Emancipatory Praxis for Cervical Cancer Health Equity in Guatemala

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Abstract: This study explores barriers and facilitators to cervical cancer screening among indigenous Maya women in Guatemala. Eight weeks of observation, active participation, informal interviews, and semistructured interviews with community organizers were analyzed using Leininger's 4-phase process to elucidate five themes: fear/shame, "machismo," education/experience, cost, and self-love. Results suggest sustainable cervical cancer screening may be possible through cultural humility, collaboration, balance of power, and emancipatory praxis. Practicing these concepts may help to build knowledge and trust between providers and community, thereby lessening oppression, empowering women, and reducing cervical cancer health disparities and disease burden among Guatemalan Maya women.

Keywords: uterine cervical neoplasms; early detection of cancer; Guatemala; healthcare disparities; health services accessibility; ethnonursing research; culturally competent care

Cervical cancer is the second most frequent cancer among reproductive-age women in the world (Bruni et al., 2017). It is estimated that over 500,000 women were diagnosed and 250,000 women died from cervical cancer in 2012, approximately 80% of whom lived in low-resource countries, like Guatemala (Benard et al., 2017). Primary and secondary prevention strategies, like human papilloma virus (HPV) vaccination and serial cervical cytology with or without HPV testing, have significantly reduced the burden of disease (Torre, Siegel, Ward, & Jemal, 2015). However, these improved outcomes have not been seen in women living in areas with limited access to healthcare services and providers (Dal Poz, Kinfu, Dráger, & Kunjumen, 2007; Driscoll, Tappen, Newman, & Voege-Harvey, 2018; Torre et al, 2015). This is the case in Guatemala, where cervical cancer remains the leading cause of cancer incidence and cancer death among women of reproductive age (Bruni et al., 2017). The estimated years of disability and life lost suffered by women with cervical cancer in Guatemala is more than 55% higher than world averages, leading to an undue burden of disease for these women and their families (Bruni et al., 2017). This is despite Guatemala's national healthcare system offering cancer screening with cervical cytology, but access

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to services is concentrated in urban centers and there is no national HPV vaccination campaign (Bruni et al., 2017). The largest reduction in cervical cancer incidence and mortality could be achieved by increasing participation in and access to screening (Saslow et al., 2012), particularly for impoverished indigenous Maya living in remote rural areas who are unwilling or unable to access screening services.

The Pan American Health Organization (PAHO) Guatemala country cooperation strategy (Organización Panamericana de la Salud, 2013) reports the greatest challenges for health in Guatemala are poverty; inequality, with greater healthcare challenges in the indigenous, rural, poor populations; and expanding systems for universal access to care (Organización Panamericana de la Salud, 2013). The indigenous Maya of Guatemala experience a disproportionately high number of health disparities and lack access to appropriate healthcare and healthcare facilities, including those providing cervical cancer screening. These women typically have little education, low socioeconomic status, a low level of health literacy, few resources, and no infrastructure for clean water or sanitation. In addition, they often have communication difficulties since most speak 1 of over 20 Mayan languages and not the Spanish spoken by the urban "Ladino" population. All of this leads to an absence of voice and inability to communicate with healthcare personnel about their health concerns or wishes (Ishida, Stupp, Turcios-Ruiz, William, & Espinoza, 2012). In most rural areas, the roads are very difficult to traverse, both by vehicle and on foot. Women tend to have many children, resulting in numerous chores and responsibilities in the home, making it difficult for them to seek healthcare. The Maya are often distrustful of the nonindigenous Spanish-speaking urban Guatemalans, or "Ladinos," stemming from a long history of marginalization with Spanish colonization and a long civil war ending in 1996, which included a targeted genocide of over 200,000 Maya (wingsguate.org). There are many cultural and ethnic barriers that must be considered. Most government-run clinics are staffed by nonindigenous personnel, where indigenous women may face discrimination. There is also a conflict between traditional medicine, preferred by rural Mayas, and modern medicine, preferred by urban Guatemalans (Ishida et al., 2012).

To combat many of these obstacles, the Ministry of Health and several nongovernmental organizations (NGOs) in Guatemala have utilized visual inspection of the cervix with the naked eye after the application of acetic acid (VIA) as an effective low-resource alternative to resource-intensive cervical cytology screening, and VIA has been endorsed by the WHO (Cervical Cancer Action, 2012; WHO, 2013). VIA provides point-of-care screening that can be performed safely and accurately by properly trained lay providers and, when combined with cryotherapy treatment of suspected lesions, offers a same-day "see and treat" approach (Driscoll et al., 2018; WHO, 2013). This is especially important, as it significantly reduces the burden of repeat visits for women who live far from health services (Cervical Cancer Action, 2012). However, even with the availability of cervical cytology and VIA "see and treat" screening services, it is estimated that less than 40% of women in Guatemala have been screened (Bruni et al., 2017). Expanding access to national and NGO-based screening efforts has clearly not been enough to decrease the cervical cancer disease burden for many women in Guatemala. Exploring and understanding factors that either hinder or facilitate a woman's ability to participate in cervical cancer screening is important for increasing participation in screening and reducing the burden of cervical cancer among indigenous Maya in Guatemala.

There have been several studies investigating women's cultural beliefs and practices that create barriers to cervical cancer screening in both high- and low-resource countries. Fatalistic attitudes; lack of knowledge; fear; stigma; a belief that Pap smear testing is unnecessary, or necessary only when ill; lack of knowledge; misconceptions; perceived quality of care; and pragmatic concerns, such as cost, lack of transportation, and conflicts with work and childcare responsibilities have been identified as barriers to participation in cervical cancer screening among women of various ethnicities in the United States (Johnson, Mues, Mayre, & Kiblawi, 2008; Percac-Lima, Aldrich, Gamba, Bearse, & Atlas, 2010; Schoenberg, Baltisberger, Bardach, & Dignan, 2010). Similar barriers to cervical cancer screening were identified in a meta-synthesis of qualitative data from women living in areas of the world with high cervical cancer incidence rates (Driscoll, 2016). These included

fatalism; a mistrust of nontraditional healthcare; feminine beliefs, where women's priorities lie with caring for family and not self; limited knowledge of and misconceptions regarding cervical cancer screening and risk factors; and a belief that participating in cervical cancer screening is an admission of infidelity or promiscuity. A major facilitator to screening was found to be community/social support (Driscoll, 2016). If women were supported by men and other family members had participated in or supported cervical cancer screening, then they were more likely to participate. Self-love and realizing that taking care of self is necessary to take care of others was another facilitator to participation in cervical cancer screening (Driscoll, 2016).

Despite extensive research in the United States and some investigations in less developed regions of the world looking at barriers and facilitators to cervical cancer screening, there is little to no research in the literature concerning Guatemalan, particularly Maya, women and their cervical cancer beliefs, behaviors, and preventive care practices. The aim of this study was to discover and explore factors that either hinder or facilitate indigenous Maya women's ability to participate in cervical cancer screening and treatment in rural Guatemala. This information may help guide future efforts to improve utilization of cervical cancer screening services and ultimately reduce the burden of cervical cancer morbidity and mortality in these women.

1. Have you been screened for cervical cancer?
2. If so, when and where was it (month/year)?
3. What made you decide to have cervical cancer screening?
4. What things prevented you from having cervical cancer screening?
5. Is there anything else about your personal experience with cervical cancer screening that you would like for me to know?
6. In your experiences as a "promadora(o)" organizing the mobile VIA/Cryo community clinic(s) or "Jornadas," why do you think women DO come to the clinics?
7. In your experiences as a "promadora(o)" organizing the mobile VIA/Cryo community clinics or "Jornadas," why do you think women DO NOT come to the clinics?
8. Can you tell me about any particular woman's story, being careful not to use names?
9. Is there anything else you would like to tell me or you think I should know?

Figure 1. Semistructured interview (SSI) guide.

Methods

Study Design

This was a qualitative descriptive study reviewed and approved by the Institutional Review Board of Florida Atlantic University.

Data

Author field notes and observations were made as an active participant in mobile community cervical cancer screening clinics for 1 week in both the Spring of 2013 and of 2014. Informal interviews with a convenience sample of local clinic organizers, providers, participants, and NGO leadership were performed. Semistructured interviews (SSI), using the interview guide in Figure 1, were conducted with a purposive sample of local community health workers and VIA clinic organizers over the age of 20 and able to speak Spanish. Participants were approached, asked to participate, verbal consent obtained, and interviews conducted in Spanish by the investigator (SDD) with the aid of a Guatemalan Spanish/English interpreter familiar with the local Maya language. Participants were given the equivalent of $25 U.S. dollars that could be applied to the purchase of a product or service of their choice from the NGO People for Guatemala, such as a water filter, school supplies, stove, latrine, and so forth, to benefit their family and/or community. The SSIs were digitally audio recorded, then later transcribed and translated into English by two independent Guatemalan English/Spanish interpreters and the author (SDD) conducting the interviews.

Analysis

Leininger's ethnographic approach and four-phase data analysis process was used to guide this study. The four phases included the author (SDD) making preliminary explanations of observations and interviews, coding emic and etic views, looking for patterns and meanings explored in context, and confirming findings and making recommendations. Reflexivity was used by the investigator in the interpretation and synopsizing of data.

Setting

Guatemala is a country of approximately 15 million people and the population is expected to nearly double to 27 million by 2050 (WHO, 2014, 2015). It is one of the poorest nations in the world, but one of the richest in fertile lands and natural resources. Guatemala has an ancient Maya indigenous population and culture that has been influenced greatly through Spanish colonization, the work of Catholic missionaries since the 1500s, and a 36-year civil war from 1960 to 1996, in which 200,000 people were killed or disappeared, most being indigenous Maya (WHO, 2014; Wingsguate.org). Currently the government agenda focuses on crime, femocide, and justice in a postgenocide/civil war acceptance of violence, with 11.5% of deaths being attributed to violence and the reality that only 5% of crimes are ever investigated or punished (WHO, 2015). As "femocide" implies, women are often the targets of violent criminal acts. A mural in one of the village clinical locations depicts the very recent and ever-present legacy of war, discrimination, and violence for the Maya in this area and throughout Guatemala, but their commitment and faith in building a better more prosperous future (Figure 2).

The interviews and active clinical observations were conducted in the Departments of Sacatepéquez and Chimaltenango, where there are hundreds of small, rural, Maya communities. The community-based cervical cancer screening clinics were held in conjunction with adult and pediatric clinics to provide comprehensive family healthcare services. Active participation and collaboration within and between the communities, the three in-country NGOs, local nurses and physicians, and Florida Atlantic University nurse practitioner instructor and student providers were required for success. Local communities helped spread the word about time and place of clinics. The largest building, usually the school, was closed for the day and used as clinic space. Local women cooked lunch for everyone working on clinic days. Exam spaces were set up in closets or created using sheets and garbage bags hung from string. Teacher's desks were converted into exam tables. Flush toilets and running water were rarely available and there was no shortage of people, dirt, and animals. Women were screened for cervical cancer using VIA and treated, as needed, with cryotherapy. Persons with skin conditions related to long days of work in the sun and exposure to pesticides, parasites, and malnutrition were common in the adult and pediatric clinics. Everyone pulled together and did the best with what they had.

Results

Collaboration

Although not addressed specifically in SSIs, the very nature of community engagement required for participation in the VIA clinics made collaboration a consistent observation. The NGO, People for Guatemala, required communities to be active participants and organizers of clinics and asked for a small monetary reimbursement of five quetzals (approximately 65 cents USD) for medical services. Informal and SSI participants repeatedly explained how these clinics were successful because their community was participatory. "There are other communities in which the people are a little more reluctant . . . but not here. They [the community] supported us with the clinic . . . it was us who organized it." Women wanted solutions for their families for clean water, clinics, roofs, and solid floors and partnered with the NGOs to get them. Only after these participatory collaborations had been successful were healthcare clinics planned. Schools were closed for the day, and

Figure 2. Mural depicting the death and destruction of the people, homes, and lands of the Maya in the civil war (left). As the mural progresses to the right, it shows the subsequent rebuilding of church and faith, schools, and agriculture, and it expresses the hope for equal rights and justice for the Maya.

men and women took breaks from their daily work so that families, mothers, teachers, and children could have a chance to obtain healthcare services. Villages that hosted clinics took pride, dressed in their best, and the mayor, or "Alcalde," would welcome everyone. A Maya woman embraced one of the nurse practitioners, both crying, saying "Thank you for taking care of me." Active community involvement was a prerequisite for the NGOs to consider organizing a community VIA clinic, and it showed.

Semistructured Interviews

Three lay community health workers/organizers were interviewed using an SSI guide (Figure 1). They were between 25 and 42 years of age; one was a Ladino social worker with a college education, and two were Maya village women's group leaders with 8 and 2 years of formal education, respectively. Table 1 offers a synopsis of the five major themes elucidated from the SSIs and the quotes supporting them.

Themes

Fear/Shame. All three women interviewed spoke of the "verguenza" or shame/embarrassment of coming for cervical cancer screening. They referred to a long history of taboo that was just beginning to wane with more open-mindedness, normalization, community experience, and involvement with cervical cancer screening. They expressed a belief that the key to decreasing shame was in the positive experiences with the community-based screenings, making it more acceptable for the next generation.

Machismo. The patriarchal structure of communities, churches, and families was apparent from observations and semistructured and informal interviews. There was a clear message from the women that they were locked in the home, subservient to men, and responsible for taking care of their families. SSI statements supporting "machismo" can be found in Table 1. When one woman described her early involvement with the community women's group, her husband would say, "Why are you going? I'm working, I need my meal, I need my lunch and if you go it won't be on time." Women in the women's group spoke of not being allowed to participate in the beginning and that only after a long time, after the men started seeing the results of the women's work, did they begin to accept other roles for women outside the home. A local physician spoke of never using a husband as a translator, as they will speak for their wives and will not let them talk or voice their opinions or let them ask their own questions. A group of about 18 women and 4 toddlers were observed sitting in a courtyard patiently waiting their turn to be seen during a clinic day, when the local "Alcalde," or Mayor, strutted up and down, beaming proudly over the accomplishments of the day. The "Alcalde" was carrying a cane, a symbol of power in both Spanish and Maya culture. Suddenly, a toddler ran off from the group of women and the "Alcalde" immediately came up and kicked the child. The women went scrambling to retrieve him and glanced nervously at each other and the "Alcalde" as he walked away. This seemed a clear demonstration of the male "Alcalde's" power over the women and children of the village. The women were quick to obey and keep things in proper order. Another observation of male dominance came on a low turnout clinic day. The low turnout was most likely due to the local Catholic priest's call for a 24 hour prayer meeting on the same day, and there was talk as to whether or not this had been done on purpose to keep women away from the clinics. The men, be they husband, mayor, or priest, had the positions of power.

Education/Experience. All of the SSI participants (see Table 1) and several informal interviews supported women being proud of more formal educational opportunities. "Grandmas didn't go to school and now women study majors." They felt that education was a way of expanding their worlds, creating more opportunities and more open minds. It allowed women to think for themselves and have their own voice without having to listen to their husbands or priest for direction in their lives. Positive experiences with participation in cervical cancer screening was seen as an improvement or benefit for those women who had not been afforded such opportunities or were not aware of the advantages of participating in screening.

Cost. In most rural Maya families, men work as farmhands, making as little as 10 quetzales per day ($1.30 USD), yet one woman said that it cost between 100–150 quetzales for a gynecologist appointment. This did not include the cost of medicines and treatments. For the poor indigenous Maya, seeing a specialist or doctor could potentially take a full year's wage. Cost as a barrier

TABLE 1. Summary of Themes

Theme	Supporting Quotes
Fear/shame	"Sixteen years ago women feared this test . . . it was taboo." "Verguenza." "Next generation seems less afraid, asks questions, more open-minded." "Women have been civilized and sensitized that the test is something normal and they shouldn't be ashamed." "There are other communities in which the people . . . are scared, but not here."
"Machismo"	"Always there has been the machismo from the men." "But the man says, 'Why are you going? I'm working, I need my meal, I need my lunch and if you go it won't be on time' . . . even as pigs that we are, women can't rule themselves, according to them, but we have the same rights." "He used to ask me, 'Do you think all women can do that?' and I replied, 'Of course they can, . . . but I need your support' . . . and little by little he started to see the experience . . . (he started saying) . . . ' Well, if you're going to do a good job then I think it's okay."'
Education/experience	"Grandmas didn't go to school and now women study majors, it is changing women's mentality and there are more open minds." "I have come, and yes, thanks to G-d, with the medicines they gave me there has been a lot of improvement." "They get encouraged . . . she went and had an improvement . . . then they get confident." "Others don't come because they have not realized the advantages."
Cost	"A gynecologist is charging 100 to150 quetzales per appointment, so to go to the doctor I need about Q200." "Because we are poor, we can't afford a specialist." " . . . the problem of money . . . you get the prescription, but you buy only what you can buy and the rest you can't get it, so you don't get the appropriate treatment." "He tells you which disease you have, what you need to take to heal, but if you don't have the money then you're only going to know what is affecting you, but you come back worse than before, because you feel demoralized . . . you can't afford the right treatment."
Self-love	"If I love myself, then I'm going to take care of my health." "There are small things that we had to do, but we came anyway." "If it is important you'll do it." "There are some that do not care about their health."

to cervical cancer screening was also supported in SSIs (Table 1). One woman talked about how even if they were able to save the money to see a physician, if something were found there would be no way to afford the medicine or treatment, so why ever go, "you come back worse than before, because you feel demoralized . . . you can't afford the right treatment."

Self-Love. The women that worked to bring the mobile cervical cancer screening clinics to their communities were committed to improving their own, their communities', and their families' lives. These women were self-empowered and this came through in the SSIs (Table 1). Statements like, "There are small things that we had to do, but we came anyway . . . if it is important you'll do it." Women who made the effort to participate in screening clinics thought that if you cared about yourself, then you would do what it takes to get cervical cancer screening. These women had self-worth and knew that if they did not take care of themselves, they would not be able to take care of their families or improve conditions for their communities.

Strengths and Limitations

A study strength was the use of local Spanish/English interpreters, familiar with the local Mayan language, for the SSIs. This may have helped to alleviate the power/inequalities of language that may be felt by these women, as Spanish is often their second language and expressions may be better captured in their native Mayan

language (Temple & Young, 2004). In addition, two Guatemalan Spanish translators were used for translation and transcription of SSIs. This meant that colloquial uses and meanings of words may have been better understood and better translated in cultural and social "context" (Chen & Boore, 2009; Temple, 2002). However, there is always the risk of losing content/context with translation of interview transcripts from one language to another, as translators' own interpretations come into play through the process of translation (Temple, 2002). Back-translation to improve the trustworthiness and validity of translation was not employed in this study, but triangulation of the English transcripts from two professional translators and the author (SDD) was used to improve validity (Chen & Boore, 2009).

The specific study location and purposive sampling of SSI participants limits the generalizability of this study. However, it is important to note that many of the concerns of women living in high–cervical cancer incidence, low-resource areas are similar (Driscoll, 2016). The purposive sampling of Spanish-speaking women involved with organizing the cervical cancer screening clinics ensured that SSI participants were aware of cervical cancer screening, were able to communicate their experiences orally in Spanish, and potentially had personal and vicarious experiences with the phenomenon of interest. Although limiting, this selection process helped guarantee that the appropriate information would be gathered. "Since qualitative inquiry seeks to understand the meaning of a phenomenon from the perspective of the participants, it is important to select a sample from which most can be learned" (Merriam, 2002, p. 12). The small SSI sample size also precluded reaching data saturation.

Researcher reflexivity was used in an attempt to decrease bias and increase the rigor of this small descriptive study. Reflexivity may have helped, but several other factors worked to weaken rigor. In particular, the fourth phase of the Leininger (2006) ethnonursing method, confirmation of findings with key informants, was not done. Only one data analyst (SDD) interpreted and explicated observations, informal interviews, and SSI data into resultant themes, making results inherent to the biases of the researcher. To improve data reliability, field notes from both authors were included as data and peer review of results was done by the second author (RG). Although a thorough discussion of rigor is important, improved rigor does not always affect the "richness" of the data collected (Cleary, Horsfall, & Hayter, 2014).

Discussion

Stigma/fear, "machismo," and cost were found to be barriers, and collaboration, education/experience, and self-love were identified as facilitators to cervical cancer screening in this study. Reflecting upon the elucidated themes and the researcher's participatory experiences brings cultural humility, collaboration, and balance of power to mind. When pulled together these concepts could all work to facilitate emancipatory praxis to ultimately reduce barriers and augment facilitators to cervical cancer screening. Emancipatory praxis may be a key to promoting women's participation in cervical cancer screening, which would bring about the greatest reductions in cervical cancer morbidity and mortality in women rarely or never screened in Guatemala and globally.

Cultural humility is a process-oriented approach to cultural competency, requiring a lifelong commitment to self-evaluation, openness to other, and recognition of the value of each individual or group (Campinha-Bacote, 2007). Cultural humility could be taught to healthcare providers through both formal and informal processes in provider training programs and active participation in collaborative community-based clinics as described in this study. Healthcare providers who learn cultural humility are open to other, value the work of all individuals, and would be less likely to discriminate based on ethnicity or gender. Respectful clinical interactions between culturally competent providers and their patients would lend to the positive experiences described by study participants as a facilitator to participation in cervical cancer screening. Positive experiences ease fear, educate and empower women, and would prompt them to participate in screening and encourage their mothers, sisters, other family, and friends to obtain screening as well. By example and continued interaction, cultural humility may spread to men of the community and work to lesson inequitable "machismo" beliefs and actions. Therefore, cultural humility could constructively effect three themes identified in this study: fear/shame, education/experience, and "machismo."

Beneficial collaborative interactions like those observed during the course of this study may work to "accommodate" and slowly "repattern"

misconceptions and interpretations of cervical cancer and cervical cancer screening for all involved (Leininger, 2006). Building partnerships with women, men, communities, and healthcare providers will build trust. Collaboration, cultural humility, and involvement of women, men, and community could normalize interactions with cervical cancer screening providers, reducing the fear and shame felt by women. Again, positive experiences will lead to trust and subsequent spread and uptake of cervical cancer screening services.

Creating a balance of power with continued cervical cancer screening initiatives, like those observed in this study, would continue to empower women without marginalizing or excluding men. There is a relationship between health and gender equality and the empowerment of women (Anderson & McFarlane, 2010). Empowerment promotes self-love. Women allowed to give voice and take action for the betterment of themselves, their families, and their communities will set an example. As one woman described, as men saw "the positive effects of our actions," they began to see that women were as capable as men and could improve the health and lives of their communities both within and outside the home. There was a movement toward respect, value, and balance of power, and the support of their husbands allowed women to better take care of themselves, their families, and their communities.

Conclusion

The practice of cultural humility, collaboration, and balance of power facilitates making a common cause with men, women, community health workers, healthcare providers, and community in "pragmatic solidarity" (Farmer, 2005). It is emancipatory praxis, a cyclic process that requires reflection and action against social injustices (Freire, 1970/2007; Kagan, Smith, Cowling, & Chinn, 2010), like inequitable access and utilization of cervical cancer screening. Boykin and Schoenhofer (2001) refer to this type of praxis as "the dance of caring persons," in which those who were involved in the oppressive and hierarchical structures that contributed to these sorts of health disparities build the courage, trust, and humility to work together. Every person has a unique contribution and is "committed to knowing self and other as living and growing in caring" (Boykin & Schoenhofer 2001, p. 36). This is what we bore witness to in Guatemala.

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