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A Qualitative Assessment of Cervical Cancer Risk Perceptions among Women in Rural El Salvador

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Abstract

Background: Cervical cancer mortality in El Salvador remains a significant burden, yet participation in screening programs is variable. To improve screening participation, we sought a greater understanding of the relationship between participation and cervical cancer risk perception.

Methods: Women in rural El Salvador participating in a cervical cancer screening program responded to an administered questionnaire from 10/2012-03/2013 describing their perceived personal cancer risk and the justifications for their views. Content analyses of responses was performed to categorize the responses and Pearson's chi-square statistics assessed associations between risk perception and justification categories.

Results: Among 409 women, 187 (45.7%) viewed themselves at risk of developing cervical cancer, 65 (15.9%) not at risk, and 157 (38.4%) uncertain. Justifications of perceived risk revealed the themes of fatalism (the concept that outcomes cannot be changed), agent causality (free will of actions that can alter outcomes), a non-exceptional view of cancer risk (all women could develop cancer), and identification of cervical cancer risk factors. Fatalistic and non-exceptional justifications were associated with a view of being at risk of developing cervical cancer ($p<0.001$ and $p<0.0001$, respectively).

Conclusion: Complex motivations and beliefs underlie cancer risk perception. Future research may allow public health programs to tailor cervical cancer education to improve screening participation.

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Introduction

Despite significant reductions in cervical cancer rates and mortality in developed nations from improved screening and management, cervical cancer remains one of the leading causes of cancer and cancer-related mortality in low- and middle-income countries [1]. In El Salvador, cervical cancer is the second-greatest cause of cancer-related mortality, with incidence and mortality rates of 25.0 and 11.8 per 100,000 women, respectively [1,2]. Much of this elevated burden can be explained by inadequate screening coverage, with recent estimates of women having participated in any screening ranging widely from 17-87% in El Salvador [2-4].

While there are numerous barriers to adequate screening coverage, studies have also found socio-cultural components and risk perception to play a significant role. [5-7] The perception of being at high-risk for cervical cancer is correlated with screening intention and prior and future screening attendance. [8-10] While epidemiologic factors have been associated with cancer risk perception, they do not fully explain risk perception. [8,9,11-15] More importantly, these risk factors are not readily modifiable by either clinicians or public health programs. Previous studies of personal cancer risk perception, including a systematic review, found that educational interventions primarily genetic counseling and educational pamphlets were ineffective at impacting risk perception over the short- or long-term, finding baseline perceived risk to be most commonly associated with post-intervention risk perception. [16] Therefore, further investigation into risk perception and the reasoning process behind one's perception of risk may yield opportunities for appropriate counseling and education regarding actual risk in an effort to improve screening efforts.

To assess the broad themes governing a woman's risk perception and motivations, it is first necessary to qualitatively describe potential factors. However, few qualitative investigations into the reasons contributing to risk perceptions have been published. A past study among Dominican and Puerto Rican immigrants in the United States noted that women perceived cervical cancer risk to be associated with sexual behaviors and lack of self-care; participants frequently reported fatalism and embarrassment. [17] With these qualitative themes as an initial starting point, we aimed to confirm, broaden, and expand upon these concepts.

The primary objective of this study is to describe cervical cancer risk perceptions among women participating in a cervical cancer-screening program in rural El Salvador and to describe the

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motivations behind women's beliefs that explain those perceptions. Identifying these specific reasons for risk perception may be used to create more appropriately targeted messages and increase the effectiveness of educational initiatives to increase cancer screening rates.

Materials & Methods

This study uses data from surveys administered in a cross-sectional study of adherence to a cervical cancer screening and treatment program involving women who participated in Phase I of the Cervical Cancer Prevention in El Salvador (CAPE) initiative, a program which examined the use of a novel human papillomavirus (HPV) test in low-resource locations [18,19]. The study was reviewed and approved by the Institutional Review Board at the University of Pittsburgh and the National Ethical Review Board of El Salvador.

As part of CAPE, women participated in an educational session prior to screening. [18] When women arrived for the education session (n=2030), research assistants verified their eligibility and served as interviewers administering questionnaires. Women were eligible if they were aged 30-49 years, not pregnant, able to provide informed consent, and without history of cryotherapy, loop electrosurgical excision procedure, or hysterectomy. As part of the adherence study, interviewers randomly selected one-third of the women attending the sessions until a target sample of 409 women were enrolled [19]. Enrollment stopped after 409 participants as it was the sample size that would allow detection of a 15% difference or greater in appointment attendance with 80% power. Interviewers were trained to read questionnaire questions to the participants verbatim and record free responses verbatim to the best of their ability. Cervical cancer risk perception was assessed with the question, "Do you think you could ever get cervical cancer?" Responses were recorded as yes, no, or don't know/not sure. Women were then prompted to give a reason in an open-ended format, which were recorded as close to verbatim as possible.

Two investigators fluent in both written and spoken Spanish and English (AR and RF) reviewed all open-ended responses from study participants. These investigators performed content analyses by independently coding each of the responses. Responses that were deemed by one or both coders as having an unclear significance were reviewed and coded jointly. Coding proceeded in an open, iterative manner with the two investigators meeting regularly to compare codes and refine the coding scheme. An initial coding scheme consisting of 13 categories was then applied by each coder to all responses and Cohen's Kappa was calculated for each of the 13 categories. Categories that showed less than excellent agreement ($k<0.80$) were further redefined by the coders and the responses were recoded utilizing the new scheme. The 13 categories were then condensed into 5 overarching themes for which Cohen's Kappa correlations were recalculated, and all were found to have a $k>0.80$. Associations between risk perception and justification category were assessed using Pearson's chi-square statistics. Responses that were coded differently by the two coders were assigned a half-point throughout the statistical analyses.

Results

Of the 410 women randomly selected to participate in the adherence study, only one woman declined participation. Of the 409 study participants, 187 women stated they believed they could develop cervical cancer, 65 believed they were not at risk, and 157 were unsure. Risk perceptions and justifications are reported in Table 1. Reviewing the responses for the motivations behind perception of risk revealed several themes: fatalism (the belief that outcomes are predetermined), agent causality (the belief that one has free will, and that personal actions can alter outcomes), non-exceptionalism (the view that one has the same risk as others in the population), and identification of accepted risk factors. These categories, which are further described in greater detail below, are distinct but not mutually exclusive, as some of the portrayed responses show.

Participant Justification For Perceived HPV Risk and Cervical Cancer Risk	Perceived Risk for Developing Cervical Cancer, n=409			Justification for Perceived Risk
	Yes n=187	No n=65	Don't Know / Not Sure n=157	p-value
Fatalism	104.5 (11)	20 (2)	58 (6)	<0.001
Agent Causality	71 (2)	33 (0)	26.5 (1)	0.07
Non-Exceptionalism	114 (6)	10.5 (1)	49 (8)	<0.0001
Epidemiological/ Personal Risk Factors	72.5 (3)	27 (2)	29 (4)	0.69

Note: Non-agreement between coders was coded as one-half of a positive categorized response; the number of instances of coder non-agreement is listed above within parentheses.

Fatalism, or the belief that outcomes are preordained, was expressed by many of our participants (n=182.5, 44.6%). This principle proposes that factors outside of one's control produce unavoidable results: that their risk for developing cervical cancer cannot be changed. Some women expressed that their destiny was out of their control, attributing risk to their conviction that God would protect them. One woman, believing herself not be at risk of cervical cancer, stated that, "I have faith in God it won't happen." Others were fatalistic but uncertain of their risk, such as another woman who replied, "you never know, but God does." However, fatalistic views extended beyond religion, such as women who stated they could get cervical cancer, "because of my family, and my father," or "you get illness even when you don't hope for it." Fatalistic views were strongly associated with a belief of being at risk of cervical cancer ($p<0.001$).

Agent causality was also identified in many responses from women as their reasoning for their cancer risk (n=130.5, 31.9%). These women believed that their own actions impacted and could change a potential outcome: the risk of developing cervical cancer. Some women cited past healthcare, such as two women who responded, "I have been checked, and it has always turned out well," and, "if you don't complete the test…" Other women cited their own sexual activity as the rationale for risk; responses included, "I don't have a partner," and, "from the moment you have sex you are at risk." Other women claimed to be at risk because, "lack of care for [her]self," or not be at risk "because I care for myself." These women believed that their actions – which they sometimes described in general or specific terms – affected their perception of their cervical cancer risk.

Some participants expressed a belief in non-exceptionalism, or the view that every woman, including herself, possesses risk (n=173.5, 42.4%). These women recognized themselves to be members in a population with the same cervical cancer risk as other women in the population. Many women who expressed non-exceptionalistic views responded using impersonal statements such as, "all women are [at risk]; we are predisposed to developing it" and "they say anybody can get it." A non-exceptional view of cervical cancer risk was strongly associated with the perception of being at risk for cervical cancer ($p<0.0001$).

Another portion of our participants used epidemiological or individual risk factors as justification to stratify their risk level (n=128.5, 31.4%). These risk factors may be either modifiable or non-modifiable and provided the context with which the patient would perceive herself to be at risk or not at risk of developing cervical cancer. Many women identified sexual history or partners, believing to be at risk, "because I have sexual relationships" or, "because of men." Other women identified their genetic or family history as modifying their source of risk, responding, "they say that the cancer is hereditary" and "nobody in my family has died of that." Others identified previous participation or lack of participation in screening ("I've never been tested") or prior gynecologic examinations ("I have taken steps like getting exams") as altering their risk. A few women also stated that their age predisposed them to developing cancer, as one woman stated "as one gets into older age it can happen."

These themes were not mutually exclusive, with the clearest examples being women whose response demonstrated agent causality by citing a modifiable risk factor, such as the woman who stated, "If I don't participate in screening then I'm at risk." Another frequent combination of themes was a fatalistic view combined with non-exceptionalism, such as women who responded that, "they [men] are giving enough women this risk" and, "we never know the partners our husbands have had."

Discussion

Our study explored cervical cancer risk perception and justifications among a novel population and in greater depth than prior publications. Among rural Salvadoran women participating in an HPV screening program, clear themes that have been previously reported in both the cervical cancer and political/social sciences literature were identified. Fatalism, agent causality, non-exceptionalism, and epidemiological risk factors were most frequently cited, and each suggests unique interventions to improve cervical cancer screening efforts. Fatalism and agent causality are mutually exclusive concepts. Agent causality the view that personal actions alter outcomes is a key pillar of health education programs. Non-exceptionalism, the view that all members of a given community possess some risk of developing an illness, is another important aspect of cancer screening programs. Additionally, educational programs often describe basic epidemiology, pathogenesis, and risk factors of illnesses. These themes have previously been mentioned in cervical cancer risk perception literature.

Fatalism has been previously reported among Latina populations across multiple health disciplines and was confirmed by our study [17,20-22]. However, investigations of fatalism are complicated by the multiple definitions assigned to the term. Definitions of fatalism include the perceptions that a diagnosis is akin to a death sentence, implying that no effective intervention exists after a diagnosis; that resistance against the inevitable is futile (also known as defeatism); and that fate is predetermined. We defined fatalism as the belief that outcomes are predetermined; the specific outcome was not the development of cervical cancer but rather the patient's perceived risk of developing cervical cancer. We selected this definition to distinguish women whose beliefs suggested that their risk was fixed. Often, these responses indicated the presence of a deeply held religious or personal conviction, which have been shown in political and social science literature to be more difficult to address via education [23,24].

In assessing fatalism, it must be recognized that women face many barriers to screening participation, including lack of healthcare access, mistrust of physicians or the healthcare system, and family/social relationships such as intimate partner violence, gender inequity, or gender stereotypes, that may contribute fatalistic views [25]. Additionally, an individual's economic capacity is suggestive of screening participation, even in countries with universal access to healthcare [26]. Therefore, fatalism and screening rates may display bidirectional causality, explaining why women with fatalistic views were more likely to view themselves as being at risk for cervical cancer. Possibly, these women did not view cervical cancer risk as predetermined, but simply believed that they didn't *personally have the means* to alter their cervical cancer risk, encapsulated by the woman who replied that, "sometimes I just can't go to get tested."

Participants frequently responded that agent causality – the belief that one may choose actions that change outcomes – justified their view of personal cervical cancer risk. A large percentage of participants expressed non-fatalistic views of cervical cancer risk, suggesting that educational programming may be effective for these individuals. Past studies of educational programs informing women of cervical cancer and its risk factors found that women with high education levels altered their perceived risk when informed of risk factors, using information to appropriately identify themselves as high- or low-risk [15,27]. Another study which repeatedly exposed women to cervical cancer messages through the media found the messages to increase risk perception, while another study found messages prompted women to attend screening [28,29].

Another theme we identified, non-exceptionalism, is a cornerstone of public health. Our study defined non-exceptionalism as the view that all members of a population, including oneself, possess risk, a view which has previously been associated with screening intention and participation in screening [8,10]. Public health education aims to instill this view in community members. Women demonstrating non-exceptionalism in their cervical cancer risk justifications were more likely to view themselves to be at risk of cervical cancer.

The final theme identified in our study was related to identification of risk factors. Many of these responses suggest that some women had previous knowledge of cervical cancer and cervical cancer screening, and that they appropriately used that awareness to determine their personal risk; this behavior has previously been reported [15,27]. This does not indicate that women always used this information accurately, as some women cited a lack of risk based upon faithful partners, which would necessarily eliminate a woman's cervical cancer risk.

The beliefs underlying cervical cancer risk justification have implications for further research and policy. Strongly held beliefs, such as fatalism, may produce a dichotomous boomerang effect wherein only those who are predisposed to believing the message will have the desired response; those who are not predisposed may reject both the message and the source [24]. This phenomenon may explain beliefs regarding vaccinations, alternative medicines, and cancer screening [23-25]. As an example, if an individual's belief construct causes them to strongly believe that only God determines their chances of developing cervical cancer, it is possible that education may be less effective: they may reject an educator who is providing information that contradicts their beliefs. Involving a religious leader in educational sessions, as an attempt to form a dialogue within the individual's belief construct, may be beneficial. Of note, while the religion of participants was not recorded in this study, over 85% of the population in El Salvador is Christian (50% Roman Catholic and 36% Protestant), and it is possible that these findings may be generalizable to other similar populations.

Our data suggests using non-exceptionalism to improve cervical cancer screening programs. Non-exceptional views underlie findings of a past study finding women who knew an individual with cervical cancer more likely to view themselves at risk of cervical cancer,

implying that incorporating community members, public personas, or celebrities impacted by cervical cancer in public health educational sessions would be beneficial [11].

The use of cervical cancer risk factors by women indicates opportunity for further education. Concerningly, some women who viewed themselves to not be at risk of cervical cancer did so because they believed their partner was faithful. Women still need to be aware cervical cancer risk remains due to the possibility that their spouse may have had previous sexual partners, and that the latency period between HPV infection and cervical cancer development may be several years.

Strengths of this study include assessing risk perceptions in a novel population, and the combined use of qualitative and quantitative responses to capture greater information. A limitation is that all of women were participating in a cancer screening educational program, with knowledge that they would be offered the opportunity to participate in a new HPV test-based screening method. Thus, our findings do not generalize to women who declined participation in the educational program. Additionally, risk perception was a secondary analysis, and therefore the study was not powered to assess these specific analyses.

Conclusions

In a novel population, we identified themes seen in previous studies of risk perception. Agent causality, non-exceptionalism, and individual risk factors are all pertinent to crafting effective cancer screening programs; these views may serve as an intermediate marker a screening program's success. Clarifying the ways individuals possessing these views are affected by educational programs and their use in predicting cervical cancer screening participation would be advantageous. We also found fatalism, further increasing the generalizability of findings and policy implications aimed towards addressing these beliefs. Importantly, studies analyzing fatalism must use a consistent definition as this is key to interpreting results. Further study into strategies which consider these views in the design of cervical cancer screening programs is warranted.

Author Contributions

All authors contributed to the study conception, design, writing and review of the manuscript, and approved the final version of the manuscript. AR and RF completed the data coding and analysis. AR wrote the initial draft of the manuscript. All authors approved the final version for submission.

Competing Interests

The authors declare that they have no competing interests.

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Data Availability Statement

The data used in this article can be made available upon request.

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