"IN A WAY IT'S A VIOLATION": PAP SMEAR KNOWLEDGE AND BELIEFS AMONG UNDERSERVED WOMEN IN SUBSTANCE ABUSE TREATMENT

by

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THESIS

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ABSTRACT

"In a Way It's a Violation": Pap Smear Knowledge and Beliefs Among Underserved Women in Substance Abuse Treatment

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Due to many factors, women in substance abuse treatment are at high risk of contracting the human papillomavirus (HPV) and developing cervical cancer. Despite this, the likelihood of accessing preventative healthcare, such as a Pap exam, is low. Substance abuse treatment facilities may be suitable access points for preventative cervical cancer screening. Using secondary focus group data, this qualitative narrative analysis examines answers given by women in substance abuse treatment regarding knowledge, experiences, barriers, and facilitators to Pap exams. The purpose of this analysis was to further understand how this population views Pap smears in order to guide best practices for increasing access to cervical cancer screening. Analysis revealed participants' awareness of their own lack of gynecological health knowledge, a desire for gynecological health information, fear and mistrust of the medical system, and uncertainty regarding gynecological procedures. If done in a trauma-informed way, offering gynecological health education and Pap smears to women in substance abuse treatment could be one way of improving access in this population.

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Chapter 1: Introduction

According to the Centers for Disease Control (CDC) (2016), with regular screening, cervical cancer is the easiest gynecological cancer to prevent. The test that checks for cervical cancer is the Papanicolaou (Pap) smear, also called the Pap test or Pap exam. High-risk human papillomavirus (HPV) infections that are persistent, meaning they do not spontaneously resolve, are the main risk factor for developing cervical cancer and its precursor lesions (Centers for Disease Control, 2015; Petry, 2014; Walboomers, 1999). HPV is the most common sexually transmitted virus in the United States (Satterwhite, et al., 2013). Approximately 20% of women in the US are infected with high-risk HPV (McQuillan, Kruszon-Moran, Markowitz, Unger, & Paulose-Ram, 2017). Although any sexually active individual is at risk for an HPV infection, there are behavioral factors that put some at an increased risk. Studies have found that sexual behavior, including lifetime number of partners, early age of initiation, unprotected sex, and history of the herpes simplex virus are risk factors associated with HPV infection and cervical cancer (Chan et al., 2002; Moscicki et al., 2001; Peyton et al., 2001; Vaccarella et al., 2006; Wezowska et al., 2013; Wheeler, 2013). Another important factor associated with HPV infection and cervical cancer is cigarette smoking (Vaccarella et al., 2006; Vacarella et al, 2008; Yetimalar et al., 2011). Given these risk factors, women in treatment for drug and alcohol abuse are likely at high risk for contracting HPV and developing cervical cancer, and it is important that they are screened regularly.

Chapter 2: Literature Review

Each decade, the United States Department of Health and Human Services releases a set of national objectives for disease prevention efforts to improve national health. This guide, called Healthy People, provides 10-year, science-based health targets and benchmarks for the US. One important objective in the most current edition of Healthy People, Healthy People 2020, is to "increase the proportion of women who receive a cervical cancer screening based on the most recent guidelines" (Office of Disease Prevention and Health Promotion, 2010, Objective C-15). The National Center for Health Statistics (2016) reports that 81.6% of women ages 21-44, and 73.9% of women age 45-64 have received a Pap smear in the last 3 years. Studies demonstrate a lower than average screening rate in women who struggle with drug and alcohol addiction, and have found that they are less likely to have been screened for cervical cancer (Kricker, Burns, Goumas, & Armstrong, 2013; Tilley, 2013). To increase preventative screening in this population, it has been suggested that substance abuse treatment centers could serve as access points for Pap smears. Although drug treatment facilities could be useful access points, it is important to note that women in substance abuse treatment have been shown to have complex mental and physical health needs, which may affect screening uptake rates. Socioeconomic factors are associated with lower than average screening rates in this population. However, Kricker, et al. (2013) found that lack of screening in women who used drugs was not correlated with socioeconomic status, indicating that other factors might be involved, such as addiction, the ability to identify health needs, and trauma history.

In recent years, prison has also been used as an access point for Pap exams for this population. Although providing access to preventative care while in prison has advantages for those who experience financial and logistical barriers, women in prison have reported physical

discomfort due to physicians not performing the exam in a gentle manner, inappropriately sized speculums, and fear regarding the cleanliness of facilities (Magee, Hult, Turalba, & McMillan, 2005). Additionally, these women described feeling afraid and embarrassed during prison exams. Others described the Pap exam during their stay in prison as "traumatic" (p. 1714). Due to jail overcrowding and limited resources, it has become common to divert individuals who have come in contact with the criminal justice system to community-based treatment programs (Steadman & Naples, 2005). Women in substance abuse treatment may have been court ordered to treatment. Thus, if substance abuse treatment centers were to become access points to preventive screenings, those who were court ordered may have similar feelings of fear as those expressed in prison populations. This is an important consideration when attempting to determine the best venue to offer Pap tests to women experiencing substance abuse problems.

Offering Pap exams to this population could help meet the Health People 2020 goal of increasing the number of women who receive Pap smears to 93% nationwide. However, the special needs of this population should be taken into consideration before substance abuse centers begin widely offering these services.

What Makes Women Seeking Substance Abuse Treatment High-Risk for Cervical Cancer?

HPV risk.

Risky sexual behavior. There are several sexual risk factors associated with HPV infection and cervical cancer. These include lifetime number of sexual partners, early age of sexual initiation, unprotected sex, and history of the herpes simplex virus (Chan et al., 2002; Moscicki et al., 2001; Peyton et al., 2001; Vaccarella et al., 2006; Wezowska et al., 2013; Wheeler, 2013). In fact, Moscicki et al. (2001) found that "risk increased nearly 10-fold for each new partner per month reported" (p.3000). The sexual behaviors of women in substance abuse

treatment increase their risk of contracting HPV. Having multiple partners, unprotected sex, and trading sex for drugs, money, or to meet basic needs are risky sexual behaviors associated with this population (Booth, Kwiatkowski & Chitwood, 2000; Edelman, Patel, Glasper & Bogen-Johnston, 2014; Johnson, Desmarais, Van Dorn, Lutnick, Kral, & Lorvick, 2016; Logan & Leukefeld, 2000; Rash, Burki, Montezuma-Rusca, & Petry, 2016; Tortu, McMahon, Hamid, & Neaigus, 2000). Women who use illicit drugs are more likely than men to trade sex for money, drugs, food, or shelter (Latkin, Hua & Forman, 2003). In a 2010 study, Burnette et al. found that 50.8% of 1606 women entering substance abuse treatment across the US reported participating in prostitution during their lifetimes. Forty-one percent of these women reported this behavior during the past year. In addition, prostitution was associated with a higher risk for mental and physical health problems, including sexually transmitted infections (STIs).

Cigarette smoking. Additionally, cigarette smoking has been identified as a factor associated with HPV infection and cervical cancer (Vaccarella et al., 2006; Vacarella et al, 2008; Yetimalar et al., 2011). Many studies have demonstrated high rates of cigarette smoking and tobacco dependence among people experiencing substance abuse issues (Grant, Hasin, Chou, Stinson, & Dawson, 2004; Guydish & Ziedonis, 2009; Kelly, Baker, Deane, Kay-Lambkin, Bonevski, & Tregarthen, 2012; McIlvain & Bobo 1999; Stark & Campbell, 1993).

High rates of trauma. Women with substance abuse issues have been found to have high rates of lifetime trauma. In 1984, Covington and Kohen conducted one of the first studies on women experiencing addiction and their lifetime rates of trauma. This study found that women struggling with addiction were abused more often, by more people, and for a longer amount of time than women who did not struggle with substance abuse. Additionally, in this study, these women reported more cases of rape and incest than their counterparts without

addiction problems. Overall, 52% of women in this study reported physical abuse, and 74% reported sexual abuse.

Other studies have found similarly high rates of trauma in women with substance abuse issues. A nationwide sample of women and men in substance abuse treatment in the VA health system found that over two-thirds of these women reported lifetime physical and/or sexual abuse (Ouimette, Kimerling, Shaw, & Moos, 2000). Another study of physical and sexual abuse among people with substance abuse issues found high trauma rates in women, with 81% of 111 females reporting lifetime abuse (Liebschutz, Saversky, Saitz, Horton, Lloyd-Travaglini, & Samet, 2002). A cross-sectional case-cohort study that assessed 459 cocaine addicted individuals recruited from drug treatment, and 459 individuals from the general community population found higher rates of trauma, as well. This study found that 58% of women who were addicted to cocaine versus 33% in the general population had experienced assault, including sexual assault (Afful, Strickland, Cottler, & Bierut, 2010). Soccio, Brown, Comino, & Friesen (2015) also found higher rates of intimate partner violence (IPV) and sexual assault among women with substance abuse problems than in the general population.

Trauma and physical health. Trauma not only impacts a women's mental health, it can also have a lasting impact on her physical health. Studies have found an association between sexual assault and poor health status in women (Golding, 1994; Lesserman, 2005). Violence, sexual assault history, and childhood sexual abuse have been associated with reproductive problems, sexual health issues, and other gynecological complications, as well (Golding, 1996; Lesserman, 2005; Mark, Bitzker, Klapp, & Rauchfuss, 2008). Weissbecker and Clark (2007) found that "more severe childhood abuse, lifetime interpersonal abuse, and lifetime exposure to other stressful events were related to poorer perceived health, more physical illnesses, more

disabling conditions, more severe somatic symptoms, more years of cigarette smoking, and more drug use" (p. 919). IPV has also been linked to increased risk of cervical cancer. Exposure to IPV is associated with cervical cancer risk factors such as smoking, stress, STIs, risky sexual behavior, decreased likelihood of cervical cancer screening, and delaying or stopping treatment for cervical dysplasia (Hindin, Btoush, Brown, & Munet-Vilaro, 2015).

Furthermore, many individuals in substance abuse treatment facilities have been involved with the criminal justice system (Steadman & Naples, 2005). Binswanger et al. (2007) found that individuals with substance use disorders who have been involved in the criminal justice system are at an increased risk for health issues.

The physical repercussions of childhood trauma have been also been documented. In 1998, Felitti et al. conducted the first study of trauma in childhood and health outcomes in adulthood. They found "a strong relationship between the number of childhood exposures (to traumatic events) and the number of health risk factors for leading causes of death in adults" (p. 250). This study examined 10 risk factors that contribute to leading causes of death in the US and included: "smoking, severe obesity, physical inactivity, depressed mood, suicide attempts, alcoholism, any drug abuse, parenteral drug abuse, a high lifetime number of sexual partners, and a history of having a sexually transmitted disease" (p. 248). In their 2006 study, Messina and Grella found that childhood traumatic events were significantly correlated specifically with gynecological health problems later in life, finding that "for an increase of 1 childhood traumatic event, the odds of having gynecological problems were increased by 15%" (p. 1846). Moreover, a meta-analysis of 55 studies on childhood sexual abuse found that females are at a "two to threefold risk compared to males to be sexually abused during childhood" (Barth, Bermetz, Heim & Trelle, 2013, p. 477).

Barriers to Accessing Care

Trauma. Experience with trauma can be a barrier to women seeking preventative gynecological healthcare. Farley, Golding and Minkoff (2002) found that childhood survivors (before the age of 18) of sexual abuse and rape were less likely to have been screened for cervical cancer. Women in this study had access to free gynecological exams, thus ability to pay was not a factor. Other studies support the findings that childhood sexual abuse is a barrier to cervical cancer screenings (Cadman, Waller, Ashdown-Barr, & Szarewski, 2012; Olesen, Butterworth, Jacomb, & Tait, 2012). IPV has also been associated with lower than average cervical cancer screening uptake rates, as the abusive partner may not allow the woman to seek screening regularly (Hindin, Btoush, Brown, & Munet-Vilaro, 2015). However, one study found that sex workers were 35% more likely to access cervical screening if they had previous contact with outreach services, such as street nurses and mobile outreach (Duff et al., 2016). This could indicate that relationship and trust can encourage this population to seek services.

Marginalization. In addition to trauma, woman who struggle with substance abuse problems experience many other barriers to accessing general healthcare. In a qualitative study of 11 African American women with histories of substance abuse who participated in prostitution, several barriers to accessing general healthcare were identified. These barriers included: lack of access to a health clinic for primary care, feeling stigmatized and mistreated by healthcare professionals, difficulty navigating the system, and lack of resources (Prince, 2013). Feeling stigmatized, mistreated, and being fearful of discrimination by medical personnel have been described in a number of studies as barriers to accessing general healthcare in men and women who experience substance abuse issues (Duff et al., 2016; Kurtz, Surratt, Kiley & Inciardi, 2005; Lang, El-Aneed, Berenbaum, Dell, Wright, & McKay, 2013; Neale, Tompkins &

Sheard, 2008; Prince, 2013). Furthermore, many in this population feel a mistrust of social service agencies, have an expectation of marginalization, and a feeling that no one cares, which decreases likelihood of accessing services when they are available (Kurtz, Surratt, Kiley & Inciardi, 2005; Neale, Tompkins & Sheard, 2008). In addition, studies support the findings of Kurtz, Surratt, Kiley & Inciardi (2005), that many women struggling with substance abuse are not able to identify their own needs (Duff et al., 2016; Prince, 2013).

Resources. Another barrier to accessing healthcare services is a lack of material resources. Women and men with substance abuse problems participating in qualitative studies have discussed difficulty making it to appointments due to transportation issues (Neale, Tompkins & Sheard, 2008; Prince, 2013). Other material resources that have been noted as lacking are money and access to a telephone (Neale, Tompkins & Sheard, 2008). Another obstacle is lack of identification. If an individual is living on the streets, he or she does not have a safe place to leave his or her belongings, and is likely to have these belongings stolen. This can lead to loss of all forms of identification. Kurtz, Surratt, Kiley & Inciardi (2005) cited this as being a barrier for accessing services, saying that "many service providers, especially those in healthcare, require proof of legal identity and citizenship status, which many women are unable to provide" (p. 355).

Chapter 3: Purpose of Study

Due to the sensitive nature of Pap tests, and considering the likelihood of previous violence and trauma, care should be taken to understand the perceptions women in substance abuse treatment have regarding Pap exams. Care should also be taken to administer them in a way that does not re-traumatize the women. Additionally, because of the likelihood of past sexual trauma, it is important to understand barriers and facilitators, as reported by the women, to

accessing this specific type of screening and following through with getting screened. These barriers and facilitators can help assess whether substance abuse treatment centers are useful access points, and determine the most effective and sensitive way to provide these services. Previous studies have assessed barriers to accessing general healthcare for those with substance abuse issues, and have focused predominately on prostitutes, or people experiencing substance abuse problems not currently in treatment. These studies were not specific to women in substance abuse treatment and their experiences with Pap smears.

The lived experiences and knowledge of this population relating to Pap exams should be examined, and may be used to guide best practices for cervical cancer prevention in this population. The purpose of this narrative analysis is to examine secondary data to answer the following research questions: What are beliefs about, and experiences with, Pap exams of underserved women in substance abuse treatment? What are perceived barriers and facilitators to accessing Pap exams? What is the general knowledge of the purpose of the Pap exam and procedures in this population?

Chapter 4: Methods

Description of Methods

This qualitative narrative analysis will examine answers to questions regarding experiences, barriers, facilitators, and knowledge of Pap exams given in a focus group setting. This information was collected as part of a cancer prevention services project that was funded by the Cancer Prevention Research Institute of Texas (PI: Felini, University of North Texas Health Science Center (UNTHSC), 2012-2016). Due to the interlaced mental and physical health issues in this population, it is likely that women in treatment have a complex relationship with gynecological health. It has been posited that quantitative research methods may miss

complexities that research participants find important (Webster & Mertova, 2007). Therefore, qualitative narrative inquiry was used to gain a deeper understanding of experiences, and to address complex issues regarding Pap smears through stories and ideas that participants shared. According to Patton (2002) narrative studies are often influenced by phenomenology. This analysis was phenomenologically informed due to the emphasis on understanding the lived experiences of the women involved (Patton, 2002). It is important to understand how the participants view their experiences, and gauge their perceived barriers and facilitators to Pap tests, to more fully understand their stories.

Data

The data being examined were originally collected by UNTHSC personnel. It was intended to inform the design of a trauma-informed, gynecological health curriculum, and cervical cancer screening, at one substance abuse treatment facility in a major metropolitan area. The study was originally approved by the UNTHSC Institutional Review Board (IRB). For this analysis, only secondary data collected by UNTHSC personnel was examined. The data used in this analysis was de-identified, and no specific, individual person could be recognized by the researcher. Since only secondary data provided from the original UNTHSC IRB approved study was analyzed, this analysis was not subject to IRB approval at the University of Texas at Arlington.

Instrumentation

In qualitative research, it is important to disclose professional and personal experiences that could lead to possible biases, because the author is the primary instrument of the study (Patton, 2002). I have a Bachelor of Social Work (BSW) degree, and as of May 2016, will have a Master of Social Work (MSW). After graduating with my BSW,

while working toward my MSW, I worked with disadvantaged women experiencing substance abuse problems and complex trauma. I worked in a major metropolitan jail, as well as in several rehabilitation facilities. From May 2015-August 2016, I had the opportunity to work on the second phase of the CPRIT funded cancer prevention project through the UNTHSC. Each week, I provided health education classes, and accompanied women to receive a Pap exam and results. My involvement in the second phase of this project, and my previous work with this population, gave me a unique perspective when analyzing the focus group data. At each phase of analysis, I was aware of possible bias due to my previous knowledge from working with this population. However, working closely with this population for several years also gave me the ability to evaluate the data with a useful and distinctive point of view that may differ from a researcher without such experience.

Recruitment and Participants

Women attending a large female-only substance abuse treatment center in Texas were recruited from both residential and outpatient programs to participate in focus groups. The center accepts a range of patients, including those with and without private insurance, and those mandated to the rehabilitation center through specialty court diversion programs. Treatment center counselors recruited participants by introducing the focus group opportunity in counseling sessions. Interested women could then choose to sign-up. Purposive sampling, a type of non-probability sampling, was used to gain an in-depth understanding of experiences from a specific group, in this case, women in substance abuse treatment (Patton, 2002). Women were eligible to participate in a focus group if they were English speaking and 18 years or older. Five focus

groups (FG) were conducted on the following dates: FG 1 and 2 on November 27, 2012, FG 3 and 4 November 29, 2012 and FG 5, November 30, 2012.

Focus Group Procedures

Five focus groups were administered with 5-10 participants in each group. Prior to beginning the focus groups, the facilitator read scripted informed consent information and allowed time for questions (see Appendix A). After questions were answered, a sign-in sheet was used to obtain consent to participate (see Appendix B). After signing in, participants were given a short survey to capture age, race/ethnicity, education level, prevalence of cervical screening, and general cervical health knowledge (see Appendix C). This data was not linked to individual focus group answers. Focus groups were audio recorded. The focus group facilitator asked semi-structured, open-ended questions specifically relating to barriers, facilitators, and perceptions of Pap smears. Additional questions regarding acceptability of self-administered HPV tests were also asked. Focus groups lasted 40-60 minutes. No monetary compensation was provided to participants, however, after each focus group, each woman was given a small gift box with feminine personal care products.

Data Analysis

To prepare the data collected during the focus groups for analysis, UNTHSC student investigators transcribed audio records of each group verbatim, and assigned a pseudonym to each participant to protect her identity. Transcripts of focus groups were uploaded to ATLAS.ti (Version 1.0.50) to organize and code the data. Next, a three-step process informed by Lindseth and Norberg (2004) was used to analyze and interpret the data. This process included naïve reading, thematic structural analysis, and critical re-reading.

First, the data were read and re-read several times, using the naïve reading process.

During this phase, the author's aim was to gain an overall understanding of the meaning of the text (Lindseth & Norberg, 2004). Next, the overall, or central, understanding developed during the naïve understanding phase was used to guide the process of thematic structural analysis. Through coding, thematic structural analysis was used to identify and develop themes and subthemes. During the first cycle, open coding was used to identify emerging themes within the data (Saldana, 2013). Next, secondary coding was used to reorganize and evaluate initial codes, and a smaller list of themes and subthemes was established. Finally, per Lindseth and Norberg (2004), the identified 3 themes and 7 subthemes were examined against initial naïve understanding for consistency. According to the suggestions of Warren and Karner (2010), a master copy of the data that was not altered was maintained and work was backed up onto a master, password protected USB drive at each step of analysis.

Chapter 5: Findings

A total of 41 women in substance abuse treatment (25 residential treatment and 16 outpatient treatment) participated in five focus groups. Participants ranged in age from 18-59 years, with the average age being 33 years old. Forty-four percent of participants had less than a high school education. Participants' self-reported race was broken down as follows: 56% white, 20% Hispanic, 22% African American, and 2% other. The sample generally reflected the demographic profile of the rehabilitation facility at the time. Of the women participating, 37% reported not having a Pap smear in the past two years.

During the naïve reading process, a naïve understanding began to emerge. The naïve interpretation developed was that participants have awareness of their own lack of gynecological health knowledge and a desire for gynecological health information. Fear and mistrust of the

medical system and uncertainty regarding gynecological health and procedures are significant parts of their experiences with Pap exams.

Themes and Subthemes

The focus of this analysis was to answer the following research questions: What are beliefs about, and experiences with, Pap exams of underserved women in substance abuse treatment? What are perceived barriers and facilitators to accessing Pap exams? What is the general knowledge of the purpose of a Pap exam and Pap procedures in this population?

Through analysis of focus group discussion, 3 main themes and 7 subthemes were formulated. The main themes were: experiences with Pap exams, fear and future, and understanding of the Pap procedure. Subthemes included: the Pap exam is a violation, the Pap is scary and uncomfortable, barriers to accessing the exam, facilitators to accessing the exam, misunderstanding the Pap exam purpose, misunderstanding the Pap exam procedure, and uncertainty about gynecological health prevention and desire for knowledge**.**

Theme 1: Experiences with Pap Exams.

One focus of this analysis was to examine beliefs about, and experiences with, Pap exams. An overarching theme of participants' experiences with Pap smears was identified. From this theme, two subthemes emerged.

Subtheme 1: Pap exam is a violation. Many participants conveyed a sense that the Pap exam is a violation. When discussing the age at which a woman should get a Pap for the first time, many women became protective at the thought of young girls receiving this exam. They conveyed a sense that a Pap smear is violating, particularly for "innocent", young girls. When discussing the idea that a mother would take her young daughter, words used to describe the exam included "violation", "feel like you're being penetrated", and "putting her through that".

Dolly described it as a “very traumatic thing”. Jasmine said, “Like, wow, I couldn’t imagine, and I have five girls, taking one of my babies and doing something like that, especially if they’re not sexually active.” Many participants had a strong reaction, and a felt need to protect their daughters from the Pap test. The process was described as being similar to sexual penetration. It was suggested that a Pap exam is so painful that a girl would not want to have sex afterward because sex is similarly painful. Jasmine added, “maybe if they do that they will not be sexually active. It'll hurt. Then they'll think holy shit I don't want to have sex because it's gonna hurt me.”

Language used to describe what it would be like to tell their daughters about Pap exams further demonstrated the sense of violation: “Telling my baby you got to get on this table, open, they’re going to stick this in you, they’re going to open you, they’re going to scrape, you're going to feel it.” The idea of a Pap exam as a violation, and sending a mixed message was supported by Jasmine’s description: “Yeah, they’re, it's like they're innocent, and then, you know, you have this stranger, you know, sitting here, and we teach our kids don't deal with strangers but yet we want you to open up your legs to a stranger. You know, they tell you to hide your cookie, but we’re asking you to put it out on front row!”

Subtheme 2: Pap exam is scary and uncomfortable. Some women described the Pap exam as a comfortable and easy process, however, in comparison to most answers, this was rare. Most women described a Pap smear with discomfort and fear. Participants reported several reasons that many women are “terrified” to get a Pap. Although, in slight contrast, there was a sense from many, that even though it is scary, it is something that a woman should do to take care of her body. This, however, does not seem to translate to action, as only 63% reported having had a Pap smear in the past two years.

Experiences with Pap exams were described as emotionally uncomfortable and physically painful. When describing the exam, Haddie stated, “Look, my God, your legs are trembling and everything.” Pat said this about the process: “every part of the Pap smear is painful to me. I don't know if it supposed to be, but it is for me.” She also said, “I want to throw up it hurts so bad.” Increasing the sense of fear and discomfort was the language used to describe the exam. Seemingly violent language was often used to discuss the process. Participants used words such as “scape,” “go in,” “open it up,” “sticking stuff in there,” and doing “horrible stuff.” Mary described her biopsy after a Pap smear as “very demeaning.”

Theme 2: Fear and Future.

Throughout each focus group, participants discussed accessing Pap exams, and reasons that they had, or had not, recently attended a screening. A central theme of fear and future was identified as participants discussed deterrents and motivators to seeking out, and receiving, a Pap exam. Two main subthemes, barriers to having a Pap test and facilitators, were identified.

Subtheme 1: Barriers. Fear was identified as a barrier to accessing a Pap exam. Participants often described a fear of diagnosis. Many discussed being too fearful to get an exam because of what might be found. This was due to their own behavior and sexual history, as well as a general fear of cancer. Mary said, “that's kind of the reason why I've avoided getting one for the last six years is because I don't want to know.” Many described a feeling, although they were cognizant that it was not true, that avoidance would prolong good health if they did have an issue. This feeling was perfectly described by Haddie: “if I don't go, and play like nothing’s going on down there, I'm going to live a little longer; I don't know, it's kind of the way I was thinking”.

Fear of the medical system and medical personnel was also discussed. Even when asked questions not related to medical personnel, such as questions regarding what constitutes a healthy lifestyle, many women returned to discussing mistrust of what a doctor might do, and his or her motivations. Although there is a desire to access preventative care, this mistrust likely leads to a decreased likelihood of getting an exam. Vanity explained: "I feel like it is good to go and check yourself up today when you need to go, but it is kind of hard in a way too, because you don't know who you can trust, and you don't know if they're going to be doing the appropriate thing."

Regarding general medical experiences, the women felt that the treatment they, or someone they knew, received was not adequate or thorough. Based on past experiences, they seem to fear that doctors do not care about them. The idea that doctors just want to make money was another way fear manifested. For example, Chloe described being "sent off because of the costs." Marsha felt that the doctor "just wanted the money from insurance." Sexual molestation and rape by doctors was also mentioned. When discussing the need for finding a trustworthy doctor, Pat said, "There are sick people out there, and you don't know what they do."

Addiction was another barrier reported. The participants generally reported that, while actively in their addictions, they were not focused on their health, particularly preventative healthcare. Sandy said, "All you're thinking about is your next high, or your next drink, or you know, so you're not really thinking about, you know, your health." Addiction was also reported as a barrier to having insurance, which impacts access to Pap exams.

Lack of financial resources was reported as a barrier to seeking preventative and follow-up care. Pat reported needing a procedure after recently being diagnosed with cervical cancer, but not attending her appointment because she could not afford the procedure. Another woman had not had a Pap smear in seven years due to lack of insurance. It was described by the women

as a “financial burden.” Others talked about trying to find a way to get an exam and having a difficult time.

Subtheme 2: Facilitators. A commonly reported reason for “taking care” of oneself by “getting checked” was thinking about children. Being an example to daughters and young women in their lives, as well as having knowledge to pass to these young girls, was a motivator for many. The thought of leaving children behind because of not getting regularly checked was discussed. Additionally, a strong sense of wanting to be there for their children was described. It is described well by Vanity as she discussed fear of the procedure, “but you think about your daughter, you think about the people that you're going to leave behind because you didn't want to care about yourself.”

Several women described having the opportunity to be in a rehabilitation setting as a facilitator. They indicated a sense of getting their lives together, and understanding that their physical health should be part of this process. Jan described her feelings in this way: “when I was out there using drugs I didn't get none of that stuff done. Until I came to treatment and I felt like I had to have everything done.” However, there was some variability in this answer, because a few said that they would not have liked to have a Pap test in rehabilitation. Many believed that the procedure had been offered by the mobile medical service that serviced the center, and they said that they had taken the opportunity to go. Others had not had the opportunity to receive a Pap smear and expressed a desire to have it offered to them while in treatment. Natalie said, “I wish you could do it now, I want the screening, I want all that.”

Next, a common reported facilitator was having general knowledge about what a Pap is checking for, and why it is important. Chasity discussed the consequences of lack of knowledge:

> I think the same thing goes with cancer and medical issues with recovery and drug and alcohol use, is that if you don't have the knowledge of what you're actually doing to yourself by using drugs or not maintaining yourself or your physical self by going to the doctor and things like that, if you don't have that knowledge…no, you're not going to make it.

Not only having knowledge beforehand, but also having a health professional explain what is happening in words they can understand during the exam was important. The women discussed not understanding what doctors were telling them, and feeling badly because of this. Studies in other populations indicate that lack of knowledge regarding Pap smears was a significant factor in not getting screened (McFarland, Gueldner, & Mogobe, 2016; Rezaie-Chamani, Mohammad-Alizadeh-Charandabi, & Kamalifard, 2012; Yanikkerem, Goker, Piro, Dikayak, & Koyuncu, 2013). The women in these focus groups identified that having knowledge would increase their likelihood of getting screened.

Theme 3: Understanding of Pap exams.

The women participating in the focus groups expressed their own understanding of the overall Pap exam processes and purpose. Understanding of Pap exams was the third overarching theme identified. Three subthemes were identified from this theme: misunderstanding of Pap exam purpose, misunderstanding of Pap exam procedure, and uncertainty about gynecological health prevention and strong desire for knowledge.

Subtheme 1: Misunderstanding Pap exam purpose. A Pap smear was most often connected with sexual activity. While the cause of cervical cancer is the sexually transmitted infection, HPV, a Pap exam only checks for cervical cancer and cell changes that could develop into cervical cancer (Centers for Disease Control, 2016). Overwhelmingly, the reported reason

for getting a Pap test was to be checked for STIs. Although, many did understand that HPV has a connection with cervical cancer. Unless requested during a Pap exam, most doctors will not test for STIs. However, many participants expressed certainty that they do. Kacey said, "I know now that they can test you for different STDs (during a Pap), I know that". Jewel said, "...my mom took me because I was sexually active at a young age, so I always figured it that's why all the girls had to go and do it." The idea of protecting oneself from STIs was reported as a common reason to get a Pap smear. When one woman corrected another that they do not check for STIs during a Pap smear, she expressed shock, "So, all those times they had me up in the stirrups to find out if I have something and they were just…" This suggests that she did not understand the importance of checking for cervical cancer, nor the purpose of the Pap exam. Another participant stated that a Pap exam was checking for HPV, specifically genital warts caused by HPV. Only one women explicitly said that a Pap smear does not check for STIs.

Additionally, not one of the 41 women identified the correct age to begin Pap exams. The age of sexual initiation was often reported as the right time to get a first Pap. This further indicates the belief that a Pap is predominantly for STI testing. Another reported reason to get a Pap exam was for young women to check that their bodies were developing as they should. The age of puberty, or when menstruation starts, was the most commonly reported age to start getting a Pap smear.

Although one said she was "pretty certain" that a Pap exam tests for cervical cancer, the majority did not appear to understand this. The word "Pap" seemed to be used interchangeably for any type of gynecological exam. Pregnancy was the number one reason given for getting a Pap test. Many others reported needing a birth control prescription as a reason they have received a Pap exam in the past. Cynthia said that a Pap exam, "tells you if your counts are high or low, or

it cautions you to look for the cancer cells or whatever" indicating that she does not fully understand the purpose of a Pap smear. Janet said that her mother took her to a Pap exam as a young girl because "her kidneys were hurting". Another reason given for girls to get a Pap was to receive the HPV vaccination. Other reasons included: sexual assault, a cyst on the vagina, and heavy periods. This lack of knowledge that a Pap smear is testing for cervical cancer can be summed up with a quote from Pat: "I think people get them at different times in their lives for different reasons." These answers indicate that self-report for a Pap exam in this population is likely incorrect, because many seem to be reporting any gynecological procedure to be a Pap test.

Subtheme 2: Misunderstanding Pap exam procedure. There was considerable variability when the participants discussed the Pap procedure. Although few could identify what area of the body was being swabbed (the cervix), and what this swab was collecting (cells), the majority did not fully understand the procedure. Many could identify some element of the procedure, but were confused about others. In an effort to identify possible alternative screenings for this population, a question was asked about a study done with a self-administered HPV test that could be done in the privacy of one's home using a special tampon. This question revealed great misunderstanding among the women about the procedure. Few understood that a Pap was swabbing for pre-cancerous cells. Instead, the swab was described as getting "discharge," a "substance," "the liquid," or "whatever they're getting from around there." Although there was pushback, some even believed that blood from menstruation could be used and tested.

Answers to the question regarding the self-administered HPV test uncovered a lack of basic anatomical understanding, and knowledge of what body part is swabbed. Although the cervix is not far inside the vagina, many said that a tampon could not possibly go into the vagina

far enough. Many believed the tampon was not long enough, saying things like it is "not even meeting with my cervix." Pat reported that the swab done in a Pap exam is going into the vagina so far that "you feel (it) in your stomach." When describing her misgivings about the self-administered HPV test, Lucy said, "unless you know like where your cervix is tilted, and jam that thing all that way, it's not going to… you're not gonna get a good result." This not only indicates a general lack of knowledge of female reproductive anatomy, but a sense that the Pap is rough and constitutes having something "jammed in". Many believe that the physician is "going up into" the cervix, "opening it up," and that "the tool" (speculum) is being inserted into the cervix. Many did not know that the cervix is swabbed during the exam. Some said the "walls" are being swabbed.

Extreme uncertainty was prevalent in most responses. Kacey summed it up well:

> For a Pap smear I don't know if that's where they go like the skin scraping, or I guess I know that you should do it at least once a year, I know that. But I'm not very educated on, you know, what's for what, and what you find out in which.

Even those who were correct expressed uncertainty in their responses. This could be because they have been piecing together information, do not trust medical personnel, and seem to get most knowledge from their peers, who are also very uncertain.

The actual procedure was often described with violent language, particularly "scraping." Many used this word to describe being swabbed, but others seemed to be confusing a Pap exam with other procedures. The violence that appeared to be connected in many participants' minds was summed up as follows: "It is very, very painful. I want to throw up. It hurts so bad. It just feels like someone's scraping you…Inside…It hurts SO bad."

Subtheme 3: Uncertainty about gynecological health prevention and strong desire for knowledge. When questioned about knowledge of a Pap exam and general healthcare knowledge, a subtheme of uncertainty emerged. When answering questions, they often ended or prefaced their answers with "I don't know," "I think," "I'm not sure," and "this is just my opinion." This uncertainty appeared to cause anxiety. Evidence of this can be found in statements such as, "I don't know a lot about the cervical cancer and I need to know because I do. I worry a lot." Still, many women had partially correct information, but were confused about some aspects of what they were describing. Many confused HPV with cervical cancer. This indicates that they had received some type of health information, but perhaps it was not explained to them in a way that they were able to fully understand.

Most of the women were aware of their lack of knowledge, and expressed a desire for correct information. Several indicated that they had signed up for the focus group to get information. Phrases like "I just want to know" and "I want to learn" were commonly used. Clarise said, "I just need to know any information that is available." When asked questions, many found it difficult to give an answer, and often asked health questions instead. The facilitator often needed to remind participants that she wanted to hear what they knew first, then they would answer questions after the focus group was over.

Chapter 6: Discussion

Clearly, women experiencing substance abuse problems have complex health needs and barriers to preventative care. The perception that a Pap smear is scary, painful, uncomfortable, and a violation were commonly reported. Given the high rates of trauma in this population, this perception of a gynecological exam is not surprising. Trauma survivors are likely to relive their experiences, or dissociate, when they are in situations that remind them of their abuse. A Pap test

may trigger this type of response. This can manifest in many ways including startling, becoming numb, feeling frozen, or even enraged (van de Kolk, 2014). When reminded of their trauma experience, women who have experienced sexual abuse may feel intense shame and loss of control (van de Kolk, 2014). This may be why, although many participants could cognitively connect that a Pap exam is a positive health habit, fear was reported as a substantial barrier to seeking this exam.

They are likely trying to avoid trauma triggers. According to van der Kolk (2014), "As long as the trauma is not resolved, the stress hormones that the body secretes to protect itself keep circulating, and the defensive movements and emotional responses keep getting replayed" (p. 132). There is a physical reaction to being triggered. The trauma survivor is rarely aware of why she reacts in a certain way, and may be avoiding a Pap exam in order to avoid this trigger. Therefore, this likely avoidance should be taken into consideration when providing access, and could point to a need for a mental health professional, such as a social worker, trained in trauma, to help the women through the process, from beginning to end. Additionally, physician training on trauma sensitivity is important. In this situation, a physician can increase or decrease anxiety, and help the woman through the process in a way that is not re-traumatizing.

Participants indicated that women who have entered substance abuse treatment may feel ready to take control of their physical health in addition to their mental health. Many felt that they were mentally recovering, and expressed a desire to translate this to their physical bodies. However, with such a complex population, this is not easy. With their own voices, they expressed uncertainty, and the desire to understand what is happening with their gynecological health. Their answers indicated a low level of gynecological health literacy, understanding of the Pap process, and the purpose of a Pap exam. They also expressed confusion regarding what they

believe they know. For this reason, gynecological health education classes, facilitated on a literate level that can be understood easily, should be considered an important part of providing access to this population . The fact that the most frequently reported source of information was their peers points to the usefulness of group education classes in this population. These classes should be trauma-informed because of the likelihood of sexual assault in childhood and adulthood. As they learn, the fear of the unknown, such as fear of diagnosis, will likely diminish due to increased understanding.

The body often has a reaction to past trauma in the present. If providing access in an institutionalized setting, such as drug treatment, the women should feel supported as they go through the process. The principles that van der Kolk (2014) discusses for long-term trauma healing, could be applied to help prepare women in substance abuse treatment for a Pap exam, and likely increase their uptake rates. During health education classes, breathing techniques, mindfulness, and body awareness could be taught to help regulate the system if a woman feels triggered before or during the exam.

Additionally, van der Kolk (2014) suggests that a good support network is crucial in trauma work, because of the need to feel safe. Allowing the women to participate in education classes together, with a trained trauma-informed educator and supporter, such as a social worker, then attending the exam as a group could foster this needed sense of safety and security. This will help stabilize fear. Covington (2008) asserts that, based on the principles of the relational-cultural theory, women have a sense of healing and growth when they have healthy connections. According to van der Kolk (2014) safe relationships “provide physical and emotional safety, including safety from feeling shamed, admonished, or judged, and to bolster the courage to tolerate, face, and process the reality of what has happened” (p. 379). It would be crucial to have

an educator who understands trauma, and could foster community, safety, and security in the group.

Limitations

Several limitations to this analysis should be noted. A number of limitations are due to the use of secondary data. First, the data was not originally collected as part of a research design. It was collected with the specific purpose of assessing knowledge to guide health class content as part of a CPRIT funded project. Thus, the questions were very specific to this purpose, and may have been leading, for example question 8 (See Appendix D): "What do you think causes cancer? Suggest the following: bad luck, due to family genes (heredity), behaviors (eating/drinking/drug use). Environmental exposure (cell phones, microwave ovens)?" Additionally, the author did not facilitate the focus groups, and had to rely solely on transcripts to analyze the data. Body language, such as head nods in agreement, or shakes in disagreement, could not be observed. Therefore, some data related to body language was likely missed.

A limitation to focus groups in general is that some participants talk more than others. The group may have missed the opinions of those who simply let others talk. Also, participants volunteered to participate in the focus groups. This likely means that only those who felt comfortable discussing gynecological issues in a group setting were captured. It is possible that this sample is missing a more highly traumatized population. This population may have been less likely to have had a recent gynecological exam, and likely has important views to share regarding best practices in providing access. Additionally, information was not collected on other factors that may influence screening perceptions and uptakes rates, such as participation in prostitution, and drug of choice.

Another limitation to this analysis is that it relies on data from focus groups from only

one substance abuse treatment center in a major metropolitan area. As with other qualitative research, the results of this analysis cannot be generalized to all women in substance abuse treatment. However, the results may be used to guide other studies with similar groups.

Implications for Practice and Research

To reach the Healthy People 2020 objective of increasing the number of women who receive Pap exams to 93%, it is crucial to reach high-risk populations who are less likely to have received a Pap. Planned Parenthood has been an access point for Pap exams in the past. However, changes in legislation in Texas now require that they provide this exam at cost, making it more difficult for this population to access an exam. Considering this, it important to think creatively about ways to provide access to this population. Policies that increase the availability of screening in unconventional settings, such as substance abuse treatment facilities, are one creative way to provide access. These data indicate that such policies may be an effective way to provide access. However, these findings also indicate that simply offering a Pap exam in this alternative setting may not be enough.

Social work professionals work to help disadvantaged populations meet basic needs, such as health needs, and to enhance their well-being. They do so in a number of ways, such as working with the larger social systems that dictate policies and procedures that impact clients, and working directly with clients. To increase Pap exam access to underserved populations in Texas, social workers must advocate for policies that bring the exams where the women are. They must also advocate for early educational interventions to increase knowledge and reduce barriers in order to help women make informed decisions about their bodies. They can also work directly with these clients to educate and empower them to access exams while in drug treatment.

Future research should focus on more specific groups who may have an even higher risk for cervical cancer, such as women who participate in prostitution at truck stops and are seeking treatment for substance abuse issues. Future research should also test trauma-informed preventative gynecological health interventions with this population. It should focus on evaluating uptake rates of women in substance abuse treatment when Pap exams are offered in rehabilitation centers along with a trauma-informed protocol, sensitive to the needs of this population.

Conclusion

The purpose of this narrative analysis was to evaluate the beliefs and experiences, barriers and facilitators, and general knowledge that women in substance abuse treatment have regarding Pap exams in order to help inform best practices in providing access. Offering a Pap test while in treatment is one way to improve access. However, women in substance abuse treatment will likely only take advantage of this access if their voices are heard. Addressing their fears and desire for knowledge will make them feel safer, and more able to have the courage to receive an exam. Physicians working with this population should also be trained to use trauma-informed techniques when working with this population. Additionally, trauma-informed education classes to empower, educate, and help alleviate fear, paired with peer support, and support from a mental health professional, such as a licensed social worker, are ways to improve the likelihood of screening uptake in this population.

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Appendix A: Informed Consent Facilitator Script

CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

"Sound Mind, Sound Body...."
Texas Cancer Prevention Grant

UNT HEALTH SCIENCE CENTER

INFORMATION SHEET FOR FOCUS GROUP PARTICIPANTS

Title: *Sound Mind, Sound Body*: Assessing knowledge and prevalence of cervical cancer screening in women seeking treatment for substance use disorders

Institution: University of North Texas Health Science Center – School of Public Health

Principal Investigator: Dr. Martha Felini, Assistant Professor, Department of Epidemiology
Co-Investigator: Dr. Raquel Qualls-Hampton, Assistant Professor, Department of Epidemiology

Thank you for participating in our research focus group. A focus group is simply a group discussion about questions we'd like to know your opinion about. UNTHSC investigators are conducting this focus group because we are interested in learning what you know about cervical cancer. The following will give you a short overview of what your participation in this focus group means and the information you decide to give me. Before you decide it is important for you to understand why the focus group is being done and what it will involve. This information sheet is for you to take with you.

Why are we doing this focus group?

Specifically, I am interested in learning what you know about cervical cancer. I would also like to know your opinion about getting checked out for cancer. I am conducting a research study to find out what women know about cervical cancer and cervical cancer screening. If you don't know what cervical cancer is, that's all right. You aren't required to know about cervical cancer to participate in the focus group. The information you give me today will help me create new educational materials to teach women who are in treatment centers like Nexus Recovery Center about cervical cancer screening and encourage them to take care of themselves by getting screened once a year. To do this, I need to find out what women already know about cervical screening, if they get cervical screening, and if not, what keeps them from getting screenings. I am interested in learning about your opinions regarding cervical cancer screening.

Who can take part?

Anyone 18 years of age or older who is in substance abuse treatment at Nexus Recovery Center.

What is involved if I participate in the focus group?

As part of the focus group, you will be joined by 5 - 9 other women who you might know already to discuss your experiences and views about cancer in women and how to prevent cancer, specifically cervical cancer. The focus group will last about 1 hour and will be led by one of the research investigators from the University of North Texas Health Science Center. She will ask questions about cancer specific to women. The discussion in the focus groups will be audio recorded. In addition, you will be asked to complete a brief 5-8 minute survey asking about your age, education, and race and what you may already know about cervical screening at the beginning of the focus group. Questions asked in the survey will include your age, education and race. Participation is completely voluntary. Whether you participate or not will not affect any program services you are receiving. You will receive no direct benefit if you participate.

What will I do with the information?

I will transcribe the focus group discussion (in other words, write down the words from the audio recording). The transcript will only be read and used by our study team and not be used for any other purpose. Your responses will help us design and adapt an education program relevant and specific to you. It will also help us create educational materials you can use.

CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

"Sound Mind, Sound Body...."
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Will everything I say to you be kept private?

Yes. All data collected will be kept confidential, including any health information. I will also ask everyone attending the focus group to keep everything that was said during the discussion confidential. You can say as little or as much as you wish. The audio recording and transcript will be kept in a locked place. Only the study team will have access to it. In the transcript itself, the names of yourself and all other participants in the focus group will not be mentioned so that you will not be identified. Personnel from Federal Regulatory Agencies and members of the Institutional Review Board may examine my records and study data.

What if I change my mind about taking part?

You are free to leave the focus group at any point, without giving a reason.

Who is leading this focus group project?

Study researchers are from the University of North Texas Health Science Center. This project has been approved by the University's Institutional Review Board, and is funded by the Cancer Prevention Research Institute of Texas. If you have any questions concerning this project, feel free to contact Martha Felini, PHD, principal investigator, at 817 735-5029 or email at Martha.Felini@unthsc.edu. If you have questions about your rights as a participant in this project, please contact the University of North Texas Health Science Center Institutional Review Board at (817) 735-0409.

Appendix B: Sign In Sheet

CPRIT CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

"Sound Mind, Sound Body…."
Texas Cancer Prevention Grant

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Are you interested in participating in this research project?
If YES -> print, sign your name & circle YES in the last column **"Thank you for your participation"**
Please complete a Pre-Focus Group Survey now.
If NO -> circle NO in the last column **"Thank you and have a great day"**

By signing-in, you
(1). voluntarily agree/consent to participate in this study;
(2). have had the chance to ask the co-investigator any questions you have regarding the study, and;
(3). have received a copy of the Information Sheet.

PRINT YOUR NAME	SIGNATURE	DATE	Do you agree to participate in the Focus Group? *(circle one)*
			YES NO
			YES NO
			YES NO
			YES NO
			YES NO
			YES NO
			YES NO
			YES NO
			YES NO
			YES NO

Investigator/Facilitator (Print) _____ Signature _____ Date _____

Witness (Print) to consent process _____ Signature _____ Date _____

IRB APPROVED
NOV 1 3 2012
University of North Texas
Health Science Center

Appendix C: Demographics and Knowledge Questionnaire

Please answer the following questions about you.

1. How old are you?: _____ years

2. What was the last grade in school you completed? *(Check one box)*

☐ 6th grade	☐ 7th grade	☐ 8th grade
☐ 9th grade	☐ 10th grade	☐ 11th grade
☐ 12th grade	☐ Graduated from high school	☐ Some college, but did not graduate
☐ College degree		

3. What is your race? *(Check one box)*

☐ Black	☐ White	☐ Native American
☐ Asian	☐ Other Pacific Islander	☐ American Indian
☐ Alaska Native	☐ Native Hawaiian	☐ Bi/Multi-Racial

4. What is your ethnicity? *(Check one box)*

☐ Hispanic	☐ Non-Hispanic

5. What is your current marital status? *(Check one box)*

☐ Married	☐ Widowed	☐ Divorced
☐ Separated	☐ Never married	☐ Partner/Committed Relationship

You are nearly finished! Please turn the paper over to finish.

6. Have you ever heard of HPV (Human Papilloma Virus)?

☐ Yes	☐ No

7. Have you had a pap smear in the last 2 years?

☐ Yes	☐ No

8. The picture below shows the inside of a woman's body. Circle the letter that points to a woman's cervix.

9. If a woman is over 40 years old, she does not need a pap smear.

☐ Agree	☐ Disagree

10. A pap smear is the same as a pelvic exam.

☐ Agree	☐ Disagree

11. A woman should have a pap smear every year.

☐ Agree	☐ Disagree

12. A pap smear tells me if I have a STD.

☐ Agree	☐ Disagree

Thank You for your time!

Focus Grou

Appendix D: Focus Group Script

"*Sound Mind, Sound Body*: Establishing cervical screening in high risk women with substance abuse disorders"
CPRIT Study: Phase I

FOCUS GROUP DISCUSSION GUIDE – NEXUS INPATIENT/OUTPATIENT CLIENTS

Date: _____ , 2012 Time: _____ AM PM

Site Location: _____ ❑ Inpatient ❑ Outpatient

Participants: _____

FACILITATOR OVERVIEW:

Hello, my name is *{focus group facilitator name}*. I am *{describe who facilitator is with – e.g., UNTHSC or Nexus}*. I am conducting a research study to find out what women know about cervical cancer and cervical cancer screening. The purpose of this study is to create new educational materials to teach women who are in treatment centers like Nexus Recovery Center about cervical cancer screening and encourage them to take care of themselves by getting screened once a year. To do this, I need to find out what women already know about cervical screening, if they get cervical screening, and if not, what keeps them from getting screenings. I am interested in learning about your opinions regarding cervical cancer screening. This focus group will last about 40-60 minutes, which includes getting permission from you to participate and completing a short survey. Your participation is voluntary, meaning you don't have to be here and you may leave this focus group at any time. Your participation or non-participation will in no way affect the services you receive from NRC. I will audio record your responses to write them down later; all of your responses and your identity will be kept confidential in the final report. I hope to use this input to improve availability and access to cervical cancer screening for women receiving substance abuse treatment. For your time and effort, you will receive a small gift box at the end of this focus group. Are there any questions? Let's get started!

Introduction: A focus group is like a group interview. I am interested in everyone's response to the questions, and there are no right or wrong answers. When responding to a question, please mention your first name only. I appreciate everyone's ideas in the discussion. If a question is unclear, feel free to ask me to repeat or to rephrase it. Let's talk first about cancer.

Topic 1 – Cancer:

1. Can you tell me what you know about cancer?
   - *Suggest the following (**PROBES**): What is it? Is it serious, like a 'death sentence'? Is cancer contagious? Are some people more at risk for cancer than others – what do they do that makes them more at risk? Can cancer be cured?*
   - *Make sure you ask: where did they hear/read/see this information (doctor, nurse, mother, aunt, family, friend, TV), do they believe the source is reliable?*
2. Have you ever had a friend or family member with cancer?
   - *Make sure to ask: what type of cancer, family member or friend, self*
3. What do you think caused their cancer?
   - *Make sure to ask: bad luck/bad mojo? behaviors (smoker, etc.), heredity (family), environment (microwave oven, telephone lines, tap water, etc).*
4. What has been your own experience with cancer?
   - *Suggest the following **(PROBES)**: have you received an abnormal test result? Had a biopsy?*
   - *Make sure to ask: how did you get your results? did you understand what the test results said? What were you supposed to do next? Did you? If not, what prevented you from doing it?*

5. Do you think you will ever get cancer?
   a. If YES => why do you think you will get cancer?

   - *Suggest the following (PROBES): due to family member (heredity), behaviors (eating/drinking/drug use), environmental exposure (cell phones, microwave ovens)?*

   b. If NO => why don't you think you will get cancer?

   - *Suggest the following (PROBES): does not run in family, behaviors (eating/drinking/vitamins), live in a clean environment, spiritual protection?*

6. Can you prevent cancer?
   a. If YES => What do you think is the best way to prevent cancer?

Topic 2 – Cervical Cancer:

Now let's talk about a specific cancer that affects women. Cervical cancer is *(see Appendix II)* cancer of the opening of the uterus. The uterus is the room where a baby lives and grows when a women is pregnant. The cervix is the door to that room and where the baby comes through during childbirth. Most of the time, cervical cancer is found in women over the age of 30 but can occur earlier.

7. Can you tell me what else you have heard about cervical cancer?
   - *Suggest the following (PROBE): What is cervical cancer? Is cancer serious, like a death sentence? Is cervical cancer contagious? Are some women at more risk for cervical cancer than others? What do they do that make them at more risk? Can cervical cancer be cured?*
   - *Make sure you ask: where did they hear/read/see this information (doctor, nurse, mother, aunt, family, friend, TV), do they believe the source is reliable?*

8. What do you think causes cervical cancer?
   - *Suggest the following (PROBES): bad luck? due to family genes (heredity), behaviors (eating/drinking/drug use), environmental exposure (cell phones, microwave ovens)?*

9. What do you think about your own risk of getting cervical cancer?
   - *Suggest the following (PROBE): are you more at risk than your friends? Sister? Mom? Why?*
   - *Make sure you ask: where did they hear/read/see this information, do they believe the source is reliable?*

10. Whatever you think your risk is, do you think you could / will get cervical cancer?
    a. If YES => *why?*
    b. If NO => *why? What is protecting you?*

11. During a cervical exam, a nurse or doctor may look for a virus called the human papillomavirus, or HPV, that may live on your cervix. What have you heard about HPV?
    - *Make sure to ask: where did you hear this information?*

Topic 3 – Pap Smears:

One way to detect cervical cancer is through a pap smear. A pap smear is a screen for HPV and can detect abnormal cells earlier before they progress to cervical cancer.

12. What has been your experience in getting a pap smear?

13. What made you decide to get or not get a pap smear?
    - *Suggest the following (PROBE): physician recommendation? Symptoms? Pain? Birth of baby? Lack of money?*

14. When do you think women should start getting pap smear?
    - *Suggest the following (PROBE): at what age? How often do you think women need to get a pap smear?*

A research study was conducted in Miami, Florida with women from different countries. They did not want to participate in the pap smear exam, but were given the option to do the pap exam themselves at home. This involved the woman inserting a tampon and removing it, and then placing the tampon in a special envelope to return to a doctor or nurse for testing.

15. What do you think about this – is this something you would be interested in, if offered?
    - *Suggest the following (PROBE): why? Like this option better than seeing the doctor/nurse? If so/not, why/why not?*
16. Would you feel comfortable administering the test yourself? Why/why not?
17. Would you prefer to conduct the test at home or come to the clinic? If done at home, would you bring the test back/mail the test in?
18. Would you trust the test results?
19. Why do you think some women would prefer this type of pap exam?

Topic 4 – Barriers/Facilitators to Cervical Screening:

A cervical exam and pap smear are sensitive. Some women may not want to get these exams.

20. We've heard that women may not get pap smears if they don't know where to go. What do you think about that?
    - *Make sure you ask: where would you tell a woman to go to get a pap smear?*
21. We've heard that women may not get a pap smear because it is uncomfortable, even sometimes hurts. What do you think about that?
22. We've heard that women may not get a pap smear because they fear the doctors may find something. What do you think about that?
23. We've heard that women who are recovering from drug addiction are less likely to get a pap smear because they have other things that are more important to them, such as finding a job and remaining sober. What do you think about that?
24. We've also heard some women may not want to get a cervical exam or pap smear if they've been sexually abused. What do you think about that?
25. What other reasons do you know of that may make women less likely to get a cervical exam or pap smear every year?
26. Thinking about yourself, what would make it easier for you to get a pap exam every year?

- *Suggest the following (PROBE): reminders (how?), having a one stop shop – primary health care and gynecologic appointments on the same day (convenience) or preventive care integrated in substance abuse treatment care, cost, location, gender of health provider*

27. There was a study done where women were able to do a pap smear on themselves at home, simply by inserting a special tampon and then mailing it to a lab for analysis. Would you be interested in something like this? Would it make you more likely to do a pap smear every year?

28. If you wanted to find out more about cervical cancer, where do you go?

This is the end of the focus group. Thank you very much for your responses. I hope to use the information to create better learning materials about cervical screening for women in treatment for substance use. I would like to give you the current learning materials that are available about cervical screening and briefly discuss with you why it is so important for us, as women. Afterward, I will hand out your gift boxes.