in the eastern Caribbean. The total population in 2010 was estimated to be 109,553, with females comprising approximately 50% of the population (WHO, 2007a). Of those, 43.3% are predicted to be 30 years and over, the group identified as high risk for cervical cancer development. The health sector is mainly government run using a centralized system that is subdivided into administrative, hospital, and community health services. Primary care services are housed within community health and can be accessed at the health centers and medical stations. There are six health centers, which serve the seven parishes of the country. Linked to these health centers are medical stations, which are the first point of contact for the community. All available preventive services can be accessed at the medical stations. For this reason, according to a report by the WHO (2007a):“Every person has access to a health facility within a three-mile radius of his or her residence” (p. 369). Five obstetricians and gynecologists serve the needs of this population.

## Grenada Cervical Cancer Screening System

The cervical cancer screening system in Grenada uses the opportunistic screening methodology. Women are advised by doctors to get screened while visiting for other health issues. At the governmental level, this is linked primarily to the antenatal and family planning services. Pap testing is available at parish clinics and medical stations at a cost of $10EC (approximately $4US). Pap testing services are also obtainable at Grenada Planned Parenthood clinics and private practitioners’ offices at a higher cost. Women are also offered this service free of cost as part of their antenatal package at government clinics. Pap smears are analyzed at five laboratories on the island as well as labs in neighboring islands used by some private practitioners (B. McBarnette, personal communication, March 25, 2010).

Follow-up services, such as colposcopy and chemotherapy, are available at the Grenada general hospital, one of the three government-run tertiary care institutions on the island. At the Grenada Planned Parenthood clinics, women with abnormal smear results are referred for follow-up to their general practitioner or a gynecologist.

In 2001, Richards and McCann (2001), in a cross-sectional study conducted in Grenada, found that of 258 women surveyed, 65% reported having had a Pap test. Approximately 64% of these women recalled having it done within the last 2 years (Richards &McCann, 2001). The researchers found significant associations between marital status and having had a Pap test ($p = 0.0001$) and age group and having had a Pap test ($p = 0.029$). Women who were married or in a common-law relationship were more likely to have had a Pap test than those who were not. In the 40–59 year age group, almost 75% of the women reported having had a Pap test; the highest among all age groups (Richards &McCann, 2001).These figures illustrate coverage levels, among this population, that are comparable to levels in developed countries. However, women living in households without telephones and those with unlisted numbers were excluded from the study. Despite the high coverage levels, cervical cancer incidence rates continue to be high. In 2005, there were 25 reported cases of malignant neoplasms of the uterus (WHO, 2007a), and in 2008, there were 10 deaths from malignant neoplasms of the cervix uteri (Ministry of Health Grenada, 2010).

Information on the follow-up rates for abnormal Pap test results in Grenada is not available since no formal tracking system is in place. Consequently, between 2005 and

2009, of the 583 (4.3%) abnormal smear results obtained from 13,642 Pap tests conducted at government clinics, no follow-up data are available (Ministry of Health Grenada, 2010). Also noteworthy is thatdata from private practitioners are not available because of a lack of a reporting system and lack of a systematic way of tracking these women.

## Problem Statement

Cervical cancer continues to be a burden in Caribbean countries despite the availability of screening programs. Researchers have demonstrated the success of organized screening systems in developed countries (Quinn, Babb, Jones, & Allen, 1999). In contrast, developing countries continue to use opportunistic screening, which is associated with poor coverage and over screening of a few (Adab, McGhee, Yanova, Wong, & Hedley, 2004). However, this opportunistic approach has also been shown to be capable of increasing screening rates (Ward et al., 1991). While poor screening coverage has been blamed for the high rates of cervical cancer in some countries (Spayne et al. 2008), many of these countries have similar coverage rates compared to developed countries but with double the mortality rates (Franco et al., 2008). A possible explanation for this disparity is the follow-up system process and quality. Murillo et al., (2008), found follow-up of abnormal Pap test results to have a stronger effect on mortality rates in Latin America and the Caribbean than screening coverage (Murillo et al., 2008). Therefore, the follow-up system in Caribbean countries needs to be explored.

An appraisal of the literature revealed numerous epidemiological studies that were conducted in developed and Latin American countries. These studies focused mainly on follow-up of abnormal Pap test results (Agurto et al., 2005; Felix et al., 2009; Martin, 2008). However, there was a lack of studies that examined the factors that facilitate utilization of the follow-up system for cervical cancer screening by women with abnormal Pap results in Caribbean countries. Moreover, no studies were found which examined the process and quality of the follow-up systems for cervical cancer screening in Caribbean or eastern Caribbean countries from the perspective of users.

As previously noted, data on follow-up is deficient in Caribbean countries (Murillo et al., 2008; Suba, 2004). Additionally, cultural differences do exist among countries, and it is recommended that programs should be tailored to the needs of the targeted populations if increased efficiency is to be achieved (Gakidou et al., 2008).For example, results of physicians' interviews from a study conducted in Nevis, West Indies, revealed that U.S. and European cancer guidelines may not be appropriate for the population in Nevis. The guidelines were deemed inappropriate because breast and prostate cancers are frequently diagnosed earlier, among that population, than the age at which screening is recommended (Felix et al., 2009).Likewise, in HPV prevalence studies conducted among Caribbean women, HPV Types 45 and 58 and HPV Type 45 were found to be the most prevalent among Jamaican women (Watt et al., 2009) and Tobagonian women(Ragin et al., 2007), respectively. These types differ from that found in other regions where HPV-16 and HPV-18 were found to be more prevalent. This result has cost-benefit and cost-effectiveness implications for the use of FDA-approved vaccines, Gardasil and Cervarix, among this population and signifies the need for culturally specific interventions.

The points noted above illustrate differences among countries and highlight the need to investigate the process and quality of the system in Grenada used for follow-up of abnormal Pap test results. Therefore, in this study, exploring women's experiences, using a phenomenological approach, provided information on the process, quality, and operation of follow-up services in Grenada. The use of a qualitative methodology enabled the collection of rich and detailed information of the follow-up procedures that are not available using a quantitative approach. This detail was necessary to identify the gaps in the system that need to be addressed to cater for the health needs of the population.

The results of this study will be shared with the Ministry of Health and used as evidence for cervical cancer screening system enhancement. Consequently, if implemented, it is expected that program efficiency and effectiveness will increase and contribute to reduced morbidity and mortality from cervical cancer. For any screening program to be successful, a relatively high screening coverage rate should be maintained, an effective screening test should be utilized, and good quality management for those who screen positive should be available. In this research, I focused on the latter part of this requirement and determined the process and quality of follow-up services available to Grenadian women who met the inclusion criteria of the study. I used two conceptual frameworks as guides.

# Conceptual Framework

## Andersen's Behavioral Model of Health Care Utilization

Andersen, through this model, posits that the use of health services is dependent not only on a facilitative structure and availability of services but also on economic, social, cultural, and environmental factors. He stated that decisions to use these services are generally determined by the gender of the health care provider, confidence in the health care system, economic resources, and family demands. Also, there are other factors, some of which are culturally specific, that impact usage(Andersen, 1995). These system and individual factors can contribute to delayed, inappropriate, or poor quality care that can produce adverse health outcomes and create a significant economic and social burden on the health care system.

Andersen conceptualized the behavioral model of health care utilization in the 1960s, and the model has progressed through several iterations following critiques of the model (Andersen, 2008). Since then, researchers have used this model to predict and explain the use of a variety of health services. The original model used the family as a unit of analysis and was useful for providing an explanation for the use of formal personal health services. The advanced model, applied in this study (see Figure 1), explains health services use by contextual and individual determinants focusing on the individual as the unit of analysis. The model is based on a systems perspective. It posits that population characteristics such as predisposing characteristics, enabling resources, and need factors (PEN) are influenced by the environment and determine an individual's health behavior, and thus, affects health outcome. The PEN themselves are affected by the health outcomes and health behavior (Andersen, 1995). The model highlights the dynamic interactions and feedback mechanisms that occur and provides the foundation for this dissertation which focused specifically on enabling resources, need factors, health behaviors, and outcomes. The health behaviors and outcomes define the process, whereas enabling and need factors and health behaviors define quality as experienced by women, with a finding of an abnormal Pap test result, who have used the follow-up system.

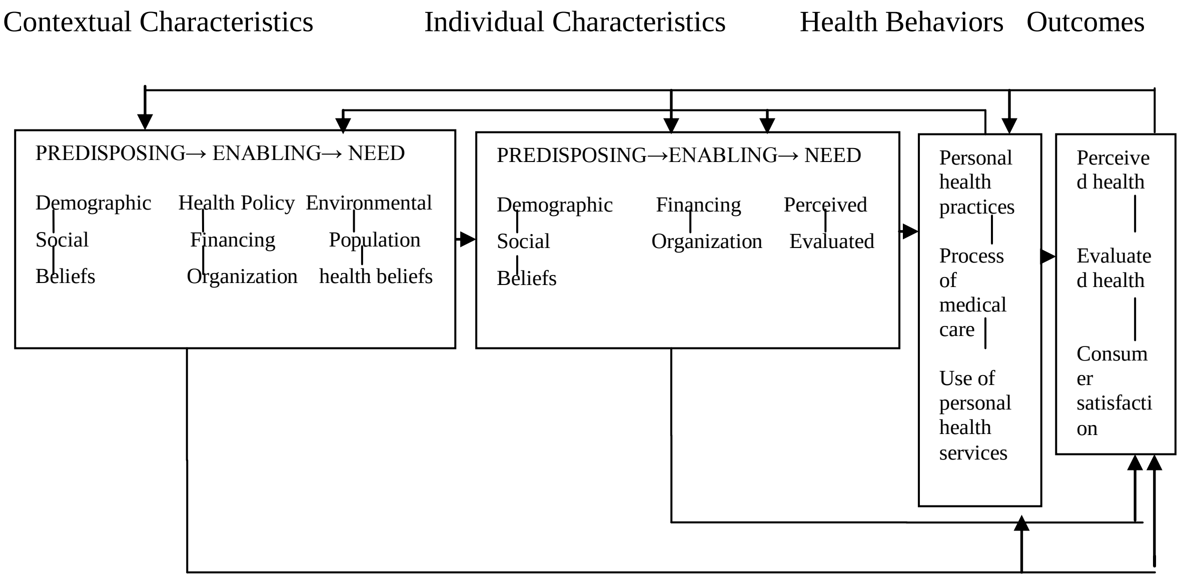

*Figure 1.* A behavioral model of health services use including contextual and individual characteristics. From “National health surveys and the behavioral model of health services use” by Ronald Max Anderson, 2008, *Medical Care*, 46(7), p.649. Reprinted with permission.

I employed Andersen’s model to investigate the process and quality of cervical cancer screening services by Grenadian women with an abnormal Pap test result. Women shared their stories based on their experiences with the system. The enabling resources and need factors, as identified in this model, formed the basis of this study.

Andersen (1995) defined enabling resources as those that facilitate use of the services. Examples of these include facilities, personnel, health insurance, having a regular source of care, social relationships, and organization of community health services (Andersen, 1995). According to Andersen (1995), need and enabling factors are useful for explaining variation in health services use, while community and personal enabling factors are requirements for use. To assist utilization, community factors such as health personnel and facilities should be accessible, appropriate, affordable, and acceptable by the targeted populations. Therefore, in addition to the availability of services, resources and knowledge of how to access services are important prerequisites for utilization. As such, income, health insurance, social relationships, travel and waiting times (Andersen, 1995), physician gender and training, and physician decision-making all contribute to health services use.

Need factors, which are divided into perceived and evaluated need, focuses on how the individual experiences illness and their healthcare-seeking behavior. Perceived need provides an understanding of care seeking and compliance behavior while evaluated need refers to treatment services that are provided by the health care practitioner (Andersen, 1995).

The enabling and need factors together with characteristics of health behaviors and outcome were the focus of this study and featured prominently in gathering information on the process and quality of the follow-up system.

In addition to the framework discussed above, I used a systems-based model for assessing care proposed by Campbell, Roland, and Buetow(2000)to define the quality of health care and provide additional dimensions of quality applicable to this study. I discuss this model in the following chapter.

## Research Questions

This research was guided by the following questions which are further discussed in Chapter 3.

How do women experience the enabling factors for the cervical cancer screening follow-up system in Grenada?

How do women experience the follow-up process for cervical cancer screening?

How does the follow-up process affect the need factors of women with abnormal Pap test results?

What are the experiences of women regarding the quality of the follow up process?

## Purpose of Study

In this phenomenological study, I provided an understanding of the experiences of Grenadian women who received abnormal cervical cancer screening results with the healthcare system. The purpose was to describe the lived experiences of women with an abnormal Pap test. The aim was to understand the process and quality of the follow-up system from a user’s perspective. Grenadian women have reported Pap test screening rates that are comparable to countries with organized screening systems. However, the cervical cancer morbidity and mortality rates are higher than the average rates in the Caribbean and globally. Hence, screening coverage may not be sufficient to explain these results. Unfortunately, published data on screening follow-up for Caribbean countries are sparse, even though this was acknowledged as being just as important as screening coverage. Furthermore, although studies have examined barriers to follow-up compliance, few studies have explored the follow-up process, quality, and subsequent effects on health outcome (Documet et al., 2008; Eggleston, Coker, Das, Cordray,& Luchok, 2007,Ell et al., 2002;).

Suba (2004) suggested that lack of use of a community participatory approach by developing countries in the identification of follow-up barriers has affected follow-up quality in those countries. In this study, in the Grenadian context, I provided an understanding of process from the perspective of those who have experienced it. Further, I explored the effects of the process on health-care-seeking behavior and illness experience of the participants. A qualitative research approach, discussed in detail in Chapter 3, was the methodology for gathering data for this study. This approach did not just identify associations between the process and behaviors but also provided a deeper understanding of those associations and the meanings that are derived by those who have lived through the process.

## Operational Definitions

*Abnormal Pap test*: This is a Pap test result where the cells sampled from the cervix are not normal (NCI, 2010).

*Cervical cancer:* This is a process whereby the normal cells of the cervix become abnormal and slowly changes into precancerous cells. These abnormal cells are classified as cervical intraepithelial neoplasia (CIN), squamous intraepithelial lesions (SIL), or dysplasia and can be detected by screening tests and treated to prevent further development into cancer (American Cancer Society, 2010).

*Enabling factors:* These are factors that facilitate or hinder the use of health services (Andersen, 1995).

*Follow-up*: This refers to the processes involved in tracking a patient after treatment for a medical procedure (NCI, 2010). For this study, it was the means used by the health practitioner to contact a woman who has received anabnormal test result(e.g., telephone call, letter, home visit, e-mail) as well as further procedures recommended or carried out by a practitioner (e.g., counselling, repeat Pap tests, or colposcopy).

*Grenadian women:*Women 18 years and above who are currently using the Grenada cervical cancer screening system and were diagnosed with HSIL (CIN 2) or above.

*Need factors:* This refers to how individuals experience illness and their care-seeking behavior in addition to the treatment services provided by the health care practitioner (Anderson, 1995).

*Opportunistic screening*:This refers to a practitioner using the occasion when a woman consults for other health problems to recommend screening or where the woman decides when to get screened (WHO, 2007b).

*Organized screening*: A screening program that utilizes a structured system. Women are registered at clinics or are formally reminded of screening via a call- recall system at times specified in the screening guidelines (Howard, 2009).

*Pap test:*A procedurewhereby a sample of cells are removed from the cervix and analysed in a laboratory. The purpose is to identify abnormal cells that could lead to the development of cervical cancer (NCI, 2010).

## Assumptions, Limitations, Scope, and Delimitations

Strengths and weaknesses are inevitable characteristics of all research study designs and as such are also present in this study's design. A major assumption was that the study participants will be open to freely and truthfully discussing their health system experiences after diagnosis with a condition which is associated with the reproductive organ. Such diseases are stigmatized by Grenadian society. Additionally, it was hypothesized that the cervical cancer screening follow-up system for abnormal Pap tests results is faulty and, thus, a major contributor to the associated morbidity and mortality rates.

The Grenadian population is relatively small and, as a result, participant recruitment was a challenge. Furthermore, women who sought health care outside of Grenada and those who were not currently seeking care were excluded from the study, thereby excluding information from a cohort that may have experienced the system in a different way. These study results may only be transferable to the Grenadian cervical cancer screening follow-up system.

Inherent in the study were biases associated with self-reporting such as recall and reporting bias. These are potential sources of bias because participants were asked to share their past experiences with the system. Some women may not have remembered clearly or might have overlooked significant points. Others, because of memorable experiences or possible negative experiences, may have over reported(Hartman, Forsen, Wallace, & Neely, 2002).The researcher's presence may also have affected the response of participants. This is noted by Carr, (1994)as a potential source of researcher bias. Besides, the emotional state of the participant at the time of the interview could have affected the responses. Additionally, this study was based on an already existing theoretical framework, which limits the development of a theory.

The study population included women with abnormal Pap test results, diagnosed as high-grade squamous intraepithelial lesions (HSIL) or cervical intraepithelial neoplasia Grade 2 (CIN 2) or higher and who were users of the Grenada health care system. CIN 2 or higher was used as an inclusion factor because most of the low-grade lesions such as CIN 1, low-grade squamous intraepithelial lesions (LSIL) or atypical squamous cells of undetermined significance (ASCUS), regress. The high-grade lesions, however, have a much greater chance of developing into invasive cancer (International Agency for Research on Cancer [IARC], 2003). The study findings on the process and quality of the cervical cancer screening and follow-up system will be shared with the Ministry of Health. The information may used to inform the development of an efficient and effective follow-up system. The results may also be relevant to other Caribbean countries with similar screening systems. Moreover, the results can be used to improve understanding of follow-up systems in Caribbean countries with a similar system and also as a base for further research studies.

## Significance of the Study

The findings from this study will be provided to the Grenada Ministry of Health, the Grenada Medical Association and the Grenada Cancer Society to assist in strengthening the current cervical cancer screening and follow-up system. The results will also be shared with womens' organizations to empower women to take preventive actions and ask the right questions. I hope that the results will be used to make sound decisions about resource allocation, increase system efficiency, and, in the long term, reduce incidence and mortality from cervical cancer. The knowledge obtained will also contribute to already existing information on factors that affect the utilization of cervical cancer referral and follow-up services in the Caribbean. Furthermore, the information gathered can be useful in making decisions regarding the provision of a comprehensive, efficient, and effective screening program and can assist in identifying the existing gaps in follow-up services. The results of the study could also provide the basis for a larger study using quantitative methods.

The concept of public health encapsulates promoting health, preventing disease, and prolonging life among populations.For this to occur, both community and government participation is paramount. Government has the responsibility for protecting the common good and providing conditions in which populations can be healthy. Therefore in this study I provide information to assist the government in achieving this mandate. The findingscan be used to improve the cervical cancer screening system and consequently reduce the burden of cervical cancer. Moreover,the resultsmay lead to a healthier and more productive nation and the resources saved can be diverted to other health issues.

## Summary

In this chapter, I presented an overview of the literature on cervical cancer, the prevention strategies used in developing countries, and the associated challenges. In addition, I discussed the conceptual framework guiding this study along with the purpose and research questions. Cervical cancer is preventable; yet, developing countries continue to suffer from a disproportionate burden of the disease. It accounts for a large proportion of YLL, affecting women when they are most productive. Although organized screening programs have been credited with a large reduction in incidence and mortality in developed countries, in many developing countries opportunistic screening is the only approach used due to limited resources. Nevertheless, efficient use of available resources can result in improvements in the current systems if empirical evidence is used in making decisions.

Investigators of this problem have illustrated the effect of enabling and need factors on screening follow-up. However, many of the studies appraised were conducted in developed countries using quantitative methodologies. Furthermore, no studies were found which examined the structure and functioning of follow-up systems in Caribbean countries. In this study I investigated the process and quality of the screening system, specifically the cervical cancer follow-up system; by exploring the experiences of Grenadian women with an abnormal Pap test result of HSIL or higher.

This dissertation is organized in a series of chapters. The current chapter provided information in which the study is grounded, the research purpose, the research questions, definitions of terms, and an introduction to the theoretical framework. In Chapter 2, I review pertinent literature and discuss general information on cervical cancer, risk factors, Pap tests, and follow-up systems. I also discuss constructs from the conceptual framework such as enabling resources, need factors, system, and provider factors and their relationship to the screening process and quality. I provide a comprehensive discussion on the study design including participant selection, data collection, data collection instrument, and analysis in Chapter 3. In Chapter 4,I present data analysis and results. The final chapter, Chapter 5, covers interpretation of the data, discussion, conclusion and implications for future research.

# Chapter 2: Review of the Literature

## Introduction

The authors of published studies have examined cervical cancer screening follow-up systems for abnormal Pap test results by focusing on barriers to follow-up using both qualitative and quantitative methods. However, very few studies examined follow-up systems from the study participants' perspective. Moreover, no previous studies examined the process and quality of follow-up systems for cervical cancer screening in the Caribbean based on the experiences of participants. In this review of the literature I provide an understanding of what other researchers have found, related to the topic, and present justification for the research area of interest. I have also organized the review around themes that have emerged from the theoretical frameworks used in this dissertation.

## Search Strategies

I used a variety of research strategies to gather data for this review. I obtained information mainly from Walden University's online library databases and eBrary. For the most part, I used EBSCO and ProQuest databases. I entered the general search terms *cervical cancer screening*, *cervical cancer/prevention and control*, *preventive health services*, *Pap smears*, *Pap tests*, *vaginal smears*, and *abnormal Pap* followed by *follow-up, adherence, compliance*, *referral*, *developing countries*, *Latin America*, *Caribbean*, *low-resource settings*, *mass screening,* and *utilization* to narrow the search. I then used the reference lists of the articles to identify further applicable sources. I located abstracts of the articles and them sorted by relevance. Additionally, I used the St. George’s University’s library and the Ministry of Health in Grenada to access books, journal articles, and government reports. I also obtained information obtained from the World Health Organization (WHO), Pan-American Health Organization (PAHO), the International Agency for Research on Cancer (IARC), and National Cancer Institute (NCI) websites. There were few appropriate empirical studies that focused on the Caribbean region; hence, I used studies conducted in Latin America and other developing countries as a proxy. I found only one relevant study in the empirical literature reviewed that was conducted in Grenada.

## Cervical Cancer and Opportunistic Versus Organized Screening

Cervical cancer, preventable and curable with early detection, continues to be a leading cause of death among women in the Caribbean regardless of the availability of effective screening tests. Organized screening programs, used in developed countries such as Finland, the Netherlands, and the United Kingdom, have accounted for a significant reduction of incidence and mortality from cervical cancer and have been shown to be more effective and cost-efficient than opportunistic screening (WHO, 2007b). However, organized screening programs necessitate adequate infrastructural resources: trained workers; surveillance capabilities; diagnostic and treatment services; call, recall, follow-up measures; and an informed targeted population (Luciani & Andrus, 2008; Sankaranarayanan, et al., 2001; WHO, 2007b).Many of the aforementioned factors are absent in developing and resource-poor countries. For this reason, many developing and some developed countries still rely only on opportunistic screening. Therefore, such countries need to make appropriate choices to maximize the use of limited resources. But, although poor screening coverage and over screening of a few have been found to make opportunistic screening inefficient (Adab, McGhee, Yanova, Wong, & Hedley, 2004), through a randomized controlled trial, Ward, Boyle, Redman, and Sanson-Fisher, (1991) demonstrated that Pap testing rates can increase when practitioners give brief advice to patients during regular visits. This is the strategy that is implemented in Grenada.

Screening coverage in Grenada is comparable to coverage in developed countries, but mortality rates are still high. This high mortality rate is the reason why it is necessary for Grenada to also focus on the improvement of the structure and quality of follow-up and treatment services that are provided. As previously discussed, follow-up also has a significant impact on health outcomes.

Noncompliance or lost to follow-up, a situation in which women who receive an abnormal Pap test result do not return for further practitioner-recommended procedures, occurs in organized and opportunistic screening systems (WHO, 2007a). However, the rates are consistently lower in opportunistic screening programs when compared to organized screening systems (Quinn et al., 1999; WHO, 2007a). New screening tests, which reduce follow-up visits, have been recommended by researchers for use in developing countries (Franco et al., 2008; Perkins, Langrish, Stern, Burgess, & Simon, 2010). One such method, the screen-and-treat method, has been tested and found to be cost effective and efficient for developing countries (Mandelblatt et al., 2002). However, the method is not recommended for use in postmenopausal women (Perkins et al., 2010), a population that continues to increase in both developed and developing countries.

Additionally, introduction of a new screening test will place a burden on developing countries(Suba et al., 2006).Suba (2004) argued that governments in developing countries should continue to use the Pap test but focus their attention on the enhancement of screening quality and follow-up services. But, he noted that a lack of participatory approaches by researchers has created a knowledge gap on barriers to follow-up and, together with weak political influence of the affected population, has contributed significantly to the problem (Suba,2004). He suggested the use of a systems approach, with a focus on people rather than technology, has the ability to create a greater impact on the reduction of cervical cancer morbidity and mortality (Suba, 2004;Suba et al., 2006).

## Cervical Cancer and Human Papillomavirus

The WHO’s (2007a) vision, as stated in the global plan, is to eradicate preventable cancer and ensure that all patients have access to quality treatment and care. But to achieve this requires a broad-based approach and political commitment. Cervical cancer, caused by the sexually transmitted HPV with many subtypes and known risk factors, is one of the few preventable cancers (WHO, 2007a). It develops gradually and may take many years to form, thus, the potential for prevention through screening. Of the over 100 HPV genotypes that exist, 40 are capable of infecting humans. Genital HPV infection is common and usually asymptomatic; however, some individuals develop pre-neoplastic lesions of cervical intraepithelial neoplasia (CIN) from high-risk types such as HPV-16 and HPV-18, while others develop genital warts from low risk types such as HPV-6 or HPV-11 (WHO, 2010). Globally, HPV-16 and HPV-18 account for approximately 70% of all cases of adenocarcinoma of the cervix with HPV-16 contributing to a greater proportion of the burden (WHO, 2010). HPV-45, the type found to be most prevalent in parts of the Caribbean(Ragin et al. 2007; Ragin et al. 2009; Watt et al. 2009), along with other low risk types are responsible for the remaining 30%. The estimated global prevalence of HPV is approximately 11.7% (Bruni et al., 2010). In the United States, Dunne et al. (2007), in a study of women ages 14–59 years, found an overall prevalence rate of 26.8% with the highest rates among the 20–24 year age group. In contrast, in Trinidad a pilot study conducted among a convenience sample of 310 women estimated the HPV prevalence at 40.6% (Andall-Brereton et al., 2009). Women 30 years or younger exhibited the highest prevalence rates, andHPV-52 was found to be the most common type (Andall-Brereton et al., 2009).

In 2012, the global age-standardized incidence and mortality rates for cervical cancerwas14.0 and 6.8, respectively, compared to the Caribbean rates of 21.0 and 8.6, respectively(Ferlay et al., 2013).The comparatively high prevalence estimates and age-standardized incidence and mortality rates is worrisome for Caribbean countries especially with their limited resources and existing opportunistic screening programs.

## Risk Factors

While HPV is a necessary precursor to cervical cancer development, there are a myriad of factors that increase a woman's chance of developing the disease. A discourse on some of these factors follows. Epidemiological studies have demonstrated significant associations between age of first sexual intercourse (AFSI), age of first pregnancy, oral contraceptive use, and high parity and risk of invasive cervical cancer development (Green et al., 2003; Louie et al., 2009; Misra, Srivastava, Singh, & Srivastava, 2009; Moreno et al., 2002). In a pooled analysis of case control studies conducted in eight developing countries by the IARC, invasive cervical cancer risk was found to increase with decreasing AFSI (Louie et al., 2009) and with increasing duration of oral contraceptive use (Green et al., 2003). Moreno et al. (2002) also found that HPV-positive women who had ever used oral contraceptives were almost twice as likely as the controls to develop cervical cancer. Furthermore, Herrero et al. (2005) found a strong association between lifetime and recent number of sexual partners and being HPV positive among a population-based cohort of 8,514 women of the Guanacaste project, Costa Rica. Herrero et al. did not find an association between AFSI and HPV infection; however, they found a higher prevalence of all oncogenic HPV types in women younger than 25 years. In another study, Misra et al. (2009) reviewed records of almost 37,000 women in India and established that women with clinical lesions had higher risks ($p<0.01$), with viral STDs being strongly associated with SIL, and Herpes simplex virus (HSV) more strongly associated with carcinoma of the cervix. High age (40+) and parity (2+) were also contributing factors (Misra et al., 2009). The aforementioned factors are of significance to Caribbean populations because of documented sexual behaviors among the at-risk population.

High-risk sexual behaviors are common among adolescents in the Caribbean. In 2008 the Global School-Based Student Health Survey (GSHS) was conducted in Grenada among students in Forms 1 to 4 in secondary schools. This self-administered survey was completed by 1,542 students, of which 44.9% were males and 55.1% were females. The results showed that 30.8% reported ever having had sexual intercourse. Of those, 16% were less than or equal to 12 years, 26.5% were 13–15 years, and 61.4% were greater than or equal to 16 years. Approximately 25% reported having had sexual intercourse with two or more people during their lifetime, and 27% reported having had sexual intercourse during the past 12 months. Of that 27%, 65% reported using a condom the last time they had sexual intercourse (Global School-Based Survey, 2008). In a similar study conducted in Barbados, 21.6% of the respondents reported having had vaginal sex, and only 52.2% reported that they had used a condom during their last sexual encounter (Kumar, Carter, Douglin, Kumari, & Jacob, n.d.). This indicated that adolescents in the Caribbean region are engaging in sexual activities at an early age and are not using condoms consistently. This has implications for HPV transmission and development of cervical abnormalities especially in the absence of an organized screening program.

## The Pap Test

Population-based routine screening using the Pap test has been credited with reducing the burden of cervical cancer in both developed and developing countries. This test was discovered in 1928 and proved to be efficacious by 1941. It detects precancerous changes in cervical cells extracted via a Pap smear (Vilos, 1998). However, there are doubts about the accuracy of this test. A published, systematic review of Pap test efficacy conducted by Nanda et al. (2000) showed sensitivity estimates ranging from 30–87% and specificity from 86–100%. However, the authors noted that most of the studies on Pap tests had weaknesses in the methods used, a conclusion shared by Fahey, Irwig, and Macaskill (1995), who conducted a meta-analysis of Pap test accuracy and found sensitivity and specificity rates ranging 11–99% and 14–97%, respectively.

Despite these findings there is evidence that demonstrates the effectiveness of Pap tests (Quinn et al., 1999). Since the advent of the Pap test, other screening tests and vaccines have been successfully tested and approved for use in specific populations. However, the cost of the vaccine is prohibitive, and resources to implement new screening tests are scarce in many developing countries like Grenada. Therefore, cervical cytology using the Pap test continues to be the only screening test available in Grenada to Grenadian women. Furthermore, whatever the screening test used, women who receive abnormal test results will have to be followed up by providers; thus, system process and quality, and provider characteristics needed to be identified and addressed.

## Guidelines for Cervical Cancer Screening/Classification System for Pap Results

The Grenada Health System is guided by the National Comprehensive Cancer

Network (NCCN) Clinical Practice Guidelines in Oncology as it relates to screening for cervical cancer (B. McBarnette, personal communication, March 25, 2010). This guide states that screening should begin approximately 3 years after the start of vaginal intercourse and no later than age 21. It recommends annual screening with conventional cervical cytology or biennially using liquid-based cytology. Women at or after age 30 with three consecutive negative cytology results may be screened every 2 to 3 years (NCCN, 2009). There are also recommendations for HPV high risk DNA testing for particular categories of women. However, only cervical cytology is available to women in Grenada. Follow-up entails a repeated Pap test within 6–12 weeks or treatment of infection if present for an unsatisfactory Pap test result; a biopsy for a suspicious lesion on the cervix; and for a Pap test which is positive for invasive cancer, a biopsy of the visible lesion or diagnostic excision if lesion is not visible (NCCN, 2009). The Bethesda System of reporting, which is described below, is recommended for use in reporting abnormal Pap tests results for which follow up procedures are specified in the guidelines. However, some health care practitioners still use previous reporting systems and the CIN terminology, for reporting results.

Precancerous cells are classified based on their appearance under a microscope. The two main types are squamous cell carcinoma and adenocarcinoma, with approximately 85% being squamous cell carcinoma. Using the Bethesda terminology the term LSIL refers to atypical cells that are mild or without epithelial changes (same as CIN 1) and HSIL refers to those precancerous cells with moderate or severe dysplasia

(CIN 2 or 3; American Cancer Society, 2010).in this study, I examined whether health practitioners adhere to the follow-up system described above.

## Follow-Up and Follow-Up Adherence

Follow-up procedures for an abnormal Pap test is recommended based on the type of abnormality as specified in the NCCN guidelines (as I discussed in the preceding paragraph). In a retrospective study conducted in the United States using medical records of 833 women diagnosed with invasive cervical cancer, Leyden et al. (2005) found that cervical cancer development was attributed to follow-up failure in 13% of the women, all of whom had access to screening and treatment services. Zapka et al. (2004) found similar results as well as Nelson, Geiger, and Mangione (2002), who surveyed health maintenance organization (HMO) and managed care organization (MCO) enrollees in the United States, respectively, and found 13% follow-up failures. These results suggested that access to care and screening compliance are separate issues as they regard cancer-screening compliance (Leyden et al., 2005). However, barriers to follow-up are many, and successful follow-up has been linked to organized or structured screening programs. Follow-up adherence was also defined differently in each of these studies. The literature reviewed suggested that timely adherence to follow-up care contributes to the reduction in incidence and mortality from cervical cancer. However, the rates of lost-to-follow-up continue to be problematic for high-risk populations in both developed and developing countries.

## Conceptual Frameworks Applicable to This Study

In the literature appraised, few studies provided extensive discussion of the relevant theories or frameworks used; however, those that noted a framework used primarily Andersen’s behavioral model of health care utilization. I discussed the relevance of this framework previously in Chapter 1. Researchers have used this framework to identify barriers and factors associated with health services use among hard to reach populations such as HIV positive persons (Andrasik, Rose, Pereira, & Antoni, 2008; Anthony et al., 2007) . Researchers have also used the model to identify predictors of utilization of health services such as colorectal cancer screening, mental health services, and services for menopausal women (Fasoli, Glickman, & Eisen, 2010; Honda, 2002; Matsui et al., 2009). Hence, I used Andersen’s model to explore the follow-up process and its quality. I used the enabling and need factors, supplemented by factors from the systems based model discussed below, to guide the experiential discussion of the study participants. Reasons for emotional and psychological barriers, such as the factors identified as barriers to accessing cervical cancer screening services among HIV-positive minority women by Andrasik et al. (2008), can best be explored through application of Andersen’s model and with the use of a qualitative research approach. The qualitative approach, using in-depth interviews, allowed for exploring thoughts, feelings, and lived experiences of participants with barriers and facilitators of the process. I used an additional model, systems based model for assessing care (see Fig 2).

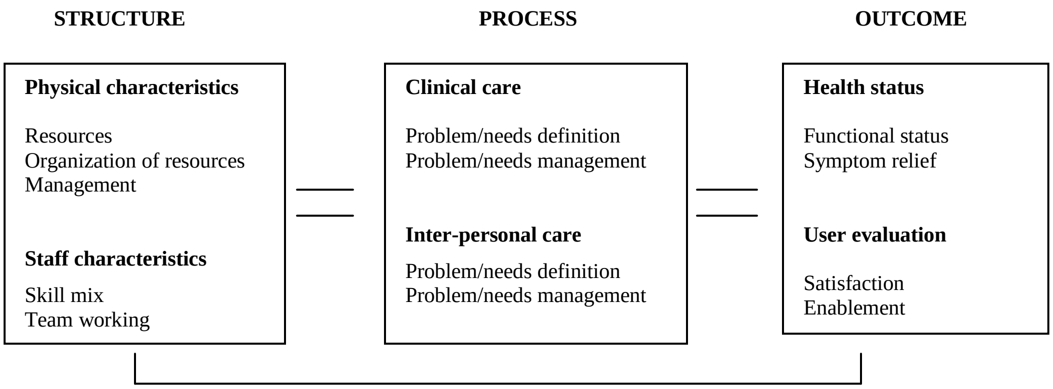

*Figure 2.*A systems-based model for assessing care. From “Defining quality of care” by S.M. Campbell, M.O. Roland and S.A. Buetow, 2000, *Social Science and Medicine*, 51. p.1613. Reprinted with permission.

The systems based model for assessing care is a framework conceptualized by Campbell, Roland,and Buetow (2000) to define quality of care. The focus of this framework is on care provided by a formal health care system for individuals and is thus relevant to this study. The model is comprised of three main components of the system: structure, process, and outcome. However, according to Campbell et al. (2000), care is comprised mainly of process, with outcome being a consequence and structure being the means through which care is delivered. While all of the components of this framework are important, for the purpose of this dissertation, the discussion focused on process and quality of health care as provided by the follow-up system for cervical cancer screening in Grenada.

Processes of care, as stated by Campbell et al. (2000), involve the interactions between users and providers of care. Therefore, clinical and interpersonal care are the two most important procedures that are associated with process. Examples of these procedures include communication of needs, diagnoses, management, and coordination by providers and users of care. Clinical outcomes are determined by individuals' health status and more importantly by their evaluation of the system as this assessment can have an impact on their use of the health system.

According to Campbell et al. (2000), quality of care is, "the ability to access effective care on an efficient and equitable basis for the optimization of health benefit/wellbeing for the whole population" (p. 1617). Thus, quality is defined by access to and effectiveness of care. Access is measured using indicators of availability of physical structures (facilities and services) and monetary costs. In contrast, effectiveness, which comprises two crucial components of process—clinical and interpersonal care—is determined by the utilization of knowledge-based care. Additionally, Campbell et al. (2000) noted that coordination or integration of care is also fundamental to effectiveness. Furthermore, Campbell et al. (2000) recommended the use of process indicators to measure quality of care if the purpose of the investigation is to make adjustments to the system.

For this research study, I determined the follow-up process for abnormal Pap results by gathering information from participants on the clinical care and interpersonal care processes. I measured quality using information on availability and affordability of follow-up procedures and effectiveness of clinical and interpersonal care. Pap testing services are available at health centers located throughout Grenada and at the Planned Parenthood at a low cost and free for antenatal visits. Thus, the structure of the system was not the main focus of this discussion.

## Andersen and Campbell’s Theoretical Frameworks

Andersen and Campbell’s models are similar in the measures proposed to determine accessibility and effectiveness of quality of care. In both models, health behaviors of both practitioners and consumers of health care determine effectiveness of the process and these are identified as indicators of quality. Andersen, however, further categorized these behaviors as predisposing, enabling and need factors. Therefore, Andersen’s model, although it does not mention the word quality, uses quality indicators to determine use of services.

The enabling resources and need factors, together with the process factors, determine health outcomes (Andersen, 1995).For this dissertation, I categorized these factors into individual and system contributing factors to guide the discussion. Eggleston, Coker, Das, Cordray, and Luchok (2007)identified a number of these factors, which are discussed below.

### Individual Factors

**Health care seeking behavior/illness experience.** Studies that have focused on illness experience and adherence have identified lesion severity as a significant factor in adherence. In a systematic review of the literature, Eggleston et al. (2007) revealed that women with less severe lesions, ASCUS, were more noncompliant but more likely to adhere to colposcopy rather than repeat Pap tests. Eggleston et al. also found lack of knowledge of Pap test purpose and follow-up examination to be associated with non-adherence. Conversely, in a study conducted in South Carolina in the United States in which the medical records of 330 women enrolled in the NBCCEDP were reviewed, Eggleston, Coker, Luchok, & Meyer, (2007) found that white women with more severe lesions were less likely to adhere to follow-up in a timely manner. In addition, Coker et al. (2007)conducted a cross-sectional study of 204 women from the southeastern United States with abnormal Pap test results who were either uninsured or underinsured (approximately 64% African Americans) using phone-based interviews and found chronic disease symptoms as a predictor to adherence within a year. Lesion severity was found not to be associated with timely follow-up in this study.

Other individual factors found not to be associated with time to follow-up included age, race, education, smoking status, and perceived physical health (Coker et al., 2007). However, according to Eggleston et al. (2007), while race was not found to be a significant factor, risk factors within race are variable. Additionally, fear, fertility, concerns, worries about examination, and treatment were identified as barriers to follow-up recommendations (Eggleston et al., 2007). The above studies demonstrated that access is not an important barrier to follow-up because all of the participants had access yet follow-up was still problematic. However, based on the results, follow-up interventions need to be race-specific and tailored to specific geographic locations.

**Social relationships.** There was a scarcity of studies that focused on social support and follow-up adherence among women with abnormal Pap results, so I also reviewed studies of other types of cancer. Crane (1996) used medical record reviews and interviews to gather data from 498 low-income, ethnically diverse public health department patients with abnormal Pap smears to determine follow-up adherence. The findings revealed that support quantity, satisfaction, and source were all associated with adherence. Social support was categorized as informational, emotional, and tangible and type of support varied by race; with strong associations found between adherence and tangible support among Latinas and adherence and knowledge of purpose of the Pap test among Blacks. Overall, emotional support had the strongest association to adherence (Crane, 1996).

Honda and Kagawa-Singer (2006) found that colorectal screening compliance among Japanese Americans was influenced by the culture of their social networks. They found that the subjective norms of family and friends were most strongly associated with adherence. Emotional support from friends and adherence were also found to have a direct relationship. Additionally, a 4-year RCT conducted among women aged 40 and over found that for women in the 40 to 51 year age group, encouragement by their social network was associated with an increased likelihood of having a mammogram. Among older African American women, Allen, Stoddard, and Sorensen (2008) found a relationship between social support and having a recent mammogram. Klassen and Washington (2008) also found positive associations between social networks and screening knowledge; emotional support, church networks, and attitudes conducive to screening and treatment; and family networks with recent screening and intention to screen. However, women with greater church networks and emotional support were less likely to choose more invasive procedures such as lumpectomy and reconstruction and also less likely to participate in clinical trials (Klassen & Washington, 2008). These results suggest that culture and social networks are important determinants of screening usage among minority populations in the United States and may also explain the lack of follow-up for more advanced procedures among older minority women.

**Culture and religion.** Fatalism and health beliefs were two other factors found to be associated with poor adherence. Nelson et al. (2002) found that women of Asian descent and Spanish speaking Latinas were more likely to delay care due to fatalistic beliefs and misconceptions about cancer. However, they found no independent associations between race and ethnicity and delays in care in a study among MCO enrollees with abnormal pap smears, all of whom had access to care.

Eggleston et al. (2007), in a comprehensive review of studies conducted in the United States, also found health beliefs (the need for Pap tests only if abnormal bleeding occurs) to be associated with poor adherence rates. In addition, Bessler, Aung, and Jolly (2007) obtained similar results and found a lack of disease symptoms to be the main reason for Pap test non-adherence among Jamaican clinic attendees. In another study, Fatone and Jandorf, (2009) found religious orientation to be a significant predictor of screening among 194 urban African American and Latina minority women who were insured through Medicare and Medicaid. They found that women who self-identified as Catholic were more compliant than those who identified themselves as Protestant (Fatone & Jandorf, 2009). These findings suggest a need for culturally sensitive education programs that address health beliefs and are tailored to specific groups.

## System Factors

Provider characteristics and logistical issues are system factors that have been demonstrated to act as both facilitators and barriers to follow up care and are discussed below.

**Organization of community health services.** The location, time and types of services offered are factors that have all been suggested by researchers as facilitative of health services use. Andersen (1995) stated that for efficient use of health services, communities must be aware of the availability and whereabouts of facilities and providers in their communities. The organization of such services usually varies by country and by type of system such as organized or opportunistic. Cristiani et al.(2007) found, within an organized screening program in Northern Italy, living in urban areas and being treated in private settings to be associated with higher rates of noncompliance. In this retrospective study where data was obtained from medical records, physicians, participants and the pathology department, 21% of the patients were lost to follow-up and 43% incompletely followed-up. The authors also found that the implementation of the reference screening protocol was inadequate (Cristiani et al., 2007). However, Eggleston, et al. (2007), found that among women living in the south eastern region of the United States that living in the rural areas was associated with poor adherence. In addition Eggleston et al. (2007), in a comprehensive literature review found that provider patient discussions on follow-up options in a previous visit and the availability of colposcopy on-site increased adherence rates. Conversely, poor physician patient communication was shown to lower compliance rates. Nevertheless, use of private versus public hospitals and physician specialty was not found to be associated with compliance (Eggleston et al., 2007).

Coker et al. (2007), recommended that using institutional factors rather than individual factors might be more significant in forecasting time to adherence for an abnormal smear, whereas Eggleston et al. (2007), suggest that cultural competency and tailoring to the needs of ethnic groups are important components of effective interventions. The review by Eggleston et al. (2007) also noted the paucity of studies that focused on provider and health-care facilities factors associated with adherence. Additionally Felix et al. (2009) suggested that in interventions designed to improve follow-up care, provider and system characteristics should be focused on. The authors of the aforementioned study, which was conducted at a family planning site, concluded that referrals were significant at sites where follow-up care is unavailable as it determined whether women sought follow-up care.

**Regular source of care.** Having a regular source of care allows individuals to develop a relationship with their health care providers to the extent that they feel comfortable to discuss health issues. Authors of several epidemiological studies have found significant associations between having a regular source of care or a personal health care provider and adequate screening usage. Mandelblatt et al.(1999) conducted interviews, using a telephone survey, with 1420 multi ethnic women in New York City between the ages of 18 – 24.They illustrated that screening use for both elderly and non-elderly women was significantly associated with having a regular source of care. Cardarelli, Kurian, and Pandya (2010), also conducted a cross-sectional study using data from the 2004 Behavioral Risk Factor Surveillance System (BRFSS) database and found a strong association between adequate screening and having at least one personal health care provider. In addition, Honda and Kagawa-Singer (2006) found a direct association between a usual source of care and adherence to colorectal cancer screening among Japanese Americans (Honda & Kagawa-Singer, 2006).

In Grenada, cervical cancer screening for the poor or for women without health insurance is performed mainly by nurse midwives at government clinics and the Planned Parenthood clinics. Patients with abnormal results are then referred to their general practitioner or a gynecologist for follow-up procedures. Thus, for many women, having a regular source of care may mean accessing care at a government clinic or the family planning clinic. Moreover, it could be counter-productive to have a usual source of care if screening is not being recommended. Richards and McCann (2001), found that almost 23% of the 35% of Grenadian women who reported never having had a Pap test said that they were never advised to have one by their health care provider (Richards & McCann,

2001) while the main reason given by clinic attendees in Jamaica was lack of disease symptoms (Bessler, et al., 2007).

**Physician recommendations.** Physician recommendations are significant to patient adherence and researchers have found strong associations with screening adherence. In an experimental study conducted by Allen et al. (2008)to measure the impact of a work-site based breast and cervical cancer education program they found provider recommendations to be strongly associated with screening participation. However, the participants of this study, were insured, educated, had high levels of income, and were professionals and therefore had access to mammography (Allen et al. 2008). Additionally, in a prospective study of women with abnormal mammograms Poon et al. (2004), found that women were significantly more likely to receive appropriate follow-up when they were told that it was needed, when their physicians documented discussion of results, when physicians explained further tests in an understandable manner and when a follow-up plan was documented on their medical record. Honda and Kagawa-Singer (2006), also found better provider and patient communication to be associated with adherence to colorectal cancer screening among Japanese Americans. These findings suggest that physicians, through open communication and rigorous record keeping, have an important role to play in reducing loss to follow-up among screen-positive women.

**Service delivery.** Follow-up for abnormal Pap test results requires multiple visits over set time periods by screen-positive women. Consequently; the location of services, costs in terms of time and money, availability of counseling services and practitioners’ characteristics are features that can impact use of services. In addition, the quality of the services offered could determine future use of services by patients. Systemic weaknesses such as poor provider interaction and communication, confusing and contradictory messages from providers and misdiagnosis by providers (Dzuba et al., 2005; Zapka et al.,2004) can contribute to poor quality experiences. This can hinder access to screening services and result in cervical cancer morbidity and mortality.

## Summary

In the preceding discussion I presented findings, conducted mainly in developed countries and among women with access to health care in the United States. In the review primarily Medicare, Medicaid or the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provided for healthcare. The study participants were largely low-income minority groups (e.g., African Americans and Latinas). Although significant findings were reported, many may not apply to women living in the Caribbean given that health system organization and cultural characteristics of participants differ.

Studies that examined individual factors such as lesion severity and its effect on follow-up produced conflicting results. Colposcopy, a more invasive and expensive procedure when compared to repeat Pap tests, was found to be preferable to repeat Pap tests. However, no reasons for this were presented and colposcopy may not be the preferred choice for women in developing countries with limited access to the service. Additionally, continuity of care as well as having a regular source of care is a characteristic of organized screening programs but may not exist for programs in many developing countries where many women access services at government clinics or wherever it is affordable. Physician recommendations, shown to be associated with follow-up, are affected by continuity of care and dependent on the degree of organization of the system. Furthermore, many women who seek screening at the Planned Parenthood in Grenada do not have access to a physician on-site and as such may not have the necessary continuity of care which is shown to increase and improve follow up.

In conclusion, in this dissertation, in addition to exploring the enabling and need factors that impact screening in Grenada, I investigated the follow-up process and quality. I also explored organizational issues of the follow-up system, the referral practices, the result management system and practices. This information I obtained using a qualitative research methodology. I requested women who had experienced the system, to share their lived experiences with the follow-up process through in-depth interviews. The results of this research may provide important information on the process and quality of the cervical cancer follow-up system. This information is sparse for the Caribbean and other developing countries. With this information, screening system follow-up can be improved and consequently morbidity and mortality from cervical cancer reduced. Saved resources can then be used to improve system efficiency and health care quality.

## Literature Related to the Method

Of the literature reviewed, I found few studies which focused on measuring the processes involved in cervical cancer screening, specifically follow-up care, and the quality of those processes from the users' perspective. Nevertheless, the few studies I found used both quantitative and qualitative methodologies either separately or in combination. However, for this dissertation I used a qualitative research method. Qualitative methods, according to Patton (2001 p.14), 'facilitate study of issues in depth and detail'. It, therefore, generates very thorough and comprehensive information, encompassing a broader scope of data. However, the method uses small sample sizes thus reducing study generalizability (Patton, 2001). For the aforementioned reasons this methodology was most appropriate for this research, since to get a complete understanding of the follow-up system, participants needed to provide a thorough description of their experiences. Furthermore, the participant pool was limited in number due to the inclusion and exclusion criteria. The issue of an abnormal Pap test result is a personal and sensitive one so the recruitment of participants proved to be a challenge further limiting the sample size. Below I have discussed studies that have used a variety of methodologies to explore the process and quality of screening systems services.

In 2005, Dzuba et al., used the WHO's three stage strategic approach to assess the cervical cancer prevention and treatment services in Bolivia. They used a literature review, semi-structured in-depth interviews and observations of health services, to gather data. Dzuba et al conducted in-depth interviews with clients at service delivery sites, community members, Ministry of Health and Social Welfare personnel, traditional healers, community leaders and medical and nursing university staff and students (Dzuba et al., 2005). This multipronged strategy provided a thorough assessment of the system.

To measure quality of follow-up Zapka et al. (2004)used a telephone survey of open and close-ended questions to examine the processes of care related to screening. The study comprised of women aged 50 and over and 18 and over with abnormal mammogram and Pap test results, respectively, and who had prepaid access to preventive services through four organizations in the United States. Additionally, in an effort to understand the screening system in South Africa, van Schalkwyk et al. (2008), using phenomenology, interviewed 15 women with advanced cervical cancer. Women were asked to share their experiences from the time they experienced their first signs and symptoms to the time they received treatment for the disease. Results of both of these studies revealed systemic weaknesses such as poor provider interaction/communication, confusing and contradictory messages from providers and misdiagnosis by providers as major reasons for loss to follow-up.

In a nationally organized screening system in New Zealand, Priest et al. (2007),conducted a descriptive study using interviews, medical record review and slide re-read to determine how best to reduce cervical cancer incidence and mortality. Data on 359 women, 80 years and younger, with primary invasive cervical cancer were collected from records and through structured interviews of the women or their next of kin. The screening system characteristics identified with cervical cancer development were: inadequate screening, missed abnormal smears, delays in investigation of abnormal smears or bleeding and a history of previous treatment of dysplasia (Priest et al., 2007).

Gage et al. (2003), in a low-resource region of Peru with an organized regional public health system, used medical records review and interviewed women with abnormal cervical cytology or their family members to obtain information on the screening system. They found that inappropriate and poor follow-up care were the main reasons for cancer development. For example, women reported a lack of systematic information regarding an abnormal result and a lack of information regarding follow-up from providers.

The aforementioned studies have all used a variety of study methods and study populations. The inclusion criteria included women 18 years and older with an abnormal cervical cytology. Abnormal cytology referred to women diagnosed with CIN 1 or above or with invasive cervical cancer. To evaluate the screening systems the authors used different qualitative methodologies, mainly semi-structured interviews with screen positive women, in combination with medical records review. Although the abovementioned qualitative studies used a combination of methods, principally interviews in combination with medical record reviews, this was not feasible for this study due to the unavailability of a cancer registry and lack of an organized follow-up system. Qualitative research, according to Creswell (2009 p. 4), ‘is a means for exploring and understanding the meanings individuals or groups ascribe to a social or human problem’. The process focuses on data collection in natural settings of the participant. In this study I used phenomenology, a qualitative approach, and I interviewed women with abnormal Pap test results of CIN 2 or higher using semi-structured interviews. I have discussed these details in the next chapter.

It is evident from the literature reviewed that there is a shortage of studies on cervical cancer screening follow-up process and quality, conducted in the Caribbean. Moreover I found no qualitative studies which examined process and quality of the follow-up system for abnormal Pap tests, using the experiences of women. Due to the comparatively high rates of morbidity and mortality, the lack of data on follow-up and the prevalence of risk behaviors among Caribbean adolescent population, as illustrated in the review, I found it necessary to conduct further research. The scientific advances in the prevention and treatment of cervical cancer make it one of the few cancers that can be eliminated from among populations. Caribbean countries, like Grenada, have relatively small populations and, with efficient screening systems, elimination of cervical cancer mortality is possible. As a result I obtained information on the follow-up process, quality of the process, effects of the process on the health care seeking behavior and illness experiences of the participants, and the associated meanings. I used the findings from this study to identify strengths and weaknesses in the cervical cancer screening system in Grenada, from the perspective of users. This information will be shared with the Ministry of Health and ultimately, may be used to assist in formulating guidelines that can contribute to further reduction in deaths from this disease.

# Chapter 3: Research Method

## Introduction

In this chapter, I discuss the research design and methodology used to answer the research questions. I also explore the process and quality of the cervical cancer screening follow-up system which are the areas of focus for this study.To achieve this, I used phenomenology, one of five qualitative methodologies described by Creswell(2007). According to Creswell (2006), a phenomenological study is most useful when attempting to comprehend “several individuals shared experiences of a phenomenon”(p. 60). Additionally, the participants are actively engaged in the process, and thus, are able to provide abundant information(Ulin, Robinson, & Tolley, 2004, p. 22). Since, the purpose of qualitative research, “is to generate knowledge of social events and processes by understanding what they mean to people …”(Ulin et al., 2004), I used phenomenology to obtain a profound understanding of experiences (follow-up) using an exploratory approach. This approach is significant given that a full understanding of the phenomenon can better inform development of appropriate practices and policies to address the issue being investigated.

A qualitative method was most suited to this study because a comprehensive description of the follow-up process and qualitycould only be obtained from those who had directly experienced it. These are human experiences that, if approached using quantitative methods, are unlikely to produce the totality of the experience.

## Researcher's Role

Initially, I obtained a list of names of registered gynecologists from the Grenada Medical Association. I contacted these health professionals, in addition to other recommended health professionals, and met with them individually to discuss the proposed research and also to seek their assistance with participant recruitment. Following this initial meeting, I distributed to these health professionals a formal letter (see Appendix A) requesting their help in the recruitment of participants. I also asked that they sign and return the letter indicating their agreement to participate in recruitment. On receipt of the signed agreements, I delivered recruitment letters (see Appendix B) to the health care practitioners for distribution to eligible participants. Potential participants who were interested contacted me directly via the contact information provided in the recruitment letter. At this initial contact with the participant, I confirmed eligibility, and set a date and time for the informed consent process (see Appendix C) and the interview. I conducted all of the interviews and analyzed the data. However, because of the large volume of data collected, a professional transcriptionist transcribed the de-identified interview recordings which I hand-delivered to her on a flash drive.

## Acknowledgement of Researcher Bias

As a current resident of Grenada and a user of the screening system, I am familiar with this monitoring system but have not experienced the follow-up system. However, I am familiar with problems experienced with the health system as reported by community members as I have assisted with several health assessments within the Grenadian communities. Nevertheless, these problems are not unique to the cervical cancer screening system. Therefore, to avoid introducing bias in the study, I used the process of bracketing, as discussed in the following paragraph.

## Research Design and Approach

There are several types of phenomenology, but the one I used in this study is transcendental or psychological phenomenology. This approach is “disciplined and systematic” and uses a non-judgmental and unbiased method to study the phenomenon being explored (Moustakas, 1994 p.22). Descriptions of the lived experiences of the research participants rather than interpretations of those experiences are central to this approach (Creswell, 2007). This criterion was relevant to this study because a description of the process as experienced by participants was critical to uncovering the follow-up process and quality issues. While researcher interpretation is a major part of phenomenology, it was less significant for this approach. However, bracketing, the practice of the researcher compartmentalizing their experiences with the phenomenon so as to be as objective as possible, is vital to this process (Creswell, 2007). This process is also called “Epoche”, a Greek term which means being non-judgmental. So, according to Moustakas (1994), the practice is crucial in the data gathering and analysis process

Previous researchers have used phenomenology to investigate the process as well as the quality of health care experiences for varying health issues. Bertram and Magnussen (2008) used descriptive phenomenology to explore the process through which women with abnormal pap smears received relevant information. They used in-depth interviews to collect data from ten participants who each had at least one abnormal Pap smear. Additionally, Skjaerven, Kristoffersen, and Gard (2010), utilized descriptive phenomenology, via in-depth interviews to collect data from 15 participants, to examine the process by which physical therapist experts promoted movement quality in their clinics. However, to measure the quality of care enhancement using Integrative Medicine, Grace and Higgs (2010) used hermeneutic phenomenology in a study where they made use of data from case studies, focus groups, and key informant interviews to understand the meanings participants attached to their experiences.

For this study I used in-depth interviews, and follow-up interviews when necessary, along with member checks to answer the following research questions, which were used to guide this study:

1. How do women experience the enabling factors for the cervical cancer screening follow-up system in Grenada?
2. How do women experience the follow-up process for cervical cancer screening?
3. How does the follow-up process affect the need factors of women with abnormal Pap test results?
4. What are the experiences of women regarding the quality of the follow up process?

## Population and Sample

I chose the study population from among women 18 years old and over, who were current users of the Grenada health system and who had an abnormal Pap test result. The inclusion criteria consisted of women with an HSIL or CIN 2 diagnosis or higher, diagnosed at least three months ago and spoke English. I selected the sample from among clinic attendees, both private and government. As recommended by Polkinghorne (1989) in Creswell (2007), I aimed to recruit between 5 – 25 individuals using purposive or criterion sampling. In this type of sampling the participants selected should have all experienced the event being explored (Creswell, 2007), and thus able to provide a wealth of information. This sampling technique is also useful for identification of "system weaknesses that become targets of opportunity for program or system improvement"(Patton, 2001 p.238). It follows, therefore, that purposive sampling was the most appropriate technique for this study, in which I aimed to divulge any weaknesses that might exist in the cervical cancer screening follow-up system.

## Instrumentation and Materials

To acquire the data to answer the research questions,I used a brief, self-administered questionnaire(see Appendix D) and an interview guide (see Appendix E) to obtain demographic information and conductinterviews,respectively.I developed the demographic questionnaire to obtain information on relevant variables alluded to in the review of the literature and these variables were used in the analysis of the data. The interview guide was developed by Engender Health and used previously in a study conducted in Bolivia. The study entitled "A participatory assessment to identify strategies for improved cervical cancer prevention and treatment in Bolivia", was carried out in 2005 by Engender Health in collaboration with the government of Bolivia and PAHO.

Mark Barone of Engender Health gave permission to the researcher (see Appendix F) to utilize the instument. The interview guide, written in Spanish, was translated for use in this study. The same source also provided another interview guide, written in English, and used in a similar assessment conducted in India. For this research, I utilized a modified version of the guide.

## Survey Instrument

The survey instrument was comprised of two parts, a self-administered demographic section and the interview guide section. The demographic section supplied data on age, marital status, educational level, employment status, health insurance status, religion, parity, and Parish of residence which I used in the analysis of the data.

The interview guide included four sections with each section comprised of central questions and sub-questions. In section one the women related their experiences with the cervical cancer screening and follow-up services. The main questions that I used to guide the interviews were: Where do you usually go for women's health services and care (reproductive health services)? Describe what took place during those visits. How were you told you would find out about the results of the examination? Explain what happened during your follow-up visit. I utilized the results of the data analysis from this section to provide information on process. In section two, I collected information on the women's' perception of the reproductive health services. The main questions I asked were: What do you think about the quality of the services at the facility where you seek health care? Where would you prefer to go for cervical cancer screening services? I utilized the results of the data analysis from this section to provide information on the quality of services. Further, I explored the possible barriers and facilitators to use of screening and follow-up services in section three. The question that I asked was: Tell me about the reasons that you may or may not return to the clinic/hospital for more screening or follow-up services. I used the data on the enabling factors that I obtained from this section to provide insight into the process and quality of the screening and follow-up services. In the final section, I asked women about their prevention and health care seeking behavior and I received information which I used to address the perceived and evaluated need factors. In each of these sections, after I asked each main question I followed-up with sub-questions and probes to elicit required information, when not forthcoming.

## Data Collection Procedure

I collected all of the data at pre-scheduled dates, times and places in private locations that were convenient to each participant, during the period May 2012 to June 2013. At the beginning of each of the data collection sessions, I read the contents of the informed consent letter to the participant and answered any questions that arose. Immediately afterward, I conducted the semi-structured, in-depth interviews which each lastedapproximately 50-90 minutes.I used the self-administered questionnaire to acquire demographic information andpre-determined open-ended questions with sub-questions to elicit informaton from the study participants.At successive interviews, I explored any new information that emergedto ensure data saturation. According to Creswell (2007, p.

60), data saturation is a process in which the interview procedure continues“until the new information obtained does not further provide insight into the category”. This techniquecontributed to providing a thorough account of the follow-up system.I audiotapedall, except one interview, and wrote notes. In the one instance the paticipant did not grant permission for me to record the interview, so I took notes of the session. On completion of each interview, I thanked the participants and requested their permission to contact them with any follow-up questions or to clarify any issues.

## Data Analysis

I used the Stevick-Colaizzi-Keen (SCK) method, proposed by Moustakas (1994) and further simplified by Creswell (2007, p. 159),to analyze the data. The SCK method is comprised of six stages: bracketing, horizonalization, clustering into themes, the textural description, the structural description and the essence of the experience. For the process of bracketing, I presented a description of my experience with the cervical cancer screening system. The purpose of this was to help me compartmentalize my experiences so as not to contaminate experiences of the participants, as their experiences should be at the heart of the study. Moustakas (1994) refers to this as “Epoche”, “a preparation for deriving new knowledge but also as an experience in itself, a process of setting aside predilections, prejudices, predispositions, and allowing things events and people to enter anew into consciousness, and to look and see them again as if for the first time” (p. 85). Therefore, this process allowed me to be as objective as possible during the data collection and analysis phases.

Next, I listened to the audio recordings repeatedly and noted any unclear information for further follow-up. These recordings were later transcribed verbatim by a professional transcriptionist. On receipt of the completed transcripts, I read each one several times and made margin notes, simultaneously. In addition, I used my interview notes to supplement the audio recordings. I initiated this process after each interview and the process continued during the data collection phase. Repetitive listening and reading allowed me to become immersed in the data and capable of identifying significant statements. Additionally, I identified missing, vague, or conflicting information and sought clarity while data collection was ongoing. Using this iterative process I coded all of the relevant statements that stood out, with each statement regarded as equally relevant. Coding involved the use of words or phrases to highlight emerging ideas. I used *a priori* codes that I derived from the guiding frameworks and literature review and open codes which I derived from the data. I defined all codes using parameters and kept notes of coding decisions taken and dates of any revisions. I recorded these changes so that I would be able to track the development of the coding scheme, which is critical to establishing data trustworthiness (Ulin, Robinson & Tolley, 2005). This completed the horizonalization process, that of listing non-repetitive and non-overlapping statements (Moustakas, 1994).

On completion of horizonalization, I grouped the statements into meaning units and then clustered them into themes. Next, I used the themes to develop the textural description of the experiences which is an account of ‘what’ the participants experienced.

Then, I presented a structural description which comprised of a description of ‘how’ the event was experienced and included my reflection on the setting and context in which the participants experienced the event. Finally, I integrated both textural and structural descriptions and, using verbatim examples, presented a combined discussion on the meanings and essence of the group experience (Moustakas, 1994).

Bertram and Magnussen (2008); Moerrer-Urdahl and Creswell (2004); and Skjaerven et al.(2010), as previously discussed, have used this method or some variation of it as the data analysis strategy. I used the computer software package, ATLAS.ti, for the data analysis process, specifically for the coding and sorting of text.

## Trustworthiness of Data

In this study, I incorporated several mechanisms to assure rigor and to ensure adherence to the criteria of credibility, dependability, confirmability and transferability; as set by Ulin et al. (2005).Firstly, the process of bracketing or “Epoche” contributed to establishing credibility as this allowed me to have a greater understanding of the event being explored, while remaining non-judgmental. According to Ulin et al. (2005), when biases are removed the researcher is able “to represent the study respondents more fully and credibly” (p. 167). To assess dependability, Ulin et al. (2005) suggests examining the ability to repeat the process and to incorporate a team approach during analysis to remove researcher bias. To establish dependability, I used an independent coder and documented each step of the method to ensure replicability. Additionally, I documented all decisions made during implementation of the study. I also created an audit trail, comprising of each stage of the data collection protocol and data analysis steps which have established validity. Further, I strengthened the SCK method with the use of direct quotes to support the findings. I also established transferability, defined by Ulin et al. (2005) as the application of conclusions drawn to other similar populations, by providing a detailed contextual description of the research in the introduction and literature review sections.

## Human Subjects Research and Ethical Considerations

This study used human subjects, so appropriate ethical decisions for their protection were paramount. For this reason, I submitted applications to the Institutional Review Boards (IRBs) at Walden University (WU) in the United States and St. George’s University (SGU) in Grenada, for permission to conduct the study. Walden University is the institution which offers the researcher’s program and SGU is the organization responsible for the supervision of research in Grenada, the country in which the research was conducted. I commenced the study after receipt of IRB approval #03-27-12-0056784 from WU and IRB approval #12003 from SGU.

To ensure the protection of the rights of the participants, I requested that they read and sign the informed consent letter as an indication of their willingness to participate in the study. In addition to the participants reading the informed consent; I answered any questions and clarified any issues for the participants. I also provided, to participants, my contact information and contact information for university (WU and SGU) research representatives in the event they needed to speak with someone else other than myself. I assured all participants that all interview content will be held confidential, secure and that any personal identifying information will be accessible only to me. I also emphasized anonymity and to illustrate this I asked participants to choose a fictitious name to be used during the interview. Additionally, I requested their permission to tape/digitally record the interview to ensure accuracy of the data and for permission for me to contact them to clarify information if it became necessary. Lastly, I discussed with participants how the study results will be communicated to them and with whom the results will be shared.

## Dissemination of Findings

Women, who had experienced the cervical cancer screening follow-up system in Grenada, provided the data for this study. To gather the data on this follow-up system, I used quality and process indicators that were used previously in two similar studies. Therefore, I plan to present the findings of this study to the Ministry of Health and other stakeholders in Grenada. Firstly, I will present a written report, together with an executive summary of the results to the Ministry of Health, the Grenada Medical Association and the Grenada Cancer Society. Subsequently, I will prepare and share oral power point presentations of the results with representatives from the aforementioned organizations and other women’s groups. In addition, I will prepare brochures, which highlight important findings, and disseminate to government clinics and private doctors’ offices. The purpose of dissemination is to provide a base for decision-making and raise awareness among women and practitioners so that they are empowered to adapt preventive behaviors and improve their practice style, respectively. Finally, I will submit articles to scientific, peer-reviewed journals for publication, based on the findings, to reach a wider audience and to share findings with members of the scientific community.

## Summary

In this chapter I provided a detailed discussion of the study methodology. I identified and provided justification for the use of qualitative research and the phenomenological study design. Additionally, I presented a focused discussion on the inclusion and exclusion criteria, purposive sampling and choice of sample size. I also incorporated a detailed discussion on the data collection and analysis plan and the strategies used to ensure data trustworthiness. Furthermore I discussed the ethical dimensions of the study and presented a plan to disseminate findings. In the following chapter, Chapter 4, I discuss the implementation of the study and findings. I also explore the challenges experienced and strategies used to overcome those challenges as well as the details of the results.

# Chapter 4: Data Analysis

## Introduction

This study was conducted to explore the reproductive health services, specifically the cervical cancer screening follow-up system, offered to women through the Grenada health system. I constructed the follow-up system and examined its quality from the perspective of users of the system. I also explored the key constructs of process and quality, using theory-based indicators derived from the literature. To do this, I used the research questions that follow to fully investigate these constructs and focus the research. The research questions are:

1. How do women experience the enabling factors for the cervical cancer screening follow-up system in Grenada?
2. How do women experience the follow-up process for cervical cancer screening?
3. How does the follow-up process affect the need factors of women with abnormal Pap test results?
4. What are the experiences of women regarding the quality of the follow-up process?

Presented in this chapter are descriptions of the participants' demographics, the data collection process, the data analysis strategy, the process by which the data were analyzed, evidence of trustworthiness of the data and the research findings.

## Setting

A major challenge for this study was the recruitment of participants. The inclusion criteria, having a diagnosis of HSIL or CIN 2 at least three months prior to recruitment, meant that enrollment was dependent on medical practitioners identifying eligible participants and distributing the invitation letters to them. Although six practitioners assisted with recruitment and reportedly distributed a total of twenty letters, there is no way of verifying this. Traditionally, in the Caribbean, reproductive health issues are not openly discussed and by extension problems with the reproductive organs are taboo further contributing to recruitment challenges.

## Data Collection

Upon receiving approval from the Walden University Institutional Review Board and the St. George’s University Institutional Review Board, I recruited participants who met the inclusion criteria for the study using non-probability, purposive sampling. This was accomplished through the assistance of health care practitioners, mainly gynecologists. The researcher met with eight practitioners, discussed the study and requested their assistance with participant recruitment. Six of the eight practitioners signed a letter of agreement as evidence of their active participation in recruitment. Ten participant recruitment letters were given to each of the practitioners with the understanding that they would distribute them to eligible participants. Each week for a total of four months, practitioners were contacted to enquire about the distribution of letters. The practitioners reported distributing a total of 20 letters.

Eleven women, all recruited through gynecologists, contacted the researcher via telephone during the period May 2012 to June 2013.There were three refusals after the initial contact was made. Two participants, who had initially expressed an interest in participating, withdrew before the informed consent process occurred. Another interested participant, who was too weak to be interviewed at the time of verbal agreement, died before an interview could be scheduled.

Consequently, I conducted interviews with eight Grenadian women who were current users of the Grenada health system, who were diagnosed at least three months prior to the time of the interview with HSIL or CIN2 or higher and spoke English. All of the interviews were interviewer-administered, one-on-one, face-to-face, digitally recorded, semi-structured sessions. The women shared their experiences on the cervical cancer screening follow-up process and quality by answering four broad questions, each with sub-questions. The interview guide, which comprised the questions and sub-questions, was used in a similar study conducted in Bolivia and was developed by Engender Health and used with permission.

At the initial contact with the potential participants, I provided an overview of the research and enquired about their interest in participating. Once the potential participant expressed an interest, I scheduled a day, time and place convenient to the participant for the interview.

I conducted seven of the interviews at the homes of the participants and one at the participant’s workplace at a time convenient to them. These times ranged from 10 a.m. to

6 p.m. on weekdays with each interview lasting approximately 30-60 minutes.
The surroundings were conducive, as I conducted all of the interviews in a private space. Prior to the start of each interview, I gave the participant a copy of the informed consent to read, seek clarity with questions and sign as an indication of agreement to participate. Next I requested the participant’s to complete the demographics questionnaire. This questionnaire provided information on age, marital status, educational level, employment status, religion, parity, insurance status and parish of residence for each of the participants.

At the time of the interview I asked each participant to choose a fictitious name to be used during the interview and to maintain anonymity. I conducted one interview with each participant except for two instances. In the first instance, I did a face-to-face follow-up interview the following week and then I did a second follow-up interview via the telephone as requested by the participant. I conducted these follow-ups to clarify information I had obtained during the interview.

All of the women I interviewed using the questions in the prepared interview guide, though not in the exact order as this depended on the responses to the questions. Interviewing continued until each person being interviewed had divulged similar information on process and quality, until I accomplished data saturation and no new information emerged. I recorded each of seven interviews using a digital voice recorder, with prior approval from the study participants. Notes of the eighth interview were hand written by the researcher, as the participant did not want to be audio recorded. Next, I wrote field notes for each of the interviews, with the date, location and duration of each interview noted. At the end of each interview, I reviewed the information to check for accuracy and also requested from the participants permission to contact them for any follow-up questions or to seek clarity. In addition, I explained how and with whom the study results would be shared and enquired about their preference for the delivery of the results. Moreover, I gave to each participant a copy of an informed consent form with contact information for the researcher and IRB administrator.

To ensure confidentiality, I stored all hard copies of the interview transcripts, signed consent forms, and demographic questionnaires in a locked drawer that only I could access. All voice recordings and other electronic data I stored on a password-protected computer that was only accessible to me. Hard copies of all data will be destroyed five years after the data have been analyzed and any personal identifiers linking participants to the data electronically will be erased.

## Participant Demographics

All eight of the study participants met the inclusion criteria. The women were between the ages of 29 and 57 with approximately 71% residing in the parish of St. George. Roughly, 88% of them were employed and no one had health insurance. At the time of interview, three of the women reported being married, four were single and one was in a common law relationship. Furthermore, 63% of the women said that they had three or more children, and 13% had no children. Additionally, five of the women attained secondary level education while the remainder achieved primary level (see Table 1).

Table 1

*Demographic Characteristics of Women Interviewed*

| Respondents ***N*** (8) | Number |
|---|---|
| Age | |
| 20-29 | 1 |
| 30-39 | 3 |
| 40-49 | 2 |
| 50-59 | 2 |
| | |
| Marital Status | |
| Single | 4 |
| Married | 3 |
| Common-law relationship | 1 |
| | |
| Education | |
| Primary school | 3 |
| Secondary or high school | 5 |
| | |
| Employment Status | |
| Employed | 7 |
| Unemployed | 1 |
| | |
| Health Insurance | |
| Yes | 0 |
| No | 8 |
| | |
| Religion | |
| Catholic | 2 |
| Church of God | 1 |
| Pentecostal | 2 |
| Seven Day Adventist | 1 |
| None declared | 2 |
| | |
| Number of Children | |
| 0 | 1 |
| 1 | 2 |
| 3 | 2 |
| 3+ | 3 |
| | |
| Parish of Residence | |
| St. Georges | 6 |
| St. David | 1 |
| St. Marks | 0 |
| St. Patrick | 0 |
| St. Andrews | 1 |
| St. Johns | 0 |
| Carriacou& Petite Martinique | 0 |

## Data Analysis Strategy

Moustakas (1994), Stevick-Colaizzi-Keen strategy for data analysis is the approach I used to guide the analysis for this study. Moustakas proposed that the steps of bracketing, horizonalization, forming theme clusters, and providing a description of the texture, structure and essence of the experience as necessary for this process. During the process of horizonalization, I listed non-repetitive statements from interview transcripts and then grouped them into meaning units or codes. I generated the codes using a priori and open coding methods. Next, I used pattern coding to cluster these meaning units into themes. Following this, I explained the follow-up process, as experienced by the participants, using composite textural and structural descriptions. Composite textural descriptions are a collation of what was experienced by each of the participants (Moustakas, 1994 p. 137-138), while the composite structural description provides a collective description of how the phenomena were experienced (Moustakas, 1994 p.142). Subsequently, I combined the descriptions into a discourse on the meanings of the group experience and supported it with relevant quotes. I used the qualitative data analysis software, ATLAS.ti, to accomplish the coding of data and sorting of text. The strategy discussed above was most appropriate because it allowed for an impartial and non-judgmental way of exploring the participants’ descriptions of experiences or phenomena (Moustakas, 1994). Accuracy in the description of experiences is an essential component of transcendental phenomenology and because the focus of this research wason reconstructing the follow-up process and describing the quality of the system, a comprehensive and precise presentation of the essence of the experiences was paramount.

## Data Analysis Process

I began the data analysis process immediately following completion of each interview. This commenced with reading of the field notes and listening to the voice recordings. I wrote margin notes alongside field notes taken at each site and notes were re-read and any follow-up questions noted. Next, I delivered copies of the de-identified voice recordings to a professional transcriptionist for verbatim transcription (see Appendix G for sample transcript). Once transcription was complete, I read the transcripts simultaneously while listening to the recordings and any discrepancies were corrected. Next I checked field notes alongside the transcripts to ensure that all experiences, emotional and physical, were captured; and were also used to supplement the data. Furthermore, I made an effort to complete the stated process within one week of the interviews, while the information was still easy to recall. Finally, I read the transcripts several times to become familiar with the data and to identify any missing, vague or conflicting information. To ensure accuracy of the data, I also read transcripts to the participants via telephone for verification.

Next, I uploaded completed copies of the transcripts to ATLAS.ti for coding using A-priori and open coding strategies. As each successive interview was coded and new codes emerged, I revisited and recoded previous interviews to reflect the additional codes. A codebook (Appendix H), which I developed and used to guide the coding process, lists the name of each code and its meaning. Using the theoretical frameworks that guided this study, I identified four broad experiential categories, linked to process and quality. These are: health behavior and user provider interactions, outcomes, enabling factors, and need factors (see Figure 3).

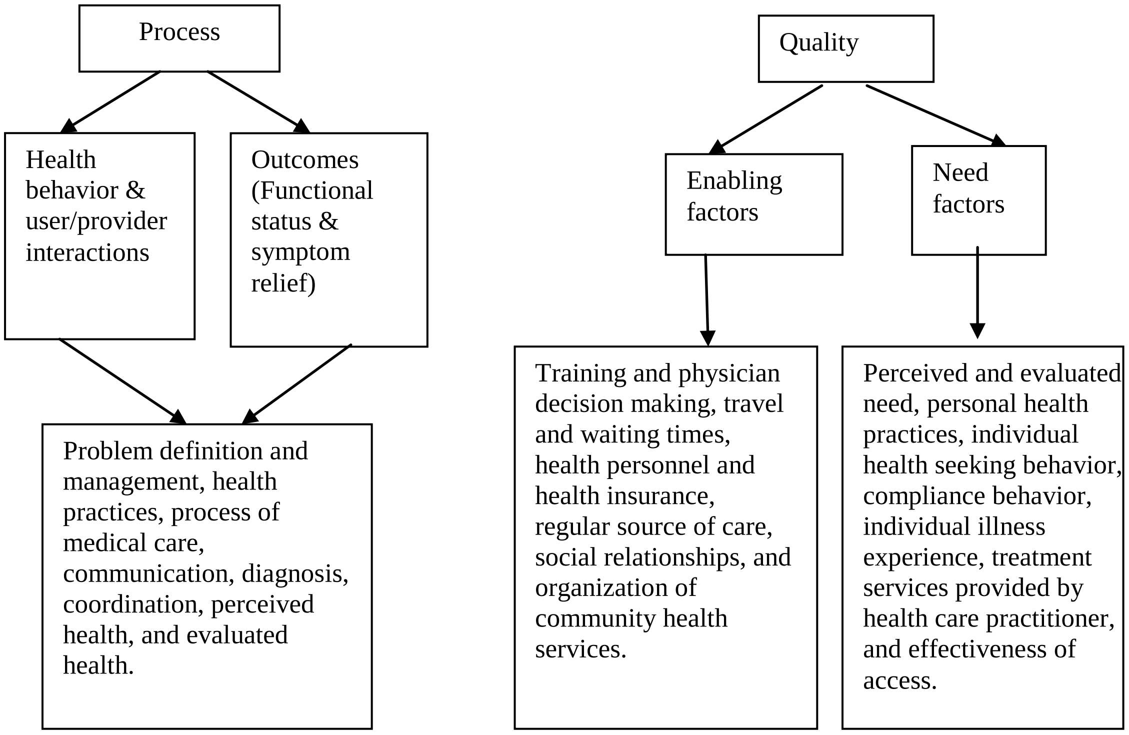

*Figure 3.* Flowchart showing links of key indicators to theoretical concepts.

For each of these experiential categories, 29 *apriori* codes were developed and open coding yielded another18 codes. As such, 47 codes were generated. The codes are listed in Table 2 as *apriori* and open codes (See Table 2).

Table 2

*List of codes arranged by category of apriori and open*

| Apriori | Apriori | Open |
|---|---|---|
| Provider communication content | Clinical diagnosis | Source of health information |
| Communication channel | Attitude to diagnosis | Exam frequency |
| Practitioner preference | Health services satisfaction | Exam attitude |
| Prevention | Health services availability | Initial exam age |
| Results notification | Support groups | Exam initiation |
| Lab location | Provider communication competence | Attitude towards health services use |
| System organization | Practice domain | Reproductive health knowledge |
| Health care attitude | Surgery site | Spirituality |
| Illness beliefs/perceptions | Health services improvement | Fatalistic attitude |
| Compliance behavior | Health services affordability | Site of 1st Pap test |
| Regular source of care | Pap test results | Pap test description |
| Follow-up frequency | Clinical care | Practitioner approachability |
| Follow-up procedures | Pelvic exam: negative vs. positive | Patient collect lab results |
| Health information sharing | | Patient takes letter to referral site |
| Health services cost | | Relative collects Pap test results |
| Timeliness of services | | No referral letter |
| | | Referral appointment made by doctor |
| | | Inpatient medication purchase |

The next stage involved data analysis by research question, using pattern coding to develop themes. To do this I grouped similar codes and examined the text for commonalities. According to Saldana (2009, p.150), this type of coding allows for the arranging and interpretation of text. Additionally, pattern codes are useful for explaining and making inferences as they combine lengthy textural descriptions into more cohesive units (Miles &Huberman, 1994, p.69). From this analysis, eight broad themes emerged from the data.

## Evidence of Trustworthiness

To ensure data reliability, I used the following strategies: adherence, with fidelity, to each step of the process as outlined, development of codes using constructs from the theories and the literature (*apriori*) and identification of codes which emerged from the data (open coding). During this process I developed a codebook. Additionally, I achieved inter-rater reliability through an independent coder, an Assistant Professor at St. Georges University (Appendix I).I shared a coded sample transcript with the independent coder, who reviewed the coding structure. Following a meeting, at which the coder suggested some changes, I then re-coded the data. Discussions at this meeting also provided some new insights into the data. The process of coding was iterative as for each successive interview coded, in addition to the a priori codes, new codes emerged. This necessitated re-coding of previous transcripts. Furthermore, in a follow-up meeting with the independent coder, a decision was taken to split one of the codes, which resulted in another cycle of coding.

In-person interviews were conducted as was previously stated and member checks were used to verify that the information recorded was accurate from the participants' perspective. Additionally, the interview guide is one that was used in similar studies conducted in Bolivia and India among similar populations.

# Results

This section provides a composite textural and structural description of experiences with the process and quality of the follow-up system. This is followed with a textural-structural description of the meanings and essence of the experiences organized by research question. The themes, incorporating the meanings and essence of experiences, which emerged from the data are discussed. The primary findings are first discussed followed by a discussion of the secondary findings and any exceptions. Quotes from the transcripts are provided in the final phase to support the findings. Numbers and fictitious names are used to refer to participants e.g., 'P1: Apple' is participant number one. In addition, although the follow-up system was being investigated, it was important to gain an understanding of the participants Pap test history to provide some context for follow-up. For this purpose, I asked participants questions that elicited information on their Pap test screening experiences. The results of the Pap test history precede the discussion on the composite structural and textural descriptions.

## Pap Test History

The participants Pap test histories varied, with none of the participants indicating that they engaged in regular screening practices. Two of the participants indicated that their first Pap test was the most recent when they were diagnosed; two had had regular Pap test during the period when their children were born; two had a Pap test as a result of other gynecological problems; one had her first Pap test through a health fair at her church; and one had her first Pap test after hearing about it from friends at her workplace.

However, after their initial tests, only the two participants with gynecological problems continued to have regular screening. For all of the participants, the most recent Pap test results were abnormal except for one participant whose result was satisfactory. However, this participant was diagnosed with cancer of the cervix and referred for radiation.

I also asked participants what prompted them to do the Pap test at the time of diagnosis. Three of the participants reported feeling unwell at that time and decided to consult a doctor. One woman stated, “I went to do one because I take in with this pain on the side” (P4: Lauren; 34 yrs, 1st Pap test), while another one stated,

> I thought I was pregnant so I did a pregnancy test and it showed that I was pregnant and I went to a private doctor and he test[sic] my pressure and my sugar and it was high so he told me to go the hospital, he type up a letter and tell me go to the hospital, they admit me and get me to see the doctor, he told me I need insulin to bring down my sugar, and when they did a next pregnancy test (at hospital) and it showed that I was not pregnant… Then after that they did the Pap smear (P1: Apple, 29 yrs, 1st Pap test).

The other five women made decisions to get screened because some time had elapsed since their last test. According to Papye, “I say I going and do a Pap smear because I didn’t do one for a long time. I think was 2009” (P2: Papye, 57yrs). In one instance, the woman had an abnormal Pap test in the United States after giving birth but on a repeat test, in Grenada the result was normal; two years later, the results was again abnormal; she stated, “Yes I did it in B, it was abnormal but when I got here I did it over and it was normal” (P5: Sherry, 35yrs).

The women reported that they had all been advised previously by practitioners to have a Pap test. However, when asked about the provider’s advice on how often it should be done the answers ranged from three months to a year, illustrating uncertainty of the duration of time. As is stated by one woman, “Every three to six months I think, she told me every six to a year, every year I think she told me too” (P1: Apple), while another one stated, “Like twice a year” (P3: Magda). It is possible also that because women did not see the test as important they did not pay attention to the advice given and thus could not remember.

When asked about the delivery of the results, the women indicated that the time for receipt of the results was generally about six weeks and that the provider usually called to tell them when the results were available. They were also told that they needed to go in to collect it since no one could collect it for them. If no one called then you were required to return to the clinic in six weeks time to collect it. However, in two instances, the results were given to relatives for delivery to the women. Additionally, one participant reported having to go to the lab to collect the results as declared here, “She (the doctor) told me to go the lab in about 2-3 wks and collect the results and bring it back to her, the doctor” (P1: Apple).

The women were also asked about the information they received from practitioners about the benefits and importance of a Pap test. According to the women, they were told

that the purpose was to test for cancer. No other information was conveyed.
One woman stated, “Well the benefit is to find out early detection of cancer cells (told by the nurse), probably others but I am not sure” (P8: Patsy).Another stated, “No normally it’s just checking for the cancer you know? Is that basically” (P3: Magda).

The women consulted practitioners in both the private and public domains/sites. Three of the women used private practitioners, two used family planning services and three used the government services. Yet, when asked about their preferences for future use, the majority, six of the women indicated that they would choose a private practitioner.

### Composite Textural Description

This composite textural description provides an account of what the women experienced as a group, thus, it presents an integrated description of their collective experiences.

The cervical cancer screening and follow-up process began with the initiation of the Pap test that resulted in an abnormal result and ended with a surgical procedure for all of the women except one for whom radiotherapy was recommended.

On receipt of an abnormal Pap test result, the participants’ processes differed depending on where the tests were done. Women who accessed services at the Planned Parenthood or a private practitioner were notified by telephone when the Pap test results were ready. At the government clinic, one woman had to collect her results from the lab, while the nurse notified the others via telephone. Women were required to present in person to collect the results. However, results were shared on the telephone in one instance and in two other instances; relatives were given the results to deliver to the women. This resulted in the test result not being shared with one woman thus delaying access to treatment services. Women mentioned being dissatisfied with the timeline for feedback about results, which was generally six weeks post testing.

On collecting the results, the nurse or doctor told the women that the results were abnormal. At the private practitioners' clinics, the doctor, usually a gynecologist, using pictures from a book, explained the client's condition and its implications and provided the opportunity for questions to be asked. Information on the next steps was also provided and explained using the same method. At the Planned Parenthood and government clinics, the women were referred to their private gynecologist or a gynecologist at the public hospital without being given any additional information. The methods used for referrals varied. In most instances a paper copy of the results was given to the women to give to their doctor, while for some an appointment was made with a general practitioner at the government clinic. For those referred by a private practitioner, a letter was provided along with a copy of the results.

Of those who were referred to the government hospital, one woman consulted a general practitioner one year later, due to the uncertainty as to who a gynecologist was, a reflection of the low literacy level. Others consulted immediately; however, due to wait time to see a gynecologist at the government hospital one woman opted to consult a private gynecologist and was later referred back to the government hospital after confirmation of diagnosis. Follow-up procedures such as Pap tests, ultrasound, blood tests and dilatation and curettage, or some combination were conducted for each woman.

Following confirmation of diagnosis, all of the women, except one, who accessed services through the government clinics, were scheduled for surgery with an oncologist who visits Grenada twice per year to provide services. Surgery was performed at the general hospital where inpatient stays were an average of six days. For the women who consulted private practitioners, colonoscopies and biopsies were recommended and or completed before removal of the uterus and/or ovaries. One woman was referred for radiation and two others chose to skip further testing and have their uteri removed, one at a facility in the United States and the other at the general hospital. No counseling was provided to any of the women at any time during the process and most of the women broke down and cried on receipt of the results of cancer.

For many participants the inpatient experiences were positive. Interactions with the nurses and doctors were pleasant and they felt cared for. The surgical procedures were successful for all, except one who, due to an error during the biopsy procedure, had her uterus removed. As in-patients at the general hospital they received services, surgery and attendance by specialists at an affordable cost. However, they were required to get a blood donor before the surgery and purchase some of their medications from pharmacies outside of the hospital. On the other hand, a couple of participants also had negative experiences with both nurses and doctors. One participant cried during her inpatient stay because of her inability, following surgery, to elevate herself on to a ‘high’ bed as instructed by the doctor as well as the refusal of the nurse to assist her with bathing. Another participant, who required repair surgery, felt poorly treated by the referring physician who refused to consult with the gynecologist who had attended to her prior to this incident. In both of these instances, the participants’ hospital stay was longer because of nosocomial infections. These incidents demonstrated a lack of standardized procedures or adherence to the procedures.

Instructions given to the women following surgery were similar. All of the women were told to return to get their stitches removed and for follow-up tests either at the government outpatient clinic or to their private practitioner. At the government clinic, this meant long waiting times for some and longer waits when it was to consult with the visiting oncologist. These were anxious moments for the women and the anxiety was reduced when they were told that all was well. During the follow-up consultations, in one instance, information was mis-communicated or misunderstood by one participant possibly due to her low literacy level or method used to share the information. Poor organization and the lack of a standardized procedure for communicating information were also revealed during the consultation sessions. Furthermore, additional relevant information regarding self-care was not provided to the women, some of whom yearned for information. This raises questions about the quality of the interpersonal relations between physician and patient.

## Composite Structural Description

The narrative explained in this section provides a general description of how all of the women experienced the system. It integrates their individual experiences into a collective description of their shared experiences.

Receiving a diagnosis after an abnormal Pap test result or being told that cancer cells were present was like a death sentence for most of the participants. Participants' responses were initially emotional and private which then gave way to information being revealed to interpersonal networks, mainly family members. Participants expressed feelings of fear and self-reflection. One participant decided to dedicate her life to God and thought of death as inevitable. All participants valued the support of family members. The support provided was predominantly emotional and tangible.

Referrals for some meant more of the same bad news and a situation, which was out of their control. So, while some complied instantaneously, others were much slower to act or were hindered by lack of resources. Those who were equipped with knowledge, information and access to resources took action immediately. Some refused to wait and follow recommended steps because of fear, and instead opted for a surgical procedure. The process appeared to be complex for others with additional and repeat testing; the results of which further confused some participants. Moreover, the timeline for accessing treatment was prolonged. Lack of coordination and weak paper trails impacted treatment-seeking behaviors for some.

After the initial shock of the diagnosis, all of the participants, with minimal fear, generally accepted surgery. Those who were informed of the disease through the use of a book of pictures stated that they were more fearful. However, the reputation of practitioners eased the anxiety experienced by some participants. This transitioned into a positive in-patient experience for most.

In-patient stays were unexpectedly good and judged based on anecdotal reports. Although, overall, the stays were relatively short most participants reported pleasant interactions with practitioners. All were required to get a blood donor prior to surgery and some were forced to purchase prescribed medication from an external source. As inpatients, two participants were traumatized from care received, resulting in a lack of trust and aversion of the system.

Follow-up procedures after surgery meant seeking services at the outpatient clinic of the general hospital for most of the women. This was an experience of long wait times and a poorly organized system. Inaccuracies in referral after surgery reflected lack of standardized procedures at the hospital. Other than a follow-up ultrasound and blood work, no other information was given to the women and counseling or referral to support groups was not offered.

## Textural-Structural Synthesis

In this section the composite textural and structural descriptions are integrated to explore and generate the true meanings of the experiences as shared by the women. The way in which the interactions and procedures were experienced is thoroughly examined to generate the real nature of the phenomenon. These experiences are further supported by direct quotes from the women. The synthesis is organized by research question. For each question, broad categories followed by the common themes that emerged from the data are presented. The findings are further sub-divided, where appropriate, by the domain through which the system was accessed; private or public; and supported by quotes from the transcripts.

## Research Question1: How do women experience the enabling factors for the cervical cancer screening follow-up system in Grenada?

Enabling factors are those skills or resources that can facilitate the follow-up and health-related behaviors of women (Andersen, 1995). In order to acquire information addressing this, the main question asked was: ‘Tell me about the reasons that you may or may not return to the clinic/hospital for more screening or follow-up services.’ This question was followed with a number of sub-questions that guided the conversation to obtain relevant information. The women were also asked about their perceptions of the services at the facilities where they seek care. Based on the theoretical frameworks used, the answers provided two broad categories of enabling factors– provider characteristics and system characteristics. Within each of these categories, the themes that emerged are discussed and quotes used to support the discussion.

### Provider characteristics.

***Interpersonal relationships.*** Generally, women expressed satisfaction with their interpersonal relationships with providers at the outpatient and inpatient facilities. They felt that the providers were friendly and accommodating, especially the nurses with whom most of their interactions occurred. As stated by one woman, “Well to be very honest with you with all the negative things I hear about the hospital I got really good treatment, all the nurses treated me well, the doctors treated me well. I had a good time I must say” (P5: Sherry). This was confirmed by others who stated that, “The staff? Yeh, very nice. The oncology department, clinic in Grand Bras, Yeh even when I was in the hospital taking the Chemo them nurse and them, they was very nice yeh” (P4: Lauren); and yet another declared, “They didn’t treat you like you were poor and that they were giving you a handout, they treated you like a patient who needed this and look after you regardless of, which I thought was really great” (P6: Mary).These relationships have been found to positively impact follow-up rates.

For most women, interactions with the doctors occurred after they received a diagnosis of an abnormal Pap of HSIL or higher. The experiences of the women at this level varied and were dependent on the practice site, public or private, where care was accessed. The participants overall reported feeling more comfortable with the private practitioners. However, a few of the participants recounted negative experiences with physicians, while they were inpatients at the general hospital and as outpatients as stated by one woman,

> I find when you asking Dr. (X) something, like he don’t want to answer. He have a thing about him, a attitude. You know it have some people you could talk with them and it have some people you could ask them and if I ask Dr. (X) as long as I

> see him, I bending meh head down till its meh time to go in, serious.
>
> (P2: Papye, public).

***Communication.*** The level of satisfaction with the information shared by providers and the methods used varied among participants by practice domain. Those who accessed care through the private practitioners reported being more satisfied.

According to the women who accessed care in the private domain, the doctors spent time explaining the meaning of the results and discussing how the recommended follow-up procedures will transpire. According to Sherry, “She explained the results to me and she showed me a book, the diagrams too and explained to me what abnormal cells were and what stage and everything” (P5: Sherry). Magda also shared a similar experience stating that her doctor used a book to explain the diagnosis, “Yes, you see her pull out her book and read and show you what it is” (P3: Magda). For these women the private practitioners, with whom they interacted, were their regular providers for gynecological issues.

At the public practice sites, the experiences shared by the women who obtained care in this area were different. Two of the women had done their Pap test at the Planned Parenthood and were given the results to take to a gynecologist, without any explanation other than that the result was abnormal. On consulting with the gynecologists, practicing at the government hospital, the women thought they were provided with vague explanations as illustrated by Papye, “Yeh he (the doctor) saw three things and they doh looking good, I don’t know what it is he didn’t explain” (P2: Papye). Mary also stated that she was not provided with explanations, “He told me, ok we gonna go to surgery. I said ok you gonna take everything out, the ovaries. He tell me yes everything and that was it” (P6: Mary).Additionally, Apple, reported that she was only told that the cervix was cancerous and that she needed to get the uterus removed, with no further explanation provided. However, while she was given the opportunity to ask questions she did not ask any because, “she (the doctor) said it had to be removed so that’s it” (P1: Apple). Yet, she did have some unanswered questions as is reflected in this statement, “sometimes I ask myself and why I was young and why they couldn’t treat me for it instead of taking out my cervix and my uterus” (P1:Apple). Another participant expressed her dissatisfaction with the lack of information shared by providers as shown in this statement,

> Oh another thing too is when I went to Dr. (Y) he asked me about having discharges and so and I said, well not really, but every now and then I seem to have this light brown discharge. And he said to me, well once you go through menopause you shouldn’t have any discharge. This is something I find doctors don’t bring to people they don’t explain to you. (P6: Mary).

***Skills of practitioners.*** All of the surgical procedures were conducted at the government general hospital by doctors practicing in the public domain, public/private partnerships or by a visiting oncologist. Of the eight participants, two received services as private patients.

The women reported mixed experiences with the medical procedures that their physicians exposed them to. Generally, they expressed satisfaction with the surgical experiences as inpatients. However, while some participants were very impressed with their physician's capabilities, others expressed disappointment with after care. This is significant as women are required to follow-up with physicians to identify relapses as soon as they occur so that appropriate action can be taken. These experiences have been shown to impact follow-up adherence as reflected in this statement by Papye after receiving a hysterectomy, "When I stay in the hospital that long is after the operation, I had got a pneumonia cold, so they say I couldn't go home to get rid of it, that's why I stay so long, but I pray I don't have to go back there" (P2: Papye).

Mary, who accessed care through the public domain, made a decision to have a hysterectomy based on a family history of cancer and the reports on the capabilities of the surgeons. These reports she received from her daughter-in-law, who is a doctor employed at the same hospital, as well as from others. According to Mary,

> Dr. (Y) is apparently he's a very good surgeon, my daughter-in-law actually saw him remove somebody's uterus through their privates. He didn't cut her at all and I met another lady who she told me Dr. (L) did it for her but hers was a big fibroid. Her fibroid was almost out of her. So when I saw her I said well how was your surgery she said Dr. (L) did it. I said well how, did she cut you? She said no she went from inside and took my uterus and the fibroid like a delivery. She was out of the hospital the next day. (P6: Mary).

Sherry, a private patient, had her procedure at the general hospital performed by her physician who worked in a public/private partnership. Her confidence in her physician was as a result of her long term, satisfactory experiences with the sharing of information in previous consultations. As a result, the unexpected outcome of her surgery did not have a negative impact on the relationship as is reflected here,

> I should say fortunately unfortunately, whatever way, I had to do the cone biopsy and on doing the cone biopsy when she (the doctor) was in the process of doing it she, the day it said I had was to do it, when she examined me before the amount of abnormal cells that day it was more than she had seen before so she had to go wider and deeper with the cone. As a result of going wider and deeper with the cone the uterus was punctured and too much bleeding so she had to just remove everything (uterus) (P5: Sherry).

While this was a major error, Sherry, expressed that she was able to cope with it,

> I took it and dealt with it even after I had the surgery after I woke up in the morning and everything and she came and told me all that happened I was okay with it I was never down or stressed or unhappy or anything. (P5: Sherry).

Another private patient, whose local physician was in private practice, chose to have her surgery done in the United States, but developed some complications on her return to Grenada. However, because she could not afford the private physician’s fees she was referred to the emergency department where she was admitted to the general hospital. She reported being unhappy with the attitude of and services provided by the consultant physician as is reflected here,

> But missy, I’m not stitching you back, you have to stay just so I’m not stitching you back (Dr’s words). So I tell her, fine. She say I’m not stitching you back, we don’t know what it is. You have to stay and heal on its own, whatever it is. Well I stayed there for nine days. Well she say they had tubes draining from me, the doctor (in the US) who did the surgery wanted to tell them to takeout the tube because I would get an infection if it there too long and it would leave. Well she (Dr K) didn’t want to speak to the doctor from the US. She just didn’t want to speak to her. She just did not want to speak to her. (P7: Jane).

### System characteristics.

***Source of care.*** The organization and delivery of health services can have an impact on utilization. For this reason, women were asked questions about whether they had a regular source of care and questions regarding accessibility to pertinent services. The majority of the women reported not having a practitioner with whom they consulted routinely on their health. Rather, their interactions with the health system occurred when they felt ill or during the pre-, peri- and post-natal care periods of their reproductive years. This is consistent with the findings in the literature where not having a regular source of care has been found to affect follow-up compliance rates(Cardarelli, Kurian, & Pandya, 2010; Carney, Dietrich, & Freeman, 1992; Mandelblatt et al., 1999).

Having access to follow-up services, while not the main factor, is important for patient compliance. Whereas the government clinics are physically accessible to all Grenadians and provide affordable services, according to the participants, important and essential services are limited or unavailable. Follow-up services for all of the participants, that is, post surgical procedures, biopsies, colposcopies and hysterectomies were all performed at the Grenada General Hospital. The majority of participants indicated that follow-up tests, biopsies, colposcopies and even Pap tests needed to be sent to Barbados or Trinidad for analysis which resulted in longer wait times for results. According to Magda,

> It does take a long time you know, sometimes about three months, yes a long time. Yes, you does wait a long time, a little while to get the results because I went in March and it take a while to get the results. (P3: Magda).

Whether the tests were done at the public or private clinics the reports were similar. Jane, who also accessed care at a private clinic, stated, “They say (the doctor) they have to send it to test and then they will call me when they get it back. Dr. (Z) used to send it to Trinidad to test” (P7: Jane), while Patsy explained, “He (the doctor) did a colposcopy and had to send it to Barbados” (P 8: Patsy).

The women also shared their concern over the availability and costs of chemotherapy and the non-availability of radiotherapy. One participant could not afford to pay for the prescribed radiotherapy and was advised to do chemotherapy, however, after the first treatment cycle with chemotherapy she had to obtain the medication to complete the treatment. She stated that she had to order and pay for the medication through a private pharmacy in order to complete the treatment as reflected here, “a private pharmacy had to order the medication and then you have to pay for the medication because the government order and they don’t know when they getting it” (P4: Lauren).

For those who accessed services via the private practitioners, they were concerned about the economic practices at this level. The women related that fees were charged for the initial consultation with the physician and the prescribed tests and additional fees were also charged for reading of the results by the physician. One woman stated, “Yes, you pay hospital fees, doctor fees and then you still have to pay for the results, for the results of the surgery, you have to pay for the results also, that’s a lot of costs” (P3: Magda). While another declared, “Doctors feel they have to charge you to see you and then charge you to read the results, which I think is quite unfortunate. It’s one of the hiccups in our system I suppose” (P6: Mary).

***Supporting networks.*** At the time of diagnosis, all of the women reported feeling distraught and helpless. None of them reported receiving any type of counseling. One woman stated,

> No, I mean they didn’t even ask you how you feeling, psychologically how you feeling. I’ve had friends ask me how I feel inside. Oh you feel empty, I don’t feel anything different whatsoever and I think my part is because I had already started

> menopause and I was 5 years into it that my body didn't miss the estrogen like a young woman would. (P6: Mary).

Instead, they recounted being told the diagnosis and referred for further treatment. The women explained that their only supporting network was their family members, as is shared here by the women,

> When he (boyfriend) come home I start crying and I tell him I have to tell him something, he ask what I crying for, I tell him bad news and then he there telling me you don't have to cry for that, if it have something you could do about it, you could just do what you have to do. Everybody supported. (P4: Lauren).
>
> Don't cry, keep courage everything will be ok. My mom and family was very supportive. They come and looked for me at the hospital. My mom spent a week with me after the surgery. She cooked for me and took care of me and helped me; my children also. (P8: Patsy).
>
> I told her (sister) I have cancer, she tell me I lie, I told her I'm not lying its serious and she started to cry. I told my boyfriend too and he asked me that if I cannot have any more children, I tell him no and he was sad. (P1: Apple)

One woman reported feelings of isolation until a follow-up visit to the general hospital outpatient clinic where she observed a number of persons with similar problems, she declared, "I ain't realize so many people have this thing, is only when I go the clinic the other day I realize" (P4: Lauren).

### Research Question 2: How do women experience the follow-up process for cervical cancer screening?

The follow-up process refers to the actions recommended to a patient by a practitioner following an abnormal Pap test result and the strategies that are used to facilitate compliance of the patient. The main questions asked of the women were: ‘where do you go for women’s health services and care (reproductive health services)? Describe what took place during those visits. How were you told you would find out about the results of the examination? Describe what happened during your follow-up visit.’ Probes were used after each main question to guide the conversation. The data codified, was grouped into two broad categories: provider health practices and process coordination.

**Provider health practices.** The participants shared similar experiences with the practices employed by providers following the diagnosis of an abnormal Pap test result. Depending on the type of abnormality, participants described being advised to have all or some of the following procedures done: a follow-up Pap test, colposcopy, cone biopsy, ultra sound, dilation and curettage (D & C), blood work and hysterectomy. All the participants, except two, reported having had a hysterectomy. However, when comparing the practice domain through which care was accessed, the types of procedures differed. The women, who used the services of private practitioners, were required to do, in addition to the follow-up Pap, a colposcopy and biopsy. For those using the government services, blood work, ultra sound and D& C were the most common procedures prior to surgery.

The women who accessed care in the public domain reported having to do a follow-up Pap test, followed by either or all of the following procedures: ultrasound, D & C and blood work culminating in a hysterectomy. One woman explained,

> They admit me and get me to see the doctor, he told me I need insulin to bring down my sugar, and when they did a next pregnancy test (at hospital) and it showed that I was not pregnant, and then they send me for an ultrasound. She did not tell me what the ultrasound read and then they examine me and then they had a lot of things/blood, pain coming inside of me maybe from my period, I don't know. Then after that they did the Pap smear, well and the next thing she told me I had to do a D&C. (P1: Apple).

Another woman stated, "He do another pap smear and when I go in the hospital what they do one two, how they does call that, not ultrasound, I did ultrasound before I go there before the operation. Yeh, they did two D & C" (P2: Papye); and yet another shared, "Yeh, because I was very hastened to do the surgery but he said let's take one step at a time, let's do a D&C, we'll do a ultrasound and then see where we go from there" (P6: Mary).

In the private domain the women who received care were each required to do a follow-up Pap test. Of the three, one forgot to do the follow-up Pap test while the other two complied. Colposcopies and/or biopsies were then recommended as was related by one woman,

> I did the colposcopy in I think April (2012), this year. They put me down to do a surgery with Dr. (C) the cancer they say they would do a cone biopsy to see if the (abnormal cells) go into to the tissues; I have an appointment to do the full biopsy. (P3: Magda).

Sherry also reported, “She wanted to see what caused the abnormal so she wanted to do a colposcopy. Yes, well that too was abnormal so a cone biopsy that’s removing the abnormal cells” (P5: Sherry). In addition Jane stated,

> And when I went in there the Doctor talk to tell me that my Pap smear come back abnormal, that they have cells there but I have to go and do a biopsy to see if its cancerous or not. I did the biopsy and when I did the biopsy it came back negative. (P7: Jane).

After completion of surgery, all of the participants reported having to report to the outpatient clinic or their private practitioner for further follow-up. Practitioners provided the appointment times to them.

**Process coordination.** The women indicated that they were notified of the abnormal Pap test results in similar ways. Usually the nurse would call and the woman would need to go in to the clinic to collect the results and the nurse or doctor would read the results to them. If the results are abnormal then the woman is referred to a gynecologist, if the attending practitioner was not a gynecologist. While this was stated, in two instances the women sent a relative to collect the results as is shared by the women,

> I didn't go and collect it for myself, when she (the nurse) call me for the results, I send my daughter to collect it for me and well me daughter, well she (the nurse) say she tell her but my daughter say she (the nurse) ain't tell her that I had to go and see a doctor. (P2: Papye).
>
> They called me and I asked, how does it look? she say, 'well', I say, it looking all right? she said 'well not really you need to come and take it to your doctor', so I said ok and I sent and picked it up right away. (P6: Mary).

This resulted in one of the women not receiving timely feedback, which contributed to a delay in seeking treatment. Moreover it might illustrate non-adherence to the recommended protocol, in the public domain, as it relates to the delivery of results. The methods used for referrals were also diverse.

Referral processes ranged from formal (structured) to very informal (unstructured) with the private practice sites operating at the former level. Women reported that they were referred to the public system if unable to afford the fees of the private practitioners, usually for surgery. They were given a letter together with their test results to be taken to the outpatient clinic of the general hospital.

At public practice sites, the first step was described as being given a slip of paper with the results to take to a gynecologist. Some women chose to go to a general practitioner or gynecologist in private practice (an additional step in the process), who then did additional repeat tests, and again, referred them to a gynecologist at the general hospital. Referral to the gynecologist at this stage involved either of the following: the practitioner making an appointment for the patient, the patient being give a letter to be taken to the gynecologist, or the patient being sent to gynecologist without a letter. Because the process of referral is sometimes informal, in one instance during a follow-up visit after a hysterectomy, one woman said the doctor told her that she needed to get radiotherapy. However, when she returned to the doctor for a second follow up visit, this is what occurred as stated by the woman,

> When Dr. (M) tell him (Dr. C) I went in Trinidad and didn't get the radiation done he ask who refer that, but he self told me that and Dr (X) told me that, that I had to get it done and he told me was to get it done as soon as possible, yeah. (P2: Papye).

This highlights weaknesses in the referral system.

In addition to the poorly coordinated referral system, access to follow-up was also affected by tardiness of the process. The majority of the women who used the government services reported longer wait times for the process. Generally, the timeline, from diagnosis to surgery, ranged from 6 months to 1.5 years. One woman took a decision to consult with a private gynecologist to avoid the long wait time, the severe pain she was experiencing, and her inability to secure an early appointment at the general hospital, while another secured an earlier appointment time through a relative who worked at the general hospital. The women explained,

> When they send to make an appointment for the one in the hospital it was like a whole six months. So I couldn't wait all this time because the pain I experiencing, I had to see what I doing, so I choose to go private. (P4: Lauren).
>
> So I told Dr (Y) that I was not interested I had started menopause at 50. So this thing has been no use to me for the last 5 years and I did not want to wait 6 months so he kind of smiled and said ok let's do a D&C you know, so he made arrangements for me to go in the following week. (P6: Mary).

## Research Question 3: How does the follow-up process affect need factors of women with abnormal Pap-test results?

The purpose here was to understand how the follow-up process affected their evaluated and perceived need for health services. Two themes emerged from the data: health related behavior and user attitude.

**Health related behavior.** Most of the women reported that they had been advised by practitioners to get a Pap test done. However, less than half of them complied during their fecund years and then discontinued the practice once that period was over. Being fearful and not seeing it as important were the most common reasons given for non-compliance. The participants' age, marital status, parity or education level did not appear to have any effect on this process. In fact, two of the three participants with more than three children had their first Pap test at the time of diagnosis. Apple stated, "No, I was just not thinking about that, they told me but I just didn't do one (a Pap test)" (P1: Apple), while Lauren explained that women who had children before said it was painful, "Yeh, people used to say but how people used to explain it, I thought it was more difficult than that. So, you know when you hear these things and them, you fraid to go and do it (Pap test)" (P4: Lauren). Papye, who also had more than three children before doing her first Pap test stated, "And I used to hear people say Pap smear they pushing up a big piece of iron inside you and that does hurt so I never wanted to do one I say I ain't going again" (P2: Papye).

Conversely, when the women received the diagnosis of abnormality their reactions were very different. All the women were compliant with some or all of their practitioners' recommendations. Two of them took the decision to skip a few steps in the follow-up process and have a hysterectomy instead. Mary who was told to do a follow-up test stated,

> I was, oh take it all out, I don't want to wait six months because at six months if it comes out abnormal all they gone do is tell me I'm sorry it has spread or its full-blown cancer or something and in my family I am not willing to take that chance you know, my grandmother had cancer of the uterus … (P6: Mary).

Another participant, Jane, who sought a second opinion in the US, stated, "but we didn't want to take chances to leave it there, so they think that I take out the uterus instead of taking this six months testing and all of that" (P7: Jane). None of the participants questioned the doctor's decision, in fact one participant stated that, "she [the doctor] told me it [uterus]have to come out, and it [uterus]have to come out" (P1: Apple).

The organization of the health system facilitated the surgical procedures for all of the women who used the government services. The preliminary tests and hysterectomies, conducted in the public domain, were affordable as none of these participants reported having difficulty paying. A possible reason for this is that the women were able to use the service provided by a visiting oncologist, who offered the surgical services biannually, at no additional cost to the patients. However, those women who chose to access services through private practice reported having some difficulty paying for the services.

Overall, the health related behaviors of the majority of women were similar. Preventive health behaviors are not regularly practiced; rather women seek health care when they recognize disease symptoms. This is explained by Lauren, who had her first pap test and was diagnosed with cancer at the same time,

> The pain I did having, I knew something was wrong. I used to have the pain when I seeing the period. The period come it finish and the pain still there and getting worse, so then I tell myself something wrong (P4: Lauren).

Patsy, who’s previous Pap test was eight years ago at the birth of her last child explained,

> In 2010 my periods came twice per month and I was bleeding when having sex but I did not go to see a doctor. A whole year passed and in 2011 I was feeling sick, I felt as though I couldn’t breathe and I came to see the doctor and was advised to do a Pap test (P8: Patsy).

As previously discussed, compliance occurred at this point. The word ‘cancer’ also tended to provoke immediate reactions from patients and at the same time, a feeling of futility as narrated by the participants. They all expressed feelings of fear and disbelief as expressed here by one participant, “First I was frightened wondering how on earth could I have this abnormal Pap, or what could cause it. I was really frightened” (P 5: Sherry), while Patsy uttered, “Oh boy it was really scary. I felt real sad. I was crying. Now I am okay, I know that it is out and I pray to God it doesn’t come back” (P 8: Patsy). Another woman stated,

> A little shocked because you never think it could actually happen to you, you feel what, I’m strong and nothing happens to me you look at my size and my sister always called me because every time I did blood work I had no cholesterol, I had no diabetes, no pressure (P 6: Mary).

**User attitudes.** Following their experiences, the women’s attitudes to health and the inpatient care they received were generally positive. For the most part, they were happy that some preventive action had been taken and felt hopeful. Yet, they yearned for information regarding behavior changes that could be useful for further prevention or reoccurrence. At successive follow-up checks, they expressed relief when told that all was well.

For all the women, in-patient care meant time spent as a patient at the general hospital. The length of time ranged from approximately one week to two months. They all, except one, spent one week for surgical procedures related to a hysterectomy. Here, their experiences were affected by length of time as patients with longer patient care resulting in poorer experiences. Furthermore, the type of care required impacted their experiences with the system. Participants who required therapy, such as colposcopies, and hysterectomies, reported more positive experiences, whether accessing care through private or government practice. The few participants who needed chemotherapy or radiotherapy expressed that they were frustrated with how the system works. This was possibly due to misinformation, and difficulty accessing these treatments. Two women mentioned that they were told that radiation therapy was available in Trinidad, Cuba and Venezuela; however, it was not affordable for them, as stated here,

> Anyway, I went by a doctor in Trinidad and he tell me I had to pay 86000 dollars for that, no that’s in Trinidad money, I think that’s 50 something thousand US , the radiation. Well, I ain’t get it done because I don’t have the money to pay for that so I come back home’ (P2: Papye).
>
> Venezuela, Trinidad, Cuba but it was so expensive. Trinidad is 56,000 US dollars, to do radiation. Well I still trying to see if I can travel to go and do the radiation. I am trying Canada now. Well I have family over there so they could always assist me you know (P4: Lauren).

Another one expressed that the government had made available opportunities for treatment in Cuba but the quota was full. Additionally, one woman reported having to purchase medication for chemotherapy, which was recommended as an alternative to radiation, at the general hospital. She stated,

> When I went to get the chemo I get the first set of treatment, it was three set I had to get, and when I went for the second set it didn't have so I had was to pay 8,000 something dollars (P4: Lauren).

While this was so, Mary articulated that costs associated with surgery and her inpatient stay was minimal since it costs much more at the private hospital.

As outpatients, the experiences of the participants varied by practice site. For women who accessed the government clinics their experiences were generally poor, with some highlighting issues with time and organization. One woman exclaimed,

> Oh lawd when I went to see Dr. (X) the first time they say one o'clock is the appointment. Well I thought when you go one o'clock you go see Dr. (X), way, I come out there about 8 o'clock the night, we (P2: Papye).

Mary who was very pleased with her experience stated,

> I will go back to the hospital and I would recommend him (Dr. Y) to anybody else, I mean I feel sorry for him and for the patients. Because it's free there's so many people and you have to spend so long waiting. That's the only thing if I had to criticize (P6: Mary).

While another participant stated, "I feel it could be better, much better because a situation like that, if you don't have what it takes, that is it, yeah" (P4: Lauren).

Overall, following the processes experienced, the women's opinion of the government health care services were mixed. Some were more appreciative of the services that are available, and the skills of the practitioners as is shared here by two of the women,

> But other than that I thought we had great service at the hospital. I think they do great for what they … They have to hide gloves if they have to use them because its shortage and I thinking you know they offer and they try their best with what they have but they really don't have much (P6: Mary).
>
> Well to be very honest with you, with all the negative things I hear about the hospital I got really good treatment all the nurses treated me well, the doctors treated me well. I had a good time I must say (P5: Sherry).

Additionally, the availability of a visiting oncologist facilitated surgeries at a low cost. However, it must also be noted that the majority of the women had not experienced any other health system. One woman, who was exposed to health care elsewhere, described poor experiences with the system. She declared,

> These people they don't want to upgrade they self. They only want to be practicing since they go to school and stay there. They only want to, they ain't going to no refresher course and see what's the latest thing they using out there. They ain't want to do nothing. They just want to stay there and make the money and ain't upgrade they self. Sad to say that but (P7: Jane).

Yet, another woman stated that she was unable to make a judgment based on her lack of exposure to other systems as is stated here, “Well I can’t really answer that one because is only down here I experience. I don’t experience nowhere else so I can’t say to say I would like to go there because of the service” (P4: Lauren).

These experiences contributed to dissatisfaction and distrust of the system by some women. It also resulted in them being hesitant to accessing care at government facilities.

### Research Question 4: What are the experiences of women regarding the quality of the follow-up process?

The framework used to guide this study, uses indicators of availability, affordability and effectiveness to determine quality of care. Hence, the indicators are applied to follow-up care as well as clinical and interpersonal care. As such, these indicators, discussed separately, are used to guide the discussion in this section.

**Availability.** Follow-up services such as Pap tests, colposcopies, biopsies, and chemotherapy are normally available through public and private practice sites but radiation therapy is not. As previously discussed, one woman for whom chemotherapy was recommended as an alternative therapy since radiation was unavailable on the island, was forced to order and purchase the medication through a private pharmacy to complete the therapy. Another woman explained that as an inpatient she had to purchase her medication,

> No, I didn’t have to pay for the D&C, but most time I had to buy me medicine for myself eh, a ‘fleet’ and all I had to buy for myself yes; when I was in the hospital I had to buy medicine for myself (P2: Papye).

This demonstrates that all treatment choices are not consistently available and radiotherapy is only available in other Caribbean countries or North America.

**Affordability.** Generally, the women who used the follow-up services, available through the government clinics and hospital, reported that they were able to pay for the services, except in the one instance where chemotherapy medication had to be purchased privately. Another woman was adamant that costs were minimal for the services received. She declared,

> But who the hell am I to complain, you know it was free. The nurses attended to you well. They made sure the IV’s was going you know. But everything was free. The only thing I paid for was my ultrasound and the pap, not the surgery, sorry I had to pay for the theater which was 270 dollars which to me is like free …but all the blood work and everything else is done for free, and x-rays before surgery and blood work after the surgery and they had you on antibiotics and painkillers after surgery. Everything was free they didn’t ask for a cent. You got your meals if you wished to eat there. That was free but they were very specific about what they gave you after surgery (Mary, P6).

Conversely, services delivered by private doctors were deemed expensive. According to one woman,

> Yes it’s a struggle, you have to think about where you getting the money, to do surgery now, they say it will cost a lot of money. 5000 dollars because I’m a private patient and if I have to go the hospital, I have to go private ward and pay a thousand dollars a day, so we trying now to see if I can go the outpatient clinic, she (doctor) have a outpatient clinic; it is costly (P3: Magda).

The women who accessed care through the private domain explained that if the general hospital is used for the procedures then as a private patient you are required to pay the hospital fees as well as a fee to the private practitioner.

**Effectiveness.** Interactions with practitioners were generally described as satisfactory, with participants who accessed care in the private domain perceiving better care or results. Six of the women stated that they would prefer to access services from private practitioners. This was interesting as originally only three of the women initiated care in this domain. However, while this was so three other women who had initiated care at public clinics had later consultations at the private clinic before being referred back to the public domain. Only two of the women said that they would prefer to access care in the public domain, one of whom was a worker at the government facility and the other had a relative working at the government facility. As discussed earlier, the women seemed to have more confidence in the private practitioners, which could be due to information shared, and the methods used. In one instance, one woman, who was referred back to the public system, stated how uncomfortable she felt interacting with the practitioner at the public facility. However, while this was so, all of the surgical procedures were performed at the general hospital; either by private or public practitioners.

All of the clinical care experiences occurred at the public facility, the government hospital, with only two instances in which patients' surgeries were performed as private patients. Mostly, the women noted that their surgical experiences were satisfactory. One woman, who was admitted to do a biopsy and had her uterus removed instead, due to physician error, also viewed the services as acceptable. Another woman was traumatized by her experience, seeking post surgical care after rupture of the stitches from the original surgery, which was performed in another country. This occurred because the attending physician was reluctant to consult with the physician who performed the surgery. As a result the participant developed an infection. However, the majority of the participants valued the post surgical care received as inpatients as mentioned earlier.

The inefficiencies in the timeliness of follow-up services were highlighted by all of the women, who were dissatisfied with the wait times for receipt of results of Pap tests and colposcopies. Six of the women expressed concern that samples had to be sent to Barbados or Trinidad for testing, which increased the length of time for receipt of results from practitioners.

Overall, regarding the quality of services as determined by the participants experiences shared, the availability and effectiveness were poor while affordability was acceptable in the public domain. However, in the private domain, availability and effectiveness of services, specific to interpersonal relationships with physicians, were seen to be acceptable while affordability was evaluated as poor. Regardless of this, one woman recognized that there are many limitations within the public system, despite which services of comparable quality are available and for which she was grateful. She stated,

> Thank God we have that service available for women for people because in these hard times where things are difficult, if we didn't have this service, this free health care, I think a lot of us would be down because I would not have gone. I would have not afforded that surgery. When I spoke to a friend of mine who used to be a nurse in England and she said, she is from Mt. M, and she had a friend in Mt. M who had the same thing the cells came back abnormal and she said the same thing. She went and got it out to Dr. (Z) and he did the surgery in a private hospital. She said girl it cost her 15,000 dollars; $5,000 for him, how much thousand for the hospital, two hundred and fifty dollars a day for the hospital. I say, well you know I don't have 15,000 dollars so you know I will have to go through the system. So if we didn't have a system to go through I don't know what would happen to people like myself or worst off because everybody thinks they are bad until they meet somebody worst off than themselves (P6: Mary).

## Summary

In this chapter I presented a discussion on the data collection, analysis and research findings. I also discussed the demographics, screening behavior of participants and site where services were accessed, factors that might have impacted follow-up practices. Subsequently, I analyzed data for each of the research questions by examining the data for patterns and forming categories based on the patterns identified. Furthermore, I analyzed each of the categories and explored commonalities and highlighted exceptions.

## Findings

The results of this study showed that practice site, public or private, had an impact on the follow-up experiences of the women. The woman's understanding of the severity of the lesion also had an impact on decision making; however, age, parity, and marital status did not appear to have any effect. All of the women were uninsured and thus the impact of this could not be determined.

When considering enabling factors, the data illustrated that the friendliness of the nurses and perceived competence of the doctors were highly valued by the women and thus facilitated the experiences. Additionally, the women were comfortable with the strategies used by private practitioners to share health information and this resulted in an instilled sense of confidence in practitioners, further enhancing the process. The 'doctor as god' philosophy, while it seemed to positively influence follow-up behaviors of the women, did not have an impact on health behaviors. Conversely, the negative attitudes and the practice of not providing relevant health information, by doctors in the public sector, hindered the process. Relatively long timelines for results of procedures and to access elective procedures negatively affected access. Furthermore, costs of services in the private sector and lack of social support services impeded follow-up actions. Women not having a regular source of care as well as low literacy levels, in some instances, also delayed the follow-up process.

The practice domains through which the system was accessed influenced the follow-up process of the women. More testing occurred in the private domain and services were more costly as women were also required to pay for receiving test results. Furthermore, at the public clinics, there was no standardized process for the dissemination of results and the referral system appeared to be unstructured resulting in women being lost to follow-up or delayed receipt of care. Poor organization of the system had a significant impact on the process.

Despite some negative experiences with the follow-up process, the women developed a greater appreciation for the services available within the health system both public and private. The women were grateful for the availability of elective procedures, especially the hysterectomy, and low cost of inpatient stays at the general hospital. Compliance with physician recommendations as well as the health seeking behaviors of participants also improved. However, the women were frustrated with the timelines for receipt of results and the prohibitive cost of radiation which made it inaccessible.

The evaluation of the quality of the services received mixed reviews from participants. The costs associated with accessing radiotherapy in another country, as well as long wait times for services resulted in delays in accessing services. Additionally, the fragmented referral system and unstructured methods for dissemination of test results further hindered access to follow-up. Moreover, the lack of health information for women further retarded the process. However, whilst this was so, the accessibility of elective procedures along with the inpatient care was rated as acceptable.

These findings are further explored in the following chapter. A detailed discussion on the ways in which they compare to findings in the literature is provided and further analysis and interpretation within the context of the theoretical frameworks are explored.

# Chapter 5: Discussion, Conclusions and Recommendations

## Introduction

Pap tests are accessible at a reasonable cost to all women in Grenada. In 2001 Richards & McCann, (2001), conducted a cross-sectional study in Grenada which revealed that of 258 women surveyed, 65% reported having had a Pap test. This rate is higher than the average cervical cancer screening coverage rate of 19% found in developing countries, where the coverage ranged from 1% to 73%, and an average rate of 63% found in developed countries(Gakidou et al., 2008). However, it is important to note that Gakidou et al. (2008) analysis was based on population surveys from 57 countries while the study done in Grenada was based on a sub-population. Judging from the coverage mentioned above, Grenada's rates are relatively high and yet cervical cancer continues to be a burden. For this reason, it is possible that the follow-up system was defective.

Follow-up, the process that occurs subsequent to an abnormal Pap test result, also impacts the rates of cervical cancer. Given that few studies have investigated this process, and no investigations were found for Grenada or the Eastern Caribbean countries with similar health systems, it was important to evaluate the functionality and quality of the follow-up system in Grenada. The purpose was to determine how the system contributes to cervical cancer rates.

To better understand the process and quality of the Grenada cervical cancer screening follow-up system, I conducted a qualitative study. I used a phenomenological approach to capture the experiences of women who used the cervical cancer screening system in Grenada to understand the operationalization and quality of the follow-up system. Additionally, I investigated system, provider, and participant factors to establish possible determinants of follow-up.

In this final chapter I provide a summary of the main conclusions and discuss the findings in relation to the research questions. Next, I examine results and interpret findings from previous research. I then use similar findings to validate the results and provide justification where results are different. In addition, I discuss limitations and propose recommendations for supplementary research. Finally, I provide recommendations for action and discuss the social change implications.

## Summary

Findings of this study indicate that characteristics of health care providers, the health system and the participants facilitated and or hindered the use of the follow-up system. Thus, this qualitative analysis revealed mixed reviews of the system as experienced by female study participants. Overall, the factors that facilitated use of the system included positive interpersonal relationships with the nurses and private doctors and information sharing techniques used by private physicians. The accessibility of diagnostic tests and treatments such as hysterectomy at an affordable cost also helped the process. Nevertheless, these positive aspects were overshadowed by impeding factors.

The follow-up process was shown to be adversely affected when care was accessed through the Planned Parenthood or government clinics. These clinics used a variety of unsatisfactory methods to deliver the Pap test results. Consequently, women failed to follow-up or chose to seek additional information from private doctors. On the whole, the monitoring process was found to be cumbersome. Factors that contributed to this include the deficiency or inadequacy of information obtained from health care providers, long waits for receipt of results and an unreliable referral system.

The referral system also contributed to the lack of continuity of care. This system, or lack thereof, was revealed to be unstructured and fragmented. Referral methods ranged from very informal, word of mouth, to formal, a letter sent to the referred doctor. The informal methods which were used mainly at public clinics, incurred additional costs for the women who chose to consult further with private physicians. This disjointed system contributed to unnecessary, repeat testing, and a longer time for confirmation of diagnosis and receipt of treatment. As a result, it impacted the quality of follow-up services.

The quality of care received was determined to be satisfactory when using measures of interpersonal relationships with practitioners and practitioner competence at private practice sites. However, at the public clinics, although the services were found to be affordable, they were deemed to be unsatisfactory when measured using the criteria stated above. Hence, quality as experienced by the women, differed by practice site.

The cost of services also had an impact on access to care. Elective procedures, such as colposcopies and biopsies, were judged to be expensive in the private sector while radiotherapy was unavailable locally to participants obtaining care in either sector.

However, radiotherapy was available regionally, but the cost was prohibitive.
Cost, as a result, acted as an inhibitor to follow-up.

A few other factors also contributed to the poor quality experienced by some participants. The long waiting time for the receipt of test results, the lack of counselling and the absence of social support networks all contributed to inefficiencies in the system. Regardless, participants with a regular provider from whom they accessed care, were better able to navigate the system and overall had more positive experiences.

These findings are elaborated upon in the subsequent section. The discussion is organized by research question and structured around the key themes that emerged from the guiding frameworks and the data. Each research question is stated, followed by a discourse on the findings.

## Interpretation of Findings

Research Question 1: How do women experience the enabling factors for the cervical cancer screening follow-up system in Grenada?

The findings show that the relationship between the females and their health care providers were mostly positive, particularly the nurses. Nurses were seen as working within limitations but were, nevertheless, competent and proficient. While this positive association was a general trend for nurses, relationships with the doctors were viewed differently. Those who sought care from the private doctors expressed having more trusting relationships that encouraged continuity of care. However, most of the women described their relationships with physicians who practiced in government clinics as unsatisfactory or inadequate. This lack of trustworthiness negatively impacted interaction at the public clinics, resulting in follow-up delays or women resorting to seeking care at private practices. As such one finding was that private practice enabled follow-up. This result is linked to the findings of more trusting relationships and better communication strategies that both occur in private practices. Therefore, private practice as an enabling factor was not confirmed by other studies. Eggleston et al. (2007) in a comprehensive literature review did not find practice type to be associated with follow-up. However, they reviewed studies that were conducted in the United States where the health care system is structured differently. More importantly, Berry et al.(2008)found that trust positively influences compliance behaviour (Berry et al., 2008). In a study done among attendees at four family practice clinics in Texas in the United States, to explore the association of commitment and trust with adherence to medical advice and eating behaviours, Berry et al.(2008), found that patients confidence in their physician positively influenced their compliance behaviour. This finding is important because many uninsured women in Grenada access care at public clinics so, to encourage follow-up and ensure care continuity, it is important to build and promote strong trusting relationships at this level.

In addition to interpersonal relationships, the data suggested that the methods used to communicate health information and the information shared, affected follow-up behaviours. When the doctors explained the health problems and made recommendations for treatments, with the aid of pictures from books, the women followed-up. This strategy was used primarily by the doctors in the private domain. These physicians, in their private practices, educated participants using the procedures named above and provided opportunities for the women to clarify issues. This approach appeared to strengthen relationships and enhance confidence in the doctor, positively influencing follow-up behaviour. Eggleston et al.'s (2007) comprehensive review of peer-reviewed studies published in the United States between 1990 and 2005 also found that provider discussions with patients on follow-up options increased adherence rates and conversely, that poor communication lowered compliance rates. Additionally, Ward et al. (1991), used a randomized controlled trial and illustrated that when women were provided with relevant health information during a routine clinic visit the screening rates increased. This finding is also supported by Chocontá-Piraquive, Alvis-Guzman, and De la Hoz-Restrepo(2010), who found , using an ecological analysis, that cervical cancer mortality in Colombia decreased when women with abnormal Pap smears received medical advice. It is, therefore, important that this practice of sharing relevant information with patients be also implemented by doctors at public clinics to increase adherence.

Previous observational studies have found direct associations between having a usual source of care and screening adherence (Cardarelli et al., 2010b; Carney et al., 1992; Mandelblatt et al., 1999). Likewise in this study I found that the three women who had personal health care providers were more compliant with screening and follow-up. Experiences in the public domain, as well as poor public perception of government services, may have contributed to women who sought care at government clinics, not having a personal health care provider. In addition, health care at the government clinics is provided by physicians who are rotated throughout the system making this a challenge. While this might be so, continuity of care can be facilitated by using a more organized screening system where women are required to register at health clinics (Howard, 2009). If instituted, this could result in a better tracking system.

Research Question 2: How do women experience the follow-up process for cervical cancer screening?

The lack of a standardized Pap test results dissemination and referral process, and relatively long wait times for the receipt of test results were critical issues identified. The consensus among women on what they understood to be a regular practice for the dissemination of Pap smear results was to report to the practitioner's office to collect the results. However, this protocol was inconsistently applied, resulting in setbacks and redundant testing. In addition, the system used for referral, was shown to be unstructured with doctors using an array of methods for this process. This lack of, or poor communication between referring practitioners might have lead to misunderstanding among practitioners, contributing to excess testing. Additionally, follow-up may also have been affected as a result of the patient becoming confused. These inadequacies suggest the need for a standardized system, the protocol with which all practitioners should be familiar.

Additionally, a significant finding was that recommended clinical procedures differed by practice site. Based on the women's reports, colposcopies and biopsies, although available, were prescribed more by private practitioners; while the doctors at the public clinics opted for follow-up Pap tests, ultrasound, and dilatation and curettage. This practice was true for the three women who accessed care in the private domain as, based on their reports, biopsies and, or colposcopies were prescribed. Only in one other instance was a colposcopy recommended to one woman who was at the government clinic. It is possible that the choices made at the government clinics were because of the costs associated with biopsies and colposcopies. These tests are provided free of cost to consumers who access care at the public treatment centres, where the government absorbs the costs. It is also likely that the diagnosis and demographic characteristics of participants influenced the choice of recommended clinical procedures.

### Research Question 3: How does the follow-up process affect the need factors of women with abnormal Pap test results?

Overall, familiarity with the system produced mixed results. The lack of access to health information led to little significance being attached to Pap testing and following-up. In addition, unsatisfactory experiences in the public system were discouraging for most of the women who were forced to access a more costly private system. However, inpatient experiences were by and large seen as positive.

A significant finding is that women were fearful of the Pap test and could not accurately recall the recommended frequency of the screening test. This lack of recall implies that women were not provided with this information or that they did not see this as important and, as a result, could not remember. The outcome was a lack of regular screening or no screening. Educating women on the subject of the purpose of screening and the nature of the test, as well as making available other tests such as visual inspection with acetic acid (VIA) and visual inspection with Lugol iodine (VILI), as was previously discussed, can help to allay fears and encourage testing. Eggleston et al.'s (2007) comprehensive review of the literature also found a lack of knowledge of Pap test purpose and follow-up examination to be associated with non-compliance.

While the majority of women perceived the follow-up process to be frustrating they described their experiences as inpatients in the government general hospital as positive. Only two women, with longer inpatient stays, reported adverse experiences. They viewed the surgical skills of the doctors, in both settings, positively. The women were satisfied with the outcomes of their surgeries and they considered physicians considered as proficient in this regard. This finding is also relevant to quality of care, as health outcomes of clinical care are determinants of quality. In addition a positive evaluation of the system by users impacts their use of the system (Campbell et al., 2000).These positive factors can be considered as strengths of the system and should be publicly highlighted to gain the trust of system users and encourage utilization of the government health services.

Research Question 4: What are the experiences of women regarding the quality of the follow-up process?

Quality of the follow-up process was determined using the measures of availability, affordability and effectiveness of requisite services. These indicators were derived from the guiding frameworks of this study and are used to steer the discussion in this segment.

Pap tests, colposcopy, and biopsy procedures are available, but the long wait times of 2 to 6 weeks for the results hindered follow-up. This finding was consistent among all participants. This waiting period was further exacerbated by the lack of a reminder system and a poorly coordinated referral system. Reminder systems are associated with organized screening programs and entail that women are contacted by health professionals to remind them of follow-up measures. However, additional resources are required for such operations and might not be feasible for resource-poor countries such as Grenada. But, use of other testing measures, such as VIA and VILI, and screen and treat methods can alleviate the wait times. VIA and VILI are appropriate as they are low cost and less invasive than the Pap test and thus would be more acceptable (Miller et al., 2000). The advantage of these tests or the rapid HPV test is that screening and treatment for localized lesions, using cryotherapy, can occur at the same visit. Also, treatment, using cryotherapy, has been recommended as being most appropriate for resource-poor countries (Chumworathayi, Srisupundit, Lumbiganon, & Limpaphayom, 2008). A review of studies in developing countries, conducted by the Alliance for Cervical Cancer, found the above-mentioned, more recent testing and treatment methods to be acceptable by the women in the studies. The use of nurses to perform the procedures was also seen as adequate (Bradley et al., 2006). This finding is important given that Grenada is a developing country where the government bears the greater burden of health care costs for the uninsured. Unnecessary repeat testing and non-compliance are possible results of the lack of a reminder system that can add to the economic burden. Therefore, the government should consider use of newer technologies that can help to lessen the financial as well as cervical cancer burden.

The lack of counselling and non-availability of social support networks were other significant findings of this study. This inadequacy resulted in anxiety in women and many unanswered questions. For example women enquired about their nutrition post-diagnosis and about symptoms they were experiencing after the hysterectomy. In a study conducted in the United Kingdom, Sharp et al.(2013) found that women who had undergone colposcopy and other associated procedures suffered from emotional distress. In addition, Tiersma et al.(2004)also found a lack of social support to be a predictor of distress in women, post colposcopy and who were awaiting biopsy results. These findings are applicable to this study given that the study populations are similar. The findings also, signify a need for interventions to address this gap. Two of the women in this study discussed receiving relevant information from their doctors post diagnosis and prior to undergoing colposcopy. The information shared, using pictures in books, was specific to their diagnosis and the proposed procedures and helped to relieve their anxiety. For this reason, it is possible that sharing of pertinent information using a similar strategy, post-colposcopy and other related procedures can help to alleviate the anguish for women. Cancer diagnosis is predominantly seen as a death sentence among this group and thus a crisis for the women. Hence, providing women with information can help them transition into acceptance and management of the disease. Counselling interventions have been recommended by the WHO as a necessity for each woman with a positive cervical screening result. Also, according to the WHO guidelines, counsellors should be trained to express empathy, provide reassurance and foster a sense of shared responsibility when addressing the health issue (WHO, 2014).

Additionally, the women were unaware of the existence of any supporting networks, so their only support group was their family members. Previous studies have found different forms of support to be strongly linked to screening and follow-up adherence (Allen et al., 2008; Crane, 1996; Klassen & Washington, 2008). While these studies were inclusive of breast and colorectal cancers, the results may be applicable to cervical cancer. Allen et al. (2008); Crane (1996) and Klassen and Washington (2008) in their studies found that participants who received tangible, informational, emotional and, or instrumental support were more likely to adhere to screening recommendations. Likewise, Honda and Kagawa-Singer (2006) confirmed that subjective norms of family and friends can have an impact on follow-up behaviours. However, I found that the women in this study received mainly emotional and instrumental support from family members and only for one participant did subjective norms of family influence screening behaviour. Although family support is encouraged, other support networks provide informational and emotional support that may not always be available from family members.

The non-availability of some tests and treatments were found to affect access to follow-up. Chemotherapy was inconsistently available while radiotherapy was not available locally. In addition, some women reported having to purchase medications while they were inpatients at the government general hospital. Hence, the women felt frustrated as they recognized, their health problem needed urgent attention. These situations illustrate the challenges faced by a health system that is strapped for resources. Thus, strengthening of the health system through public-private partnerships may assist in addressing the problem of resource scarcity. Oluwole and Kraemer (2013) illustrated the successful use of this approach in Africa, a developing region like Grenada, to increase cervical cancer screening rates, vaccinate girls with the HPV vaccine and train health workers in the ‘see and treat’ approach (Oluwole & Kraemer, 2013).

Another crucial finding was that the costs of tests and treatment were seen as acceptable at the government clinics but not at the private clinics. Regardless, women chose to consult with clinicians at private clinics. A possible explanation for this behaviour is that the government system was seen as inefficient. Requesting consumers to pay a small fee for services at government treatment centres and using the acquired resources to improve system efficiency, together with the forging of public-private partnerships as discussed earlier are potential solutions for improving the efficiency of the system.

## Theoretical Implications

Results from this study are corroborated by Andersen's and Campbell's theoretical frameworks, the frameworks on which this study was designed. Andersen, in his behavioural model of health services use, proposed that availability of services only is insufficient to facilitate use of services, but resources, knowledge, social relationships, having a regular source of care and other enabling and need factors are also required.

Grenada's health system is structured, with a clinic located within reach of all members of the population (WHO, 2007a), and screening services are available at each of the clinics. Yet, testing and follow-up behaviours are poor. All women in the study explained that they were directed to do a Pap test, but they either failed to have it done or were inconsistent in their screening behaviours. In a national prevention program in Colombia, Chocontá-Piraquive et al. (2010), also found that the availability alone did not encourage the use of services. These findings are supported by Andersen's framework in which he suggests that availability of services is not enough, but there are need and enabling factors that help to explain the use of health services.

Andersen (1995) postulated that the presence of both contextual and individual enabling factors is essential to facilitate service utilization. An example of one such factor proposed by Andersen and found in this study is that of social relationships. These relationships were shown in this study to influence utilization of the system for screening and follow-up. For example, one participant was encouraged to begin screening by a nurse in her church group while another was influenced by "girl talk" at work. A third person decided to get tested along with her mother and sisters. These examples illustrate the positive impact of social relationships on utilization of cervical screening.

Having a regular health practitioner has also been identified by Andersen’s model as an enabling factor for use of health services. This study also found that the three women who had a doctor with whom they usually consulted for their health care needs were more compliant than those without a usual physician. This finding is consistent with other observational studies conducted by Gonzalez et al. (2012) and Hee Yun Lee, Eunsu Ju, Pa Der Vang, and Lundquist (2010) that found a usual source of care to be an enabling factor for breast and cervical cancer screening adherence. In addition Brennenstuhl, Fuller-Thomson, and Popova (2010), conducted research on colorectal cancer screening among women in Canada’s publicly funded health care system and also found having a family doctor to be an enabling factor for screening. While the focus of these studies were on other types of cancer, the findings are applicable to this study given that health services in Grenada are mainly government run and all participants accessed care at the government hospital.

Campbell et al. (2000), in their systems-based model for assessing care, suggested that interactions between users and providers are critical for successful processes and good quality care. In this study I found that the quality of interaction impacted follow-up behaviours of women, as well as care, received. All participants who had a personal health provider explained that procedures were explained to them in a comprehensible manner, and this contributed to them complying with their physician’s instructions. On the contrary, weak interactions with physicians resulted in non-compliance. For example, in one instance a participant was told to consult with a gynaecologist but failed to do so because she did not understand what that meant. Additionally, two participants contracted infections as inpatients as a result of what they perceived to be weak interactions with their doctors. One was forced to climb up on a ‘high’ bed and was inconsistently provided with help to clean herself post-surgery, while the other developed an infection due to the attending doctor refusing to consult with her previous physician and remove inserted tubes in a timely manner. One woman stated that she “prayed” that she did not have to return there for services. These experiences impacted the participants’ perceptions of the system.

The perceived need for care was also impacted by interpersonal relationships with providers and the referral system. For example, one participant consulted nationally and regionally to garner support for radiotherapy that she understood, from the doctors with whom she had consulted, that she needed to obtain as part of the treatment protocol. However, she was unsuccessful and on her return for a follow-up visit was told that it was never advised. This example highlights the inadequacies in coordination by providers, diagnoses management and communication. These areas have been identified by Campbell et al. (2000) as vital processes of care that can impact the health status and health needs of individuals.

Although all of the enabling and need factors highlighted in these frameworks were not identified in this study, lack of a regular source of care, interpersonal relationships, social relationships, lack of trust, and communication were all substantiated. These factors are all interrelated as illustrated in both Andersen's and Campbell et al.'s frameworks.

## Limitations of Study

Although findings highlight the importance of healthy interpersonal relationships and standardized protocols for referrals and the dissemination of results, this study has some limitations that need to be acknowledged.

One major limitation of this study was the sample size and scope. Recruitment proved to be a major challenge. The inclusion criteria of women with CIN 2 results or higher, restricted recruitment to be done by doctors. For this reason, physicians were requested to identify potential participants and distribute invitation letters to them. Interested participants were asked, via the invitation letter, to call the researcher. Through this method, eight women were recruited, all users of the Grenada health system, who resided in three of the seven parishes. Even though their experiences helped to provide a better understanding of the functioning of the system, a larger and more representative sample, inclusive of women from all of the parishes, insured and uninsured, and with varying educational levels would have made the results more generalizable to Grenada and transferable to populations in the Eastern Caribbean with similar cultures and health systems. To overcome the challenge of recruitment, for any future research physicians will have to be engaged to recruit patients directly. Reproductive health problems, including below the belt cancers, are topics that are not openly discussed or shared within the Caribbean culture but rather are seen as a private matter (Thomas, Saleem, & Abraham, 2005) and are sometimes linked to promiscuity. Therefore, collaboration with doctors to directly recruit participants might be the only short term solution. Furthermore, in the long run, increased public education may help to alleviate myths and remove barriers to recruitment. Additional research using a larger and more representative sample size can compare experiences of women with primary and secondary education to those of tertiary level education, insured versus the uninsured and also examine cultural beliefs.

Additionally, it is possible that the women who volunteered for the study could have had different experiences from those who did not. Some may have had extremely pleasant or unpleasant experiences with the system that might have caused them to over-report, resulting in reporting bias. Women who seek health care outside of Grenada and those who were not seeking care during the recruitment period were also inadvertently excluded from the study, excluding information from a group that may have experienced the system in a different way.

Another limitation of this study is the lack of triangulation that weakens the internal validity. All the information obtained was based on the reports of those with lived experiences of the system, providing rich, thick descriptions of the process as experienced. Additional information was obtained from available reports from the

Ministry of Health and information from the Director of the Oncology Department. Future studies should focus on health care practitioners' experiences.

Finally, researcher bias is inherently a part of this phenomenological study. To overcome this bias, the process of bracketing and the use of theoretical frameworks were strategies applied. Bracketing assisted with the compartmentalization of my personal experiences so as to prevent contamination of information collected from the study participants. In addition, the use of the theoretical frameworks focused the interview, as a structured interview guide was adhered to throughout the interview process. However, my presence may also have affected the responses of the participants.

## Recommendations for Action

As a result of these findings, I recommend a number of strategies that the Grenada Ministry of Health can utilize to strengthen the organization and quality of the cervical cancer screening follow-up system. One significant finding of this study is the lack of trust in the government provided services. This absence of trust developed due to a negative public image, the difficulties experienced manoeuvring the system and the lack of access to treatment services such as radiotherapy. Although this was so, the women also recognized strengths in the system. These identified strengths can be used to augment the system.

One such strength is that of the positive relationship with the nurses with whom most interaction occurred. For this reason, a recommendation is that this relationship be capitalized upon and used to strengthen the system to assist in changing the negative public image. The nurses' roles can be reconfigured to incorporate dissemination of health information as well as provision of counselling to women, providing support in two areas in which the system was shown to be deficient. This sharing of information can be done via the telephone, as cognitive interventions using this medium have been shown to improve follow-up rates. A qualitative meta-analysis conducted by Yabroff, Kerner, and Mandelblatt (2000), found a significant increase in adherence rates for women who received cognitive interventions via the telephone. The benefits of this will be two-fold as women will be provided with relevant health information and coping strategies, which can have a positive impact on follow-up and thus reduce morbidity rates from cervical cancer. However, this might require mandatory continuing education for nurses to ensure that they are equipped with the knowledge and skills to fulfil this role. It will also ensure that effective communication strategies are employed.

The use of community outreach and counselling has been shown to impact follow-up positively. Engelstad et al. (2005), in a randomized controlled trial conducted in the United States among women 18-74 years old with an abnormal Pap test result, found women in the intervention group to be twice as likely to obtain follow-up at 6 months than the control group (61% vs. 32%, $p$=0.001). The intervention comprised of a centralized computerized tracking system and community health advisors who provided counselling tailored to the needs of the participant, follow-up reminders and assistance in scheduling and accessing follow-up. In Grenada, community health nurses can be used to fulfil this role as presently they provide care via neonatal and postnatal home visits.

Furthermore, it is recommended that a reminder system can be instituted to reduce lost to follow-up cases. At present, the Primary Health Care (PHC) system in Grenada is being revitalized. The aim is to focus on preventative care at the community level. As a result, it is a suitable time to provide suggestions for change that will lead to improved health behaviours. In this PHC system, the nurses can contact patients, via telephone or other electronic means, to remind them of their appointment times for Pap tests or other follow-up procedures. The use of this method can enhance Pap smear screening, reduce the numbers of lost to follow-up cases and thus reduce the delays in seeking care.

Another major finding of this study is that women do not have a regular health care provider from whom they seek care. For this reason, I propose that, under the revitalized PHC program, women be required to register with their Parish health clinics, at which they will be assigned a PHC provider. It is anticipated that this will result in a more organized screening system with better management of patients and improved continuity of care.

To address the faulty referral system, an added recommendation is for the implementation of a standardized referral protocol, which all health care practitioners should be required to follow. These set of rules should be available in every Parish health clinic as well as hospital departments. New recruits should be oriented to these procedures. The implementation of such a procedure would facilitate the monitoring process and allow for continuity of care. Additionally, doctors should also be encouraged to attend professional development sessions, refresher courses or continuing medical education to enhance or maintain their medical acumen.

Additionally, due to the fear of Pap testing and low follow-up rates, I suggest the use of other screening methods. Methods such as VIA, VILI and the screen and treat method, have been recommended for use in developing countries (Mandelblatt et al., 2002). According to Cervical Cancer Action (2012), 24 countries have introduced VIA as their national screening programs and 29 as pilot programs. Grenada is listed as one of the countries currently piloting that program and should move to adopt it as soon as possible.

Although the introduction of additional screening tests will require extra resources, continuing education and partnership building do not. The government of Grenada can take advantage of the presence of the St. George’s University and request their assistance in providing continuing education for nurses and doctors and for providing specialty health care. Presently, the oncologist/gynaecologist, who visits twice per year and provides services such as hysterectomies, does so through the University. This collaboration can be extended to other areas of need. Furthermore, the use of other public-private partnerships can be explored as, according to Oluwole and Kraemer (2013), they make resources available and also avoid redundancy and maximize the expertise and efficiency of participating organizations (Oluwole & Kraemer, 2013).

## Recommendations for Further Research

Although this study has identified some important gaps in the screening and follow-up system, there are still some unanswered questions that researchers can explore. For example, to better understand the impact of other factors on the process and quality of the cervical cancer screening follow-up system future researchers can use a quantitative study and include women with a CIN 1 diagnosis or higher. Such a study would investigate the impact of insurance status, socio-economic status, literacy levels, culture and religion on the screening and follow-up process. The reasons for the lack of trust in the government system also need to be explored, so the issue of trust and its relationship to compliance, in this setting, needs further investigation. Additionally, a mixed methods study with doctors and nurses investigating awareness and adherence to screening guidelines, communication skills, and practice styles could also provide a deeper understanding of the causes of the problems in the government system and highlight any existing gaps that might need to be addressed.

## Social Change Implications

Public health’s mission is to ensure that populations are healthy. To ensure that this occurs, governments have a key role to play in the provision of quality health care. However, individuals also have to take responsibility for their health by adopting healthy behaviours and shrewdly accessing the services that are available. Therefore, it is imperative that populations are made aware of the existence of services, the locations and the potential benefits that they can derive. These services should also be appropriate, acceptable and affordable to facilitate use by populations.

At the individual level, one implication of social change includes broadening the knowledge base and skill sets of nurses. This portfolio will enable them to counsel and provide pertinent health information to women. With relevant health information, women can then make more informed decisions about their health and improve their health-seeking behaviours. The benefits of this are two-fold as women are empowered and healthcare workforce efficiency is increased. Ultimately this can result in reduced morbidity and mortality from cervical cancer.

Publicizing the success stories of patients and consumers of government health and highlighting the strengths of the system are other changes that can have a positive impact. For example, advertising the cost of services when compared to that in the private sector, showcasing the physicians and nurses and featuring patients with their success stories. If done, this can assist in changing the negative public image of the health system. As a result, a more preventive approach to health can be emphasized as consumers will be more likely to access services of an acceptable quality and at an affordable cost.

From a broader perspective, the gaps and weaknesses identified in this study can be used to inform planning for increased efficiency and effectiveness of the system. The Ministry of Health can prioritise and target areas for resource allocation. This strategic approach will ultimately contribute to an improved quality of care and a reduced burden on the health system.

At present, the Grenada government is in the process of revitalizing its primary health care program, so this is an opportunity to provide recommendations that could be useful in improving the system and thus improve health outcomes. If Grenada is to achieve the MDGs and improve health outcomes, then changes will need to be made to the way care is provided and accessed. Furthermore, with the presence of SGU on the island more strategic collaborations can help to guide the growth and development of this system to strengthen the prevention and primary care approach

## Conclusion

In this study I have identified common problems that are present in many developing countries and highlighted the importance and the value to patients of a good provider and patient interpersonal relationship. The findings illustrate that it is possible to provide acceptable levels of care with minimal resources when such resources are used efficiently. Additionally, an important finding is that nurses are valuable resources and, therefore, they can play a more impactful role in health systems in developing countries. Furthermore, the results signal that there is a clear need for health information dissemination using strategic communication methods.

Regarding costs, the results of the study illustrated that charges for government services were affordable and that participants were willing to pay more for services in the private sector even though it was available for less in the public sector. This behaviour was mainly due to the lack of trust in the government services further emphasizing the need for an enhanced public image of government services. One way to achieve this is to build public confidence and streamline the system to increase efficiency. The media can be used to publicize the success stories and emphasize the positive characteristics of the system. This strategy may assist in enhancing the public image and encouraging use.

The importance of structure was also underscored in this study. The way in which participants navigated the system was hampered by the lack of a standardized referral and Pap test result dissemination process. Implementation of a standardized protocol in both instances may have resulted in better health outcomes.

Finally, the government health system is used as a last resort for some and the only one for others. What I found in this study was that all of the participants, whether they initiated care in the private sector or not, had their treatments at the government general hospital. Therefore, it is in the interest of everyone, consumers and providers of care, that these services are of better quality and more accessible. A more successful system will require a collaborative effort between the public and private sectors.

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# Appendix A: Letter to Health Care Practitioner

Dear Sir/Madam,

I am a doctoral student, enrolled at Walden University, and currently conducting my dissertation work in Grenada. My research area of focus is the cervical cancer screening system, specifically follow-up and referral, in Grenada. I am interested in finding out about the cervical cancer screening system follow-up process and quality of the cervical cancer screening system in Grenada. To do this I will need to talk with women who have experienced the system.

This will be done through a qualitative research design employing phenomenology. This method requires that participants would have experienced the phenomenon, which in this case would be the cervical cancer follow-up system for abnormal Pap tests of HSIL/CIN2 or above. In-depth interviews will be conducted whereby women will be given the opportunity to share their experiences with the system.

Therefore, I am requesting your help with the recruitment of the study participants. These women must be 18 years or older, speak English, and have received a HSIL/CIN 2 or above Pap test result. The planned timeline for data collection (interviews) is January to March 2012.

The results of the study will be made available to the Ministry of Health, health care practitioners and other stakeholders. It is hoped that the results will be used to identify the strengths and weaknesses of the program and inform any structural changes if it becomes necessary. This will contribute to a reduction in morbidity and mortality rates from cervical cancer.

Thank you for your help. Please sign below to indicate your agreement to participate in recruitment.

Regards,
Christine Richards
PhD Candidate
Walden University

I hereby agree to assist the researcher with recruitment of participants for this study.

Signature: ………………………………………………………………………….…

Print Name: ……………………………………………………………………….

# Appendix B: Participant Recruitment Letter

(Insert Date)

Dear Madam,

I am a doctoral student enrolled at Walden University conducting research in Grenada for my dissertation. I am conducting a study to examine the cervical cancer screening system process and the quality of the services offered from the perspective of those who have experienced the system. The results of the study will be provided to the Ministry of Health in Grenada to assist them in improving the screening system. It is expected that this will be of benefit to all women who use the screening system and will contribute to the reduction of morbidity and mortality rates from cervical cancer.

This letter is an invitation for you to be a part of this study. To be a part of this important study I will need to ask you some questions in person and at a time and place that are convenient to you. Your name will not be linked to any information provided and together with your answers will be kept confidential.

Please consider being a part of this important study. It is hoped that the results will be of benefit to all women who use the cervical cancer screening system in Grenada.

If you would like to be a part of this study, or if you have any questions please call me at [redacted] or email me at christine.richards@waldenu.edu

Regards,

______________________

Christine Richards, MPH
PhD Candidate
Walden University

# Appendix C: Participant Informed Consent

## Introduction and Purpose

My name is Christine Richards andI am a doctoral student at Walden University conducting research in Grenada for my dissertation. The purpose of this research study is to gather information on the cervical cancer screening system in Grenada. I would like to understand the screening system's follow-up process and information about the quality of the screening services offered based on your experiences. This information will be used to inform recommendations to the Ministry of Health for improvements to the existing system. You have been selected to participate because you have experienced the system and I would like you to share those experiences with me. Please follow along as I read this consent letter and feel free to ask any questions before you make a decision about being a part of this study. You are free to decide whether or not you want to participate.

## Study Procedures

If you agree to be a part of this study, you will be asked to complete a short demographic questionnaire and participate in an interview. This interview will be conducted in person at a time and place of your choice. The interview will last for approximately 60-90 minutes. It will be tape-recorded and I will also take notes during the interview. This is to ensure that the information collected is accurate. You can refuse to answer any question and can stop the interview at any time. There are no penalties for refusing to participate or stopping the interview at any time. After the interview is completed, I may need to call you to verify the accuracy of the information or to clarify any answers that were unclear. The entire research process should be completed within 2-3 months.

## Risks

Being involved in this study will not harm you physically, however, talking about your experiences may bring back unpleasant memories. If this happens and you need help your health care practitioner will provide any help you might need. I will ask you some personal questions and you can choose whether you want to answer them or not.

## Costs

There are no costs attached to you being a part of this study.

## Benefits

By being involved in this study you will not benefit directly, but it is expected that the information you provide will contribute to improvement of the cervical cancer screening system from which all users will benefit. Additionally, your participation will demonstrate support for the need for community input in understanding and addressing health issues affecting women. There is no monetary payment for participating in this study.

## Confidentiality

All information provided during this interview will be held strictly private. Your name will not be on the tape recording nor in the transcription or on anything else that could link you to reports of the study. The tape recording and notes will be kept under lock and key in a cabinet in my office. Your name and telephone number will be kept locked in a separate cabinet. Only my doctoral committee members and I will be allowed to listen to the audio recording.

Your participation in this study is voluntary. If you have any questions about the study before or while participating please feel free to ask. On completion of the research I will be happy to share the findings with you. You can contact me via telephone at [redacted] or by email at Christine.richards@waldenu.eduwith any questions you may have.

If you want to talk privately about your rights as a participant, you may contact the Director of Research at Walden University, [redacted], at [redacted]; or the St. George's University IRB administrator, [redacted], at [redacted]

Do you understand the information that has been read to you? Do you have any questions? Please sign this letter indicating that you have consented to be a part of this study. A copy of this letter will be given to you for your records.

Signature of Participant: ________________________________ Date: ___________

Signature of Researcher: ________________________________ Date: ___________

# Appendix D: Demographic Questionnaire

Thank you for agreeing to answer the questions on this questionnaire. The answers to these questions will be used to assist in data analysis and interpretation. Your answers will be strictly confidential. Your name will not be written on the questionnaire and no one else except me will have access to this information. Please read the question carefully and mark an X in the box next to the appropriate answer.

1. What is your age? __________

2. What is your marital status?

☐Single

☐Married

☐ Common-law relationship

☐ Divorced

☐ Widowed

3. What is your highest level of educational attainment?
   ☐ Primary school
   ☐ Secondary or high school
   ☐ Professional college (e.g. technical, teacher training, secretarial)
   ☐ University
   ☐ Never attended school

4. Are you employed? ☐ yes ☐ no

5. Do you have health insurance? ☐ yes ☐ no

6. What is your religion? ___________________

7. How many children do you have? ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ more than 3

8. In which Parish do you live? ☐ St. Georges ☐ St. Davids☐ St. Marks
   ☐St. Patrick ☐ St. Andrews ☐ St. Johns ☐Carriacou& Petite Martinique

**THANK YOU FOR YOUR TIME AND PARTICIPATION!!**

# Appendix E: Interview Guide

## 1. Experiences with cervical cancer screening and follow-up services

- Where do you usually go for women's health services and care (reproductive health services)?
    - Has this always been so? Where did you go previously?
- Describe what took place during those visits?
    - Did examinations include a pelvic exam? Pap test?
    - What were you told about the benefits of such an examination?
    - Did your provider (nurse/doctor) tell you the reason for such an exam?
        - Probe – what did they say
    - How often were you told the exam should be done?
    - How did you feel about the examination?
    - When was the first time you had such an exam?
        - How did you feel about it?
- How were you told you would find out about the results of this examination?
    - How long did the doctor say it would take to get the results back?
    - In reality, how long did you have to wait to receive the results?
    - How did you find out about the results of the examination?
    - How were you notified about the need to return to the health center/hospital/clinic for follow-up? (Were they read, told or written?)
    - Did they explain the importance of the results?

    - Did they give indications according to the results?
- Describe what happened during your follow-up visit.
    - What information were you given about the result?
    - Were any additional examinations conducted?
        - What was the outcome?
    - What were you told about the anticipated next steps?
        - What treatment options were discussed?

2. **Perception of Services**

- What do you think about the services at the facility where you seek reproductive health services?
    - What do you think about the quality of the medical care
    - Quality of the counseling?
    - Friendliness of the staff?
    - Average waiting time?
    - Cost of services?
    - Did the providers carefully explain the procedures to you?
    - Were you able to ask questions of your providers?
    - Were you satisfied with the answers you were given?
- Where would you prefer to go for cervical cancer screening services?
    - What would you suggest or recommend be done to improve women’s health services at this clinic?

3. **Possible barriers and facilitating factors to screening (follow-up) services**

- Are you likely to return to the clinic for another Pap test?
    - For other services? (follow-up)?
    - What might make it difficult for you to do so?
    - What could help you change your opinion?
    - What could make it easier for you to do so?
    - Did you have to pay for follow-up services? (colposcopy etc.)
    - Were you able to pay that amount?

4. **Health Seeking Behavior and illness experience?**

- Describe how you felt when you were told about your results?
    - Was there anyone with whom you shared your results?
    - What did they say to you?
- **Are there any questions or comments you would like to add?**

**THANK YOUFOR SHARING YOUR TIME AND YOUR THOUGHTS ON THIS IMPORTANT ISSUE!**

# Appendix F: Permissions

**To :**

Mark,

Thanks for your prompt response and for permitting me to access and use the Guide.

Christine Richards

--------------------------------------

Original E-mail

From: Mark Barone<MBarone@engenderhealth.org>

Date: 02/11/2011 04:07 PM

To: 164ichards164.richards@waldenu.edu

Subject: RE: Request for interview guide

Hi Christine…

Ilana forwarded your email to me and asked me to send you the interview guide for clients from the Bolivia assessment. I am afraid I only have that guide in Spanish. In case that is a problem for you, I am also attaching a client interview guide that we used in a similar assessment we conducted in India, which is in English, and may help.

I hope you find them useful. Good luck with your research.

Date: Wed, 9 Feb 2011 14:45:22 -0500

From: 165ichards165.richards@waldenu.edu

To: ilanadzuba@hotmail.com

Subject: Re: Request for interview guide

Ilana,

Thanks for responding. Can you direct me to the next best person or place to contact?

Thank you.

Christine Richards

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Original E-mail

From: IlanaDzuba<ilanadzuba@hotmail.com>

Date: 02/09/2011 11:48 AM

To: christine.richards@waldenu.edu

Subject: RE: Request for interview guide

Dear Christine,

Your dissertation project sounds very interesting. I am no longer affiliated with EngenderHealth (the organization that conducted the cervical cancer prevention assessment in Bolivia) and I do not have ready access to the tool that you request. Sorry I cannot be of help.

Best of luck with your research,

IlanaDzuba

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Date: Sat, 5 Feb 2011 15:58:00 -0500

From: 166ichards166.richards@waldenu.edu

To: ilanadzuba@gmail.com

Subject: Request for interview guide

Dear Ms. Dzuba,

I am a public health PhD student specializing in community health education and promotion. For my dissertation my focus area is cervical cancer in Grenada, specifically the follow up system. I am using phenomenology to explore the quality of the follow-up system for cervical cancer screening here in Grenada. To this end I am requesting permission to use the interview guide that was developed for ‵ A participatory assessment to identify strategies for improved cervical cancer prevention and treatment in Bolivia’ I am interested in the questions used in interviews with the clients at the service delivery sites.

Please let me know whether this is available for purchase or the procedure involved in accessing the interview guide.

Thank you for your help.

Christine Richards

PhD Student

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# Appendix G: Interview Transcript

## Experiences with cervical cancer screening and follow-up services

**Researcher**: Where do you usually go for women's health services and care (reproductive health services)?

**Participant:** Usually I would go to a gynecologist. In recent times, Dr. Z.

**Researcher**: Has this always been so? Where did you go previously?

**Participant**: No when I having kids in those days it was Dr. N. (private doctors)

**Researcher:** Describe what took place during those visits?

**Participant:** Well, I would tell them what my problem is and if it's for a routine check up they would do a pap smear or whatever the problem is, pregnancy or whatever.

**Researcher:** Did examinations include a pelvic exam? Pap test?

**Participant**: Over the years, yes

**Researcher**: What were you told about the benefits of such an examination?

**Participant**: That if there was any abnormalities, they would discover it early and be able to deal with it. Well cancer and I can't specifically remember them using the word cancer but I implied that most of these checks are done as a preventative thing.

**Researcher**: Did your provider (nurse/doctor) tell you the reason for such an exam?

**Researcher**: Probe – what did they say

**Researcher:** How often were you told the exam should be done?

**Participant**: Yearly

**Researcher**: How did you feel about the examination?

**Participant:** Alright, I mean to me it's just something that needed to be done and you just do it. It's like childbirth. The child have to pass out and it gotta come out and that was it. I didn't have a choice in the matter in other words

**Researcher**: When was the first time you had such an exam?

**Participant:** Must have been after I had kids but I had kids early, I got married at nineteen and my first child was 20, so it had be after say twenty one twenty-two kinda thing.

**Researcher**: How did you feel about it?

**Participant**: Alright. I mean it was discomfort just another one of those things I guess women have to go through, you just do it.

**Researcher**: How were you told you would find out about the results of this examination? Participant: They would send it to get it tested and let me know when the results are in.

**Researcher**: Would they call you?

**Participant**: Yes most times because I think in those days, they send it overseas and if it was done here so most times the doctors' offices would call you and tell you the results are in or something. Most times you have to go in. doctors feel they have to charge you to see you and then charge you to read the results, which I think is quite unfortunate. It's one of the hiccups in our system I suppose.

**Researcher**: How long did the doctor say it would take to get the results back?

**Participant**: Usually 4-6 weeks

**Researcher**: In reality, how long did you have to wait to receive the results?

**Participant**: I mean you not talking bout this last one. Generally, probably about that 4-6 weeks. It took about 6 weeks but that was done here. Because the lab here where I was doing it but as the woman it was in family planning. The woman in family planning pointed out it was the nurse. The lab here does it for the whole island, so they always packed with work, so she tell me don't expect the results between 4-6 weeks and I got it back in 6 weeks. Even my uterus and so they took to test did it, apparently its being done here now too.

**Researcher:** Do private practitioners here send it to this lab?

**Participant**: Well only thing I can tell you is what T told me they sent hers to Trinidad but I don't know if that's a preference from doctors or if. But family planning here who did mine sent it locally. I guess it because it a government institution, I mean they charge to do it, not as much as other doctors but they charge 50 dollars.

**Researcher**: How did you find out about the results of the examination?

**Participant**: Well I was having a conversation with my aunt and she said to me. She was going to family planning to get her pap smear done, that's my mother's sister and I said to her lord I haven't had one done in about 10 years. She said well come with me nuh I going to family planning. Its only 50 dollars and the place is clean and you know nice and so then I said ok then well let me know when you thing, when we could go and she got my mother and my other aunts and all 4 of us went and got it done and truth in fact I was quite impressed and they were very efficient. The nurse was very professional the place was clean you know she didn't make you feel self conscious or anything you know it was didn't take very long either but I went very early. I went at 8 o'clock and she told me we will get back to you within 4 to 6 weeks. We'll call you when the results are in and it did take about 6 weeks.

**Researcher**: How were you notified about the need to return to the health center/hospital/clinic for follow-up? (Were they read, told or written?)

**Participant**: They called me and I asked, how does it look, she say well, I say it looking all right? she said well not really you need to come and take it to your doctor so. I said ok and I sent and picked it up right away and my daughter in law is a doctor at the hospital, so called her and asked her if she could come and have a look at it and she read it and she said they had ticked off abnormal cells, but they did not tick off any growths or other thing. They just ticked abnormal cells and she said to me listen a lot of women would show these abnormal cells and sometimes when they do the other pap smear it disappears other times it shows it increased because they recommended a repeat pap smear in six months which would have made it September because it was done in march and initially I said ok; but then talking to my sister she said why wait six months why don't you just go find out go see a doctor, and find out so my daughter in law told me about this Cuban gynecologist at the hospital who she has seen do surgery and she thought he was quite good, Dr Y was his name so she arranged for me to go to him one of his clinic days and I saw him and he was quite amused that I was oh take it all out I don't want to wait 6 months because at six months if it comes out abnormal all they gone do is tell me I'm sorry it has spread or its full-blown cancer or something and in my family I am not willing to take that chance you know, my grandmother had cancer of the uterus, she was around my age when I remember as a child going to the hospital and visit her when Dr. N did the tests and they had to take everything out and so I'm just not willing and I think in the back of my mind I always felt that if it's one thing that's gonna get me it cancer of the uterus I don't know why. I don't know if in my child's mind and my grandmother but I was about ten or twelve, and I was old enough to see what they did to her, to go see her and knew that they cut her right open, but in my mind growing up I always know I think the one thing that gon get me is cancer of the uterus. I don't know why. I had three normal births, I had pregnancy no problem with pregnancy no bleeding, no lying down in bed. I mean I was like a damn horse I got pregnant nine months later push push the child was out and go but I don't know why it just played on my mind that I should keep and eye on my uterus and so I told Dr Y that I was not interested I had started menopause at 50. So this thing has been no use to me for the last 5 yrs. and I did not want to wait 6 months so he kind of smiled and said ok let's do a D&C you know so he made arrangements for me to go in the following week which was his day a Wednesday and try to do a D&C. What they gave me to try and put me to sleep didn't work so I was awake so he was talking and he tried to get in and I could hear the urgency in his voice when he started rattling on off to his assistant in Spanish and she came to me and said how old did you say you were again and I said 55 and she went and she chatted with him again and she came back and said and he speaks English so I knew instinctively

I knew he didn't like what he saw so I said to her its cancer isn't it and she said no no don't go there yet. What we will do, she said your uterus is very closed and very hard and for your age it should not be like that. she says Dr. Y said he not worrying to try and do anything we will book you for surgery and take out everything as you asked he said he will take out the cervix the uterus and the ovaries right because face it they didn't go into the uterus to check for cancer it the cervix they swiped so if I'm doing that just take everything. so two weeks later in think I went in and they did it and he said when I went in and saw him I asked how it looked and he said he couldn't see anything with his naked eyes but it had gone to the lab, which to me means they were so many negative things about it that I still feel there were some sort of cancer cells growing I'm just hoping that they got it and they took it out, which means every year I just have to do some sort of checks to make sure nothing pops up anywhere else, but I'd be very surprised if it came back clean because speaking to her doctors like my brother in law who's been a gynecologist for 15 years that what he did was the right thing it just was not good signs. So I was kinda glad I was proactive. Even it comes out clean I will say thank you lord, I still wont regret taking the action because the risks is not worth you know especially with my family. I'm sure T told you my aunts we have an aunt right now who has cancer on the lung right. So we have an uncle in Canada who died of cancer it just seems, but in our family thank god. If I have to say thank god about cancer, it didn't seem to affect anybody young. The older ages like my aunt she the youngest it happened to and she's 67. We have no twenty year oh yes my cousin L she had throat cancer at twelve and she was the second case that the institute in Canada had seen of a child having throat cancer at that age and the successfully removed it and she is now a woman in her twenties and doing well but again it seems to be all thyroid related things. My grandmother was the only one with the uterus and presumably I followed her.

**Researcher**: Did they explain the importance of the results?

**Participant**: no they just handed me the they had it ticked off with cells LC something present they ticked it off they didn't tick off anything else oh another thing too is when I went to Dr. Y he asked me about having discharges and so and I said well not really but every now and so I seem to have this light brown and he said to me, well once you go through menopause you shouldn't have any discharge this is something I find doctors don't bring to people they don't explain to you as when you're young you have these discharges as a young woman and as you get older and I just thought in the back of my mind, I just think you know because my period and I still have the ovaries a little bit of abnormal blood comes because it wasn't something to wear a panty liner but it was something there and it will happen occasionally and but not something to have me all alarmed about. I did have started having a little smell and having cancer of the uterus they tell you to look out for things it kinda had me a little concerned like I wonder if something is going on there, but I don't know but every instinct in me was to get it out all now so lets see if my instinct was full of crap or woman intuition. I went straight to Dr. Y.

**Researcher**: Did he tell you what else you had to do?

**Participant**: No he said he wants to see me on the 24th presumably with my results

with everybody who has anything to do with the government labs kinda laugh and say I'd be surprised if it would be ready so soon because my surgery was the 27th of June. They don't think by the 24th of July which is when I'm supposed to see him that it would be ready because the lab is swamped, you know but I was suggested to call them a week before I go and find out if its ready, so if it is I'm supposed to take it to him on the 24th. I don't know if at that time he will tell me the next step based on that but I was told by other doctors that usually if it's pretty bad the naked eye they can tell by the condition of the uterus and the ovaries what will happen. So I felt kind of could that he said he couldn't see anything. Hopefully whatever it, it was in time.

**Researcher**: Why did you go to family planning?

**Participant**: Because it was cheaper, financially it was cheaper and after talking to my aunt and she told me it's a nice clean place and they are very professional. It's the same nurses that work in doctor's office. It's the same ones that's doing it and I must agree with her that once I was there I would recommend that people go to family planning for that because I didn't do any other test I understand they do other things, but, oh I also did an ultrasound before I did my surgery at C H, something imaging. But I've done ultrasounds with her before and she also works in the hospital she's also one of the ultra sound ladies at the hospital.

**Researcher**: Did they give indications according to the results/ tell you what the results were?

**Participant:** yes because she’s a school friend, she went to school with me,

she except for little cysts she saw on my uterus she saw a black shadow but she couldn’t tell me that black shadow was him trying to get into the uterus with the D&C or if in fact that’s what the problem is, but there was definitely it was definite to me a black swatch she showed it to me .Just a black line covering the uterus, she tell me I don’t know if that’s the problem why he couldn’t get in but from him trying to get in there’s some damage because I did have some bleeding a little spotting, maybe a day or so. So the ultrasound was done before the surgery.

**Researcher:** Describe what happened during your follow-up visit. What information were you given about the result? Were any additional examinations conducted? What was the outcome? What were you told about the anticipated next steps? What treatment options were discussed? (These questions were previously answered by the participant)

**Perception of Services**

**Researcher**: What do you think about the services at the facility where you seek reproductive health services?

**Participant:** I think I was well treated. Its free I am very appreciative. I was in an open ward with ladies but the place was clean. When I broke my leg I was on another ward and I think that ward was better run than this one but who the hell am I to complain you know it was free. The nurses were attained to you well. They made sure the IV’s was going you know. But everything was free. The only thing I paid for was my ultrasound and the Pap, not the surgery, sorry I had to pay for the theater which was 270 dollars which to me is like free but in the economic times to be honest if I could've financially paid for it I would have because I felt almost guilty in using a system, because I have a right as a Grenadian. I paid my taxes for all these years why I am I feeling bad like all these women here with their computers and their laptops and they plug in everything and her I am trying not to abuse any of their systems but I'm a Grenadian and I have a right to use it like everybody else. I have a bank account, but I was very appreciative of it, I could've gotten that service and the level of service, you know the doctors like Dr. Y came every day, asked you how you were feeling and they checked the cuts asked the nurse about your charts. So it's not like they just did it and threw you on a bed and left you there kinda thing so I really have nothing to complain about.

**Researcher:** What do you think about the quality of the medical care? Quality of the counseling?

**Participant**: No, I mean they didn't even ask you how you feeling, psychologically how you feeling. I've had friends ask me how I feel inside. Oh you feel empty, I don't feel anything different whatsoever and I think my part is because I had already started menopause and I was 5 years into it that my body didn't miss the estrogen like a young woman would. Which I'm very grateful for.

**Researcher:** Friendliness of the staff? Average waiting time?

**Participant**: it was like two weeks he only has about one or two days a week that he does surgery, and when the nurse his assistant was trying to give me august or something; I said no I need to do it now and she went to chat with him in his other room and she came back and said ok what about the 27th which was about in two weeks, I said yeh. So I don’t know if he insisted or told her it was urgent enough to stick me in I don’t know. All I know she gave me that would’ve been like 2 weeks.

**Researcher**: Cost of services?

**Participant**: 270 dollars which is fees for major surgery; I think minor was 90, Intermediate, I don’t know what kind of surgery that is, that is 120 or something like that and major was 270 which you paid at the government place at the hospital before you went in. but all the blood work and everything else is done for free, and x-rays before surgery and blood work after the surgery and they had you on antibiotics and painkillers after surgery. Everything was free they didn’t ask for a cent. You got your meals if you wished to eat there. That was free but they were very specific about what they gave you after surgery. They put you on very soft things, according to my mother a lot of the old wives tales, there a lot of truth to it.

**Researcher**: Did the providers carefully explain the procedures to you?

**Participant**: no, when he told me ok we gonna go to surgery I said ok you gonna take everything out, the ovaries he tell me yes everything and that was it. I don’t know if because I went in there so determined that I didn’t get emotional when I told him I wanted to take it out like some other women will he would’ve spent more time. I just went in and said listen I have a family of cancer, take it out, I don’t want it. He said what happen if you want another child? I said I will sell it to you, so I think maybe my frame of mind made him think he didn’t have to discuss anything with me

**Researcher:** Were you able to ask questions of your providers?

**Participant:** yes

**Researcher**: Were you satisfied with the answers you were given?

**Participant**: Yeh, because I was very hastened to do the surgery but he said lets take one step at a time, let's do a D&C, we'll do a ultrasound and then see where we go from there.

**Researcher**: Where would you prefer to go for cervical cancer screening services?

**Participant**: Well if I have to use family planning, I know they use other things like I've never had a mammogram. If I have to go do something like that I think I will use them again. I didn't get anything negative from them, even the girl that asked me the simple questions, she took you into a separate room so the other people waiting couldn't hear the kind of questions she was asking. They even did a HIV test at the hospital, which again was free because they don't do it unless surgery of course they want to know. You have to get two blood donors, which I think is a great way of having the blood bank have people you know having blood is by having surgery every time you have to get two or three people to donate blood on your behalf. I didn't need any of the blood so they have to keep, which I thought is a really good idea. I will go back to the hospital and I would recommend him (Dr. Y) to anybody else, I mean him I feel sorry for him and for the patients because its free there's so many people and you have to spend so long waiting. That's the only thing if I had to criticize when I went back after surgery. I got out of the hospital on the Saturday and they wanted me to see him on the Tuesday, which was one of the interns, and I said to take out stitches. So I said on Tuesday its six days you don’t take out stitches on six days, well they said to me you have to go to the clinic, so I said ok and I got to the clinic quarter past seven so I took a number, which makes no sense because they call u whenever they want but anyway I took a number I was number eleven and by 10:30 I was feeling so bad because its only six days after surgery I was exhausted, I went to the nurse and said well have you forgotten about me and I know there were people but my thing is that you see an older person you can see she’s had surgery; While you have all the people line up to do test, slip you in. all it is, is to check my bandage I didn’t have to see the doctor all I had to do was see the assistant. To check my bandage she agreed with me why would they send you to get you stitches after six days. She looked at it, and this now was after eleven so this now they could use commonsense in handling cases like that you see someone who has just had surgery. These pregnant ladies have to wait their turn to see the doctor well slip the other person in to see the doctor his assistant you know. I mean with me she took 10 seconds she looked at the cut, redressed it and said she felt so sorry for me she said next time don’t come here, go to the ward where you had your thing and I’ll remove the stitches down there for you and that’s what I did, I still had to wait I mean but not 5 hours. That’s the only thing I had to criticize and I said you know it’s free and everybody here had to wait like you and I looking at them and thinking anybody with a little common sense could organize the patients better. It have older women there in their 80’s and they sitting there exhausted and you have these young ones and you know they have to wait well slip them in between and get these older ones out of here. But other than that I thought we had great service at the hospital. I think they do great for what they have and I was lying there thinking I wish I had a million dollars I would donate to buy supplies and stuff for these nurses to use. They have to hide gloves if they have to use them because its shortage and I thinking you know they offer and they try their best with what they have but they really don't have much. I wish I could have contacts to donate stuff to them because they really do try, those nurses I mean they check, they learn your name by the second day they come and ask how you doing today, how was your night you know, even the young ones in training. I think that comes from being a small island you know they are very pleasant and become very chatty and once they discover you are Grenadian like them, you know. So I spent three days Wednesday, Thursday, Friday, Saturday they let me out. Three days, two days before too they made me check in on the Monday so they can do the x-ray of my chest and the blood work, that was the Monday. And then the Tuesday, they did the blood work but I think they keep you in there because they want to make sure you don't eat you know. So I spent the whole week (hospital). I was there Monday and left on Saturday.

**Researcher**: What would you suggest or recommend be done to improve women's health services at this clinic?

**Possible barriers and facilitating factors to screening (follow-up) services**

**Researcher**: Are you likely to return to the clinic for another Pap test? For other services? (follow-up)?

**Participant**: Family Planning, yes

**Researcher**: What might make it difficult for you to do so? What could help you change your opinion? What could make it easier for you to do so?

**Researcher**: Did you have to pay for follow-up services?

**Participant**: (Colposcopy etc.) no. this clinic (outpatient) is free. The outpatient clinic it's also held at the hospital

**Researcher**: How much was the pap smear?

**Participant**: 50 dollars

**Researcher**: Private?

**Participant**: I think it's a hundred something and then you have to pay them for the visit and also its not included as a visit so you have to pay 120 for the Pap smear and then see them so it can work out to be an expensive joke in these times. I didn't feel ill to say I needed to see a gynecologist. I needed a pap smear done because the best of my knowledge I needed one before the hurricane and after the hurricane is 8 yrs that's why I can say it's probably 10 years

**Researcher**: Is there a reason why you hadn't had one (Pap test) in so long?

**Participant**: No but it started bothering me you know and every time somebody bring up it I say I need to get one done. I really need to get one done it just bothered me as I said I just always felt.

**Researcher:** Were you able to pay that amount?

**Participant**: Yes

**Health Seeking Behavior and illness experience?**

**Researcher**: Describe how you felt when you were told about your results? How did you feel about the results?

**Participant:** A little shocked because you never think it could actually happen to you, you feel what, I'm strong and nothing happens to me you look at my size and My sister always called me because every time I did blood work I had no cholesterol, I had no diabetes, no pressure. I mean my pressure went up the other day and I mean I don't know if it was just post surgery thing but I have nothing wrong with me and I'm overweight so this coming to me it was like alright and I'm thinking and it came with I just knew something was wrong. I just knew and it was like ok I'm not gonna sit back like my aunt and blahzay about this thing I don't use it anymore and as far as I'm concerned if I have to go to a doctor I'm going to tell him just take it out. I don't need it my son is 30 yrs old, he is my last child. I've been through menopause for five yrs I don't need all this crap in me and I'm not willing to say oh well its part of me and emotional about, take it away.

**Researcher**: Was there anyone with whom you shared your results?

**Participant**: Oh, my whole family the whole. My mother put me in the grave immediately. Oh my god my daughter have cancer and no no-no, but my mother is the voice of doom, we call her.

**Researcher**: Your husband?

**Participant**: Yeh he was concerned I mean everybody was a little bit, you know when you grow up not having anything really wrong with you; Healthy for most of your life that when it does happen you kinda think it's not supposed to happen I'm not supposed to be sick. I mean when I broke my leg I'm sitting there with both bones shattered and I'm sitting there like I'm not supposed to be sitting here these things don't happen to me. T came by and I told her that and she said you think you should wait 6 months and I told her your kinda right you know even if these things, the chances of it disappearing is real but the chances of it developing is very real too and how would you feel if in September you go back and they say oh it has developed and it has spread you know. I don't want to regret anything I'm not 21 to say oh I want to have kids so I thought well what. So it was a message from god you know go and get the Pap smear done and get everything.

**Researcher**: What did they say to you?

**Participant:** he was telling me just do what I have to do to get better and get it over with. My husband is terrified of hospitals and doctors and he keeps telling everybody oh my wife is a strong woman but in my mind it's just its something I needed to do. Nobody would do it for me. There's certain thing you have to do and that's one of the things I said you know lets bite the bullet and get this over with.

**Researcher**: Are there any questions or comments you would like to add?

**Participant**: no not really. Thank god we have that service available for women for people because in these hard times where things are difficult, if we didn't have this service, this free health care, I think a lot of us would be down because I would not have gone. I would have not afforded that surgery. When I spoke to a friend of mine who used to be a nurse in England and she said, she is from Mt. M, and she said L had a friend in Mt. M who had the same thing the cells came back abnormal and she said the same thing you said. She went and got it out to Dr. Z and he did the surgery in a private hospital. She said girl it cost her 15,000 dollars; $5,000 for him, how much thousand for the hospital, two hundred and fifty dollars a day for the hospital. I say, well you know I don't have 15,000 dollars so you know I will have to go through the system. So if we didn't have a system to go through I don't know what would happen to people like myself or worst off because everybody thinks they are bad until they meet somebody worst off than themselves. So you look at all these women in the hospital and all these older people and if it wasn't for that. Now I agree we should pay something for beds. I think it's terrible that you have people coming in there that they have five cell phones that they plugging into government electricity and all kinds of luxuries and you're in a free bed. Why is that? You know even if its, they have people who can't do it and I understand that but they have people who can, you know pay 5 dollars a day for a bed, you know just little things. Little bits here and there can really help the free system by paying, I mean 270 dollars is nothing for surgery, for that kind of surgery. I know because when I spoke to my sister in law in the states she says honey just for anesthesiologist to put you under over here is 20,000 dollars. You can't enter a US hospital without having insurance. She said I can't even offer you to come here because you can't afford it . I was very grateful for the fact that we had that system and Dr. Y is apparently he's a very good surgeon my daughter-in-law actually saw him remove somebody’s uterus through their privates. He didn’t cut her at all and I met another lady who she told me Dr. L did it for her but hers was a big fibroid. Her fibroid was almost out of her. So when I saw her I said well how was your surgery she said Dr. L did it. I said well how did she cut you? She said no she went from inside and took my uterus and the fibroid like a delivery. She was out of the hospital the next day. Unfortunately my wound was retroverted and still very high so when I asked Dr. Y about that a vaginal removal he said to me it was too high and my daughter in law said its better they cut you because when they open you they can see inside, have a visual. So if anything else is going on inside they can tell you. But to me that was amazing that he could’ve have done it vaginally because the recovery time is next to nothing you know you have not cuts or nothing like that. My surgery was an hr and he said to me if it wasn’t for all the fat he would’ve done it in under an hr which is amazing because it’s less time to keep you under for what I thought for what they offer, that was really amazing. They didn’t treat you like you were poor and that they were giving you a handout they treated you like a patient who needed this and look after you regardless of which I thought was really great. The system need a lot of work we need a lot of supplies. Which is so sad. I wish I could find some organization that I could say send things all the gloves. I mean it have people there who take antibiotics and zantac because of their stomach and the hospital l have to send them out to buy it or send their family out because the hospital don’t have to give them. It’s true everything is free but it’s so sad that they don’t have basic things that they lack. I had surgery twelve days ago you think I could run a marathon. I’m just on some antibiotics because when they took my last blood work, my white blood cells was a little elevated. So I think it’s a urine infection from putting the catheter and I think that’s what it is. I’ve been on it for four days now it’s made a difference other than that I feel great.

THANK YOUFOR SHARING YOUR TIME AND YOUR THOUGHTS ON THIS IMPORTANT ISSUE!

# Appendix H: Code Book

| | **Code name** | **Definition** |
|---|---|---|
| 1 | Provider communication content | Health Information shared by provider with patient, |
| 2 | Source of health information | Resource from which patient obtains reproductive health information |
| 3 | Communication channel | Pathway through which test results are shared with patient |
| 4 | Practitioner preference | Practitioner (type)favored by patient |
| 5 | prevention | Screening, health behavior |
| 6 | Exam (Pap test/pelvic exam) frequency | Practitioner recommendation for regularity of pap test |
| 7 | Exam attitude | Feelings about the Pap test |
| 8 | Initial exam age | Age of 1st Pap test |
| 9 | Exam initiation | Reason for getting pap test at that time of diagnosis |
| 10 | Exam cost | Price of pap test |
| 11 | Results notification (Pap test) | Timeline for receipt of results |
| 12 | Lab location | Where Pap tests are sent for analysis |
| 13 | System organization | Procedure when using services |
| 14 | Attitude towards health services use | Feelings about free use of govt. health services |
| 15 | Health care attitude | Feelings about health of self |
| 16 | Illness beliefs/perceptions | Beliefs about health/illness |
| 17 | Compliance behavior | Conformity of participants to practitioners instructions |
| 18 | Regular source of care | Clinic or practitioner usually accessed |
| 19 | Reproductive health knowledge | Participant knowledge of reproductive system |
| 20 | Follow-up frequency | Practitioner Recommendations re frequency of follow-up |
| 21 | Follow-up procedures | Actions taken by practitioners at follow-up |
| 22 | Health information sharing | Methods used by practitioner to share health information. |
| 23 | Health services cost | Monies paid for services |
| 24 | Timeliness of services | Duration of time taken for procedures |
| 25 | Clinical diagnosis | Physicians findings |
| 26 | Attitude to diagnosis | Feelings of participant after learning of diagnosis |
| 27 | Spirituality | Religious beliefs |
| 28 | Fatalistic attitude | Cancer as a death sentence |
| 29 | Health services | Patient acceptability/rejection/comfort with services |

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|---|---|---|
| | satisfaction | |
| 30 | Health services availability | In-country presence of physician recommended treatment/preventive services (chemo etc.) |
| 31 | Support groups | Disease-specific groups available to patients |
| 32 | Provider communication competence | Patient's comprehension of info shared |
| 33 | Practice domain | Private or public |
| 34 | Site of 1st pap test | Where 1st pap test was done |
| 35 | Pap test description | Participant's description of pap test procedure |
| 36 | Surgery site | Where surgery done |
| 37. | Health services improvement | Participant recommendation for service improvement |
| 38 | Health services affordability | Participant's ability to pay for services |
| 39. | Pap test results | Results of pap test/normal or abnormal |
| 40. | Clinical care | Clinical procedures done by practitioner to participant |
| 41. | Pelvic exam (+ve/-ve) | Pelvic exam performed by practitioner yes/no |
| 42. | Inpatient medication purchase | Patient purchases medication for use in hospital |
| 43. | Practitioner approachability | Patient comfort with communicating with dr. |
| 44. | Appointment made by dr. | Dr. makes appointment for patient to see physician referred to. |
| 45. | No referral letter | Patient referred to specialist by provider without a referral letter |
| 46. | Relative collect Pap test results | Relative given pap test result to take to patient |
| 47. | Patient takes letter to referral site | Patient given letter by practitioner to take to referral site |
| 48. | Patient collects lab results | Patient goes to the lab to collect the lab results (Pap test) |
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# Appendix I: Credentials of Independent Coder

Kamilah Thomas-Purcell, PhD, MPH, CHES

2001 - Bachelor of Health Science, University of Florida

2003 - Master of Public Health, University of North Carolina at Chapel Hill

2010 - Doctor of Philosophy, University of South Florida