Lost to Follow-up:

A Study Exploring Barriers to Care at UNC Women’s Hospital Dysplasia Clinic

by

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ABSTRACT
Management of Cervical Intraepithelial Neoplasia (CIN) includes a long time course of surveillance in which many women are “lost to follow-up.” Inadequate management of early dysplastic changes that may progress to CIN contributes to an increased likelihood of mortality from invasive cervical cancer in the state of North Carolina. The aim of this qualitative study is to understand women’s knowledge and perceptions of cervical dysplasia in order to tailor counseling for improved follow-up. Thirteen women with varying levels of cytological abnormalities from pap smear screening were interviewed prior to their colposcopy appointment at a referral hospital. In addition to recalling significant anxiety and fear about the possibility of cancer, women exhibited an unexpected lack of knowledge about cervical dysplasia and human papilloma virus (HPV) despite counseling at previous clinics. Financial and cost barriers were less significant to seeking care than understanding of prognosis. This study reveals an opportunity for better pre-testing and pre-screening counseling about the causal role of HPV and the potential disease course following cytological abnormalities to increase women’s likelihood of referral follow-up.

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INTRODUCTION

Cytological abnormalities are detected in approximately 5% of pap smears in the United States, peaking in women of reproductive age.\textsuperscript{1} These abnormalities are then confirmed and staged through examination with colposcopy and cervical biopsy. Human papilloma virus (HPV) is a precursor to cervical intraepithelial neoplasia (CIN) and cancer. Although the body’s immune system is able to clear most HPV infections, persistent dysplasia requires aggressive follow-up and excision if lesions progress to high grade dysplasia (CIN 2–3) or invasive cervical cancer. Current treatment guidelines for low-grade dysplasia (CIN 1) include regular surveillance with colposcopy and biopsy at six- to 12–month intervals\textsuperscript{2} Cervical cancer screening programs cost approximately $2.3 billion yearly with management of dysplasia costing $1,275 – $2,349 per case.\textsuperscript{3} Follow-up failure rates have been estimated to be as high as 70%, indicating not only disruption to clinical practice, but also a failure in service delivery.\textsuperscript{4}

The objective of this study is to examine factors that contribute to women’s lack of follow up after abnormal pap smear for diagnosis and treatment. In central North Carolina, many public health departments refer women with abnormal pap smears to the UNC Women’s Hospital Dysplasia Clinic. This regional referral center serves over 1200 women per year, approximately 150-180 of whom have high grade dysplasia that requires excisional treatment. In 2011, the clinic patient population was 23.6% non-Hispanic black, 44.6% non-Hispanic white, and 26.2% Latina and 5.6% other according to the hospital’s intake demographics. The clinic provides services to many women who are uninsured; only 17.8% of the clinic’s patient filed private
insurance claims and 13.3% were enrolled in the Medicaid or Medicare program in 2011. Despite “Charity Care” covering 27.6% of the clinic’s patients, 41.3% were classified as “Self-pay” and paid for services out of pocket. The demographics of the patient population of the UNC Dysplasia Clinic represent women whose marginalized status as minorities and lack of insurance increase vulnerability to substandard surveillance and more serious health outcomes.4

Without appropriate diagnosis and treatment procedures following an abnormal pap smear, lesions may progress to high grade dysplasia or invasive cervical cancer. The North Carolina cervical cancer rate is higher than the US rate (9.4 versus 7.7 women per 100,000, respectively); rural North Carolina counties have annual cervical cancer incidence and mortality rates up to twice that of national US rates.6 The Carolina Framework created by Cervical Cancer Free NC initiative cites inadequate follow-up care after abnormal screening results as causing one in ten cervical cancer deaths, disproportionately affecting minority women and rural groups.7 Lack of insurance and poor access to medical services have been cited as barriers to rural women receiving pap smears which may explain their higher risk of cervical cancer mortality.8 Systems-based barriers to care such as appointment cost and travel time have been known to decrease clinic attendance for cervical cancer screening programs;7 however, these barriers have not been analyzed in a qualitative fashion or compared to less tangible barriers. Qualitative interviews would allow evaluation of “shadow costs” of environmental constraints associated with clinic attendance, such as childcare, transportation, and missed time at work. These obstacles may contribute to women not attending referral appointments at the UNC Dysplasia Clinic, since the majority of the patient population is uninsured and travel considerable distances. Many women referred to the UNC Dysplasia Clinic already have a history of cytological abnormalities;
although first referrals for low-grade lesions are common. Twelve percent of women presented to the clinic with a history of CIN 2–3 in 2011; these women are at the highest risk for invasive cervical carcinoma. The purpose of the study is to explore how informational, emotional, and logistical processes that follow receiving abnormal cytology results affect women’s decisions to attend medical follow-up at a referral hospital.

METHODS

Recruitment

This is a descriptive, qualitative study of barriers to diagnosis and treatment for cytological abnormalities detected by pap smear screening. Qualitative research methods allow for deductive investigation of hypothesized barriers to care as well as inductive discovery of other contributory factors. For this study, adult English-speaking patients new to the UNC Women’s Hospital Dysplasia Clinic were interviewed prior to their referral appointment for colposcopy. Women who met inclusion criteria were recruited following examination of vital signs by a nursing assistant. Rather than having to return to the clinic waiting room until the time of their clinical evaluation, women were offered an opportunity to participate in the study. Patients who were interested in participating in what was described as a brief interview on their experiences with cervical dysplasia were brought to a private exam room. Participants were compensated with a two-hour parking pass. The interviewer obtained verbal consent based on an IRB-approved script that emphasized anonymity, confidentiality, and lack of influence on their subsequent medical care. So as not to influence questions and probes, patients’ dysplasia histories were retrieved by a second researcher who did not interview participants.
Interviews

A semi-structured guide was used for interviews with questions based on literature review and pre-interview hypotheses; however, the open-ended nature of the questions was designed to capture experiences outside the realm of hypotheses. Based on patient demographics and interactions within the UNC Dysplasia Clinic, we hypothesized that psychological impact of diagnosis, lack of knowledge about cervical dysplasia, and the cumulative “cost,” both financial and in terms of convenience, would be the most significant barriers to attending referral colposcopy appointments. A conceptual model for barriers to care can be found in Appendix 1. Questions were designed to initiate discussion within the broad topics of psychological impact, knowledge, and cost with probes directed at education, insurance, and overall impact of diagnosis. The interview guide is included in Appendix 2.

Interviews were conducted by a fourth year medical student during clinic hours. Sample size was estimated to be approximately 20 patients or until redundancy of responses was met. Participants were recruited using convenience sampling and were considered to be representative of the clinic patient population based on available demographic information from the clinic’s quantitative database.

Analysis

Interviews were audio-recorded and transcribed verbatim. Transcripts were analyzed using a grounded-theory approach to discover emerging themes. Interview questions were designed to assess perceptions of disease based on knowledge and attitude as well as logistic difficulties in attending clinic, but responses were coded regardless of question. The data were coded by the
interviewer in Atlas.ti.6. Initial analysis of the text through reading at face value generated repeated words and meanings which were labeled as codes. On second reading, these codes were grouped according to similar topics that had recurred throughout multiple interviews. These topics were then related to important themes from previous research and to the investigation’s hypothesis that determined women’s responses to diagnosis and their actions in maintaining surveillance.

RESULTS

Thirteen women were interviewed between February and April 2012. No women declined to be interviewed. By the time 13 women had been interviewed, saturation of responses had been met and themes had emerged according to both prior hypotheses and new themes through induction.

Liminality and Cancer

In describing their initial reaction of receiving abnormal pap smear results, almost every participant noted significant emotional distress. While this reaction dissipated over time and was alleviated by receiving more information and explanation of the results, a residual ambiguity persisted between their hopes and fears. Previous qualitative research on women’s experiences with cervical dysplasia described the rite of passage between health and disease as “liminality,” a term that encompasses the uncertainty inherent in the transition from receiving normal versus abnormal pap smear results.8

Many women noted that they never anticipated receiving abnormal results and quite a few were unaware of what was being screened during a pap smear. One woman noted she only underwent
pap smear screening as a stipulation to receive birth control and was therefore unprepared for receiving abnormal results. Once they received abnormal results, women oscillated between fearing the potential for cancer and believing that the abnormality would resolve. The difficulty in finding the appropriate balance between reassurance and alarm was exhibited in one participant’s desire for more information:

Um, I had to ask a lot of questions to find out what I wanted to know. I don’t feel like a lot was told to me up front. I feel like they were kinda minimizing a lot of things just to make me feel better and I wanted to know the worst case scenario of where this could go. And I wanted to be realistic as to where we were; I didn’t want to brush anything under the rug either. I want[ed] to know how bad it could be and I don’t feel like that was really explained to me. I had a lot of questions.

Some women experienced mixed feelings to the word “cancer” being used by providers in explaining the need for referral appointments. Many women noted that the possibility of cancer made the need for diagnosis of cervical dysplasia seem serious and motivated them to seek further care. In addition, referencing “cancer” also helped eliminate ambiguities in terminology:

It’s very scary because you don’t know what abnormal means. And then they say you have some dysplasia, and I didn’t really know what that meant as far as, you know, what that entailed and, you know, how serious it was. And then, you know, they say the word “cancer,” and you’re like, Oh my God, Cancer?!
Many women described a perpetual residue of anxiety persisting after the initial upset from diagnosis had resolved, often linked to their fear of cancer. The phrase “back of your mind” was used by multiple women:

You always worry in the back of your head, is this going to need surgery? Is this going to lead to something, cancer or something else like that. It’s always on your mind. No matter how bad, they can be like, ‘it can or it can’t be’ but, girl, you know, always in the back of your mind, it could lead to that.

Liminality acknowledges the pervasive sense of disorder that accompanies a diagnosis of cervical dysplasia and the experience of existing in a state between health and illness. The counterintuitive persistence of anxiety despite increased knowledge and education was recognized by many women:

Then after I started gathering information up on it and stuff, it was really not, really anything to be nervous about, not really, but it does still kinda make me nervous.

Persistent low levels of anxiety and fear appeared to motivate these women to attend referral appointments. Of the 13 women interviewed, only 2 cited their anxiety and fear as causing delay or procrastination in seeking follow-up. Most women suggested their fears of cancer served as motivation to ensure rigorous surveillance and took pride in being pro-active regarding their health.
Fears about Fertility

Concerns about the impact of cervical dysplasia on future fertility desires was an unexpected finding that emerged throughout the course of interviews and was shared by the majority of women. Two women were specifically concerned about the association between excisional treatment and preterm birth, although more women were able to articulate a general fear about cervical dysplasia affecting their ability to have children:

Because it’s major for me, because, for me personally. I want another child but I don’t– it was hard for me to get my first one, so I don’t want [it] to be, like, anything that would prolong having another one. You know, I don’t want to be, like, forty years old when I’m pregnant, or not being able to have kids at all. So it, that was major for me.

Three women received their first abnormal pap smear during or following pregnancy which negatively impacted their feelings about childbearing. One woman was concerned that she could have given her son HPV in utero and had associative feelings of guilt. Two women associated pregnancy with dysplasia. Their abnormal pap smears during pregnancy discouraged them from future child bearing despite a previous desire for more children:

‘Cause I never had anything like this, so as soon as I had my baby, I mean, that’s when everything started changing in me and that’s when they told me I had an abnormal pap smear. So I guess that was the problem, but I don’t know. But I don’t really want to have any more kids right now. Not right now. . . Yeah, I wanted a boy and a girl. Now I just have my little girl and I don’t want any more.
Fears about fertility compounded fears about mortality, both of which are unusual thoughts for young women of reproductive age, introduced with the diagnosis of cervical dysplasia. The gravity of these concerns served as motivation for women to seek more information, both independently and through their healthcare provider at appointments. Uncertainty pervaded women’s responses to abnormal pap smears as they questioned both what their prognosis entailed and how they had acquired the abnormality.

Causal Connections

All women described wanting to know more about the causes of abnormal pap smears. Many were interested in why they had an abnormal result and what means existed to prevent recurrences in the future. These causal questions were also linked to anxiety:

That’s probably the hardest part about it, like with anything. When you find out, it’s all the “Why me?” questions and how do I deal with it, what do I do to fix it, and is it fixable. And those are the worrisome things. I try not to bog myself down with it a lot. I don’t, you know, want to become depressed or anything like that. I don’t think it’s that serious, but it’s still really, really hard.

These concerns suggest a paucity of understanding about the nature of HPV and its influence on cervical dysplasia. One of the three women who mentioned HPV and knew that a vaccine existed still didn’t understand the causal connection between HPV and abnormal pap smears. As interviews progressed, questions probing women’s knowledge of HPV were included and their
answers confirmed the lack of awareness. The few women who did know about HPV still desired more education and increased awareness:

Because, to me, HPV isn’t something I heard about until I was like 20 and I’m only 24, and you know what I mean, if it has been around for as long as it has, well, like, why don’t we, you know, have any more information. You know, why aren’t people, you know, informed sooner.

Although women had difficult existential questions of why they had received bad news, they also had a number of factual questions about the nature of their condition, questions that remained unanswered after their initial results. Lack of understanding about cervical dysplasia was not limited to HPV and spanned a breadth of topics ranging from hygiene to pregnancy.

Myths and Misconceptions

In addition to a lack of knowledge about HPV and cervical dysplasia, many women had misconceptions about the screening process. Two women believed personal hygiene practices such as soaps and vaginal douching caused abnormal pap smears. One woman believed she was being screened for ovarian cancer:

Um, I don’t know. I really was thinking, like, I guess, to avoid the ovarian cancer and the problems that women have. My thing was mostly fertility, and making sure we can still reproduce and stuff, and keep check of the ovaries and stuff like that.

Another woman believed that she already had disseminated cancer that was causing fatigue and weight loss. Only three women had understood, before receiving their first abnormal result, that pap smears screened for cervical cancer.
A number of women struggled with even pronouncing the term “colposcopy” and physically appeared flustered. This physical representation correlated with their overall lack of health literacy, with regard to cervical cancer screening, diagnosis, and treatment. Most women referenced doing research though the Internet and friends or relatives, especially those in healthcare fields, to learn more about the causes of cervical dysplasia and expressed desire for more information from their physicians. They also mentioned that they had to ask questions in order to learn more about their results rather than being educated by their health care providers during their clinic visits or on receipt of results:

I kinda researched myself, in particular, and I told the doctor that I went on the Internet. And he said, you know, sometimes the Internet is not the best place for you because it can scare you. And it scared me, I was like, Wooo.

The use of phone calls and letters to give the diagnosis was also described by the women as alienating, in that it precluded reassuring explanation and information about the meaning of an abnormal pap smear. In addition to most women conducting research on their own, many of them turned to a support person, often a friend, sister, or mother, for information and reassurance, support that was also utilized in attending their referral appointments.

Minimizing Logistical Barriers

Despite a stated average transportation time of a 45 – minute drive and a majority with lack of insurance, only two women cited these as reasons why they had missed appointments. Even after
numerous probes about missed work, childcare, and transportation, most women brushed aside these inconveniences as trivial when compared to their perception of prioritizing health. As one participant succinctly surmised, “No, I mean, you gotta do what you gotta do. I mean, I take my health very seriously.” The autonomous decision to seek health care seems to be a self-perpetuating phenomenon among participants and even a source of pride.

Lack of insurance was mentioned by a few women as a barrier to care, albeit one superseded by the perceived importance of follow-up:

I would come regardless of if I had to rack up hundreds of thousands in bills, you know. But, it’s like, you don’t want to be in debt either [laughs] You know. But I haven’t had insurance since I was 18, so, you learn to deal with it. You don’t go to the doctor when you should go, and you pass it off until you absolutely have to, you know. . .Because they told me I could have cancerous cells and I don’t want to– that’s not something that you play with.

The unfortunate abnormal pap smear results and the follow-up appointment that ensued were often the women’s only interactions with the healthcare system. Many were screened during their pregnancies, indicating an important time for education and the need for thorough informed consent about what is being screened for and why.

Trust in Referral Center

While we initially hypothesized that the journey to the referral center was a burden for colposcopy patients, a number of women said they preferred receiving care at UNC as opposed
to their local health departments. They mentioned a high level of trust in the care, as well as freedom from judgment. Two women said they appreciated the increased anonymity of receiving care outside their towns:

You know, I know a lot of people and my family knows a lot of people and even for, I mean, being down here, they serve everybody and I don’t feel like I’m going to run into somebody that I know. I know there are laws and there’s confidentiality and things that you can’t break but at the same time, when you know somebody and you see somebody, you’re like, Oh, they know. And I just feel like there’s more chance for something to get out and, you know. I’ve always had a great experience here.

Positive experiences at the referral center were also characterized by thorough education. The women praised the reputation of the hospital and the programs put in place for those without insurance.

DISCUSSION

The aims of this study were to explore in depth the psychological, knowledge-based, and cost-related barriers to follow-up that prevent women from being adequately screened following an abnormal cytology result. Qualitative interviews allowed an in-depth investigation of women’s knowledge and perceptions about their disease process that identified numerous areas for improvement in patient education. Results suggest that women are less likely to let environmental constraints and costs prevent follow-up when they firmly believe their health is at
stake. Although lack of insurance created an obstacle to care-seeking, the availability of care at the referral site was believed by most women to be acceptable and even preferable. Few studies have examined non-system–based barriers to follow-up for cervical dysplasia. A systematic review of factors associated with follow-up care for an abnormal pap smear indicates a wide variety of influences, ranging from characteristics of the patient, psychosocial factors, and aspects of the healthcare system. Women’s knowledge and perceptions about cervical dysplasia may influence their decisions to seek care and maintain surveillance of their dysplasia. Numerous quantitative and qualitative studies have documented significant psychological distress following diagnosis and throughout the surveillance period but don’t examine whether this anxiety serves as motivation or intimidation to maintain follow-up. In this study, we sought to determine how the psychological impact of diagnosis, in addition to other structural barriers, affected the decision to seek care.

Knowledge of the causes of cervical dysplasia, particularly the role of HPV, has been found to be low among women, even after they received education, including informational pamphlets. Although the link between HPV and cervical dysplasia would not address the existential aspect of why the women developed dysplasia, increasing scientific knowledge may dispel some feelings of confusion or guilt. While lack of knowledge about HPV and dysplasia has been linked to increased anxiety, how knowledge and anxiety contribute to surveillance has not been evaluated. HPV knowledge has been shown to have mixed effects on women’s perception of disease, either increasing feelings of stigmatization or increasing health-related behavior.
By examining the women’s knowledge about, attitudes toward, and the psychological impact of cervical dysplasia, clinicians can learn how to better educate and inform their patients in ways that may encourage better surveillance adherence. Our results indicate a need for better pre-screening informed consent. With many women unaware of the reason for pap smear screening until they receive an abnormal result, questions of informed consent during screening are raised. Although increased screening is an admirable public health goal, it should not come at the cost of women’s health autonomy. Explaining the rationale of screening and the prevalence of abnormal results prior to pap smear screening will ideally lessen the psychological shock and anxiety many women experience on diagnosis of cervical dysplasia. Education should be favored to help women interpret the results of their pap smear, which are increasingly being reflex tested for HPV. HPV screening helps reduce pap smear screening errors, information especially valuable to women who are ambivalent about referral follow-up. Understanding their HPV status as well as the natural course of the disease with immune fluctuations may help answer the common question of “Why me?” that arose in many interviews.

Public knowledge of HPV and cervical dysplasia has increased since the development of the quadrivalent HPV vaccine. In the years since Gardasil was approved and marketed to prevent HPV infections that cause cervical dysplasia, one would hope that knowledge about the causal relationship would be better known among the general population. While one in three adolescent girls in North Carolina has received the HPV vaccine; less than 3% of the patients from UNC Dysplasia Clinic have been vaccinated. As only a few women interviewed expressed knowledge of the vaccine, referral appointments present an opportunity for discussions about the HPV vaccine.
Education should not focus solely on HPV but should also address women’s individual concerns, which may include mortality and fertility. Concerns for future fertility identify a knowledge gap in how excisional treatments affect cervical competence and should be addressed by providers even at the early diagnostic stage. With many misconceptions regarding fertility, it is important for providers to counsel using evidence-based research, which is equivocal regarding excisional procedures and preterm birth in the US. Although concerns about cancer generated fear and anxiety that often served as motivation for follow-up, the repeated use of focus on “health” in women’s interviews suggests that a positive, pro-active approach may be acceptable and bypass risk of undue negative psychological effects.

An important limitation of this study is the selection bias that the women interviewed were those who were seeking health care and those who were able to overcome logistic barriers. The small sample size and recruitment strategy also limit the generalizability of the data. These data does not necessarily reflect women who did not come for their referral appointment or women who have never even presented for pap smear to start. Because half the women dying from cervical cancer were not receiving regular pap smears, this study is does not address those women most at risk of presenting with advanced dysplasia. Although some interview questions attempted to address reasons why women had missed appointments in the past, the women who were able to attend clinic may be inherently different from those who frequently miss appointments. Women who attend the clinic may have better logistic aid through strong support systems, since many noted they had family or friends to drive or provide childcare. Women who attended clinic stressed the importance of their health; women lost to follow-up may have a different
psychological framework to approaching their diagnosis. By interviewing women who did
follow-up on their referral, we cannot know what reactions are different among women who do
not follow-up. However, noting the barriers overcome by women interviewed with health
seeking behaviors provides insight into support and education that may be required to engage
women who do not engage in health care. Future studies could use telephone contact to interview
women with multiple missed appointments to address their barriers to follow-up and perhaps
even provide them compensation for travel or missed work.

Conclusions:
Frequent follow-up appointments for surveillance of cervical dysplasia represent many
opportunities for more thorough education that may increase referral follow-up and improve
women’s health outcomes. Uninsured women frequently must overcome several financial and
geographical barriers to receive care. This study explored the knowledge and perceptions about
follow-up for abnormal pap smear screening results described by women with health seeking
behaviors. These data provide information for development of improved pre– and post–
screening education that includes raising HPV awareness in order to promote improved follow-
up for referral visits.
REFERENCES:


Appendix 1:

Pre-test framework for barriers that prevent adequate follow-up and surveillance for abnormal cytology results
Appendix 2:

Interview Guide

Opening: Can you tell me what brings you here today? Prompt: How did they explain that to you? What were the doctor’s reasons? What does that mean to you?

Knowledge: What do you think a pap smear is/means? What have you been told about your results/need for follow up? Prompt: What information, if any, do you wish you had been given about your pap smear? What questions do you still have? (Those are important to discuss with the doctor you are about to see). Overall, do you feel you have been well-informed about cervical dysplasia?

Anxiety: How did you feel/think/react when you heard that you had cervical dysplasia? Prompt: Have you been affected by having an abnormal pap? How does this change the way you feel about your health? What, if any, physical symptoms do you feel? In what ways has having an abnormal pap affected you psychologically?


Closing: Is there anything you else on your mind about cervical dysplasia that you want to discuss or ask?