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Acceptability and feasibility of a community based participatory research project comparing cytology and urine HPV DNA testing for cervical cancer screening in Yap, Federated States of Micronesia

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ABSTRACT

Non-invasive, self-collected sampling methods for HPV DNA detection in women, which are reliable, efficient, and acceptable have the potential to address barriers to cervical cancer screening in underserved communities, including low-middle income countries (LMIC) such as the island nation of the Federated States of Micronesia (FSM). Urine-based HPV testing has not been rigorously evaluated in clinical trials. A pilot community-based participatory randomized control research project evaluated use of urine HPV testing as a more culturally- and human resource appropriate method of cervical cancer screening in Yap State, FSM. Women participated in a cervical screening intervention using pap vs. urine test (N = 217). This manuscript described attitudes about screening feasibility and preferences. Stakeholders and women participants were interviewed (N = 23), and a survey also evaluated women's screening preferences (N = 217). Qualitative content thematic analysis with multiple coders identified themes from interviews on acceptability and feasibility of screening tests. Women research participants were comfortable with the urine test (95%), despite limitations in some to provide samples. While 82.0% indicated that they felt comfortable with Pap smear, they also preferred a clinician (42%) to do the Pap smear, explaining that they preferred having a trained worker instead of themselves to do tests. Women want to be screened but accessibility remains a challenge. Education and training of professionals and community members alike will improve clinical skills, research capacity, knowledge of screening tests and behaviors including prioritizing HPV screening and testing.

1. Introduction

1.1. Cervical cancer research in Federated States of Micronesia

Globally, cervical cancer is the third most common cancer in females and the second most frequent cause of cancer death, with the majority of cases, including a large proportion of late stage cancers, occurring in low-resource settings [1]. Cultural, social and geographic barriers impact access to cervical cancer screening in resource limited countries [2]. Human papillomavirus infection (HPV), primarily oncogenic types HPV 16 and 18, is the principal cause of nearly all cervical cancers [1]. Along with prophylactic vaccinations for HPV, screening remains an important component of cervical cancer prevention strategies. HPV DNA testing has proven to be an important adjunct to cervical cytology (Pap) screening for the early detection of precancerous lesions [3]. Recent studies have demonstrated that HPV DNA testing has higher sensitivity than Pap smear testing [4,5]. In March 2014, the U.S. Food and Drug Administration advisory panel recommended that HPV DNA testing could serve as the primary tool for cervical cancer screening.

The Federated States of Micronesia (FSM) is comprised of 607 volcanic islands and atolls scattered over 1 million square miles of the Northwestern Pacific Ocean. The land area totals 704.6 square kilometers, with 7192 square kilometers of lagoon area. The FSM consists of four geographically separate states: Chuuk, Kosrae, Pohnpei, and Yap [6]. FSM is one of the most resource-limited US Affiliated Pacific Island (USAPI) jurisdictions, suffers large cancer health disparities, but also has some of the strongest community-public health partnerships in the USAPI [7].

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Micronesian women disproportionately suffer from cancer disparities having among the highest rates of cervical cancer in the world including women in Yap State. Yap has an age-adjusted cervical cancer incidence rate of 20.4 per 100,000 (2007–2012) which is twice the incidence rate in the US. Only 28% were diagnosed at Stage 1. Seventy percent of the women diagnosed in 2007 or later have died [8]. Funding limitations presently allow 4–10% of women to receive cervical cancer screening per year by traditional cytology or using visual inspection with acetic acid (VIA) in accordance with the 2010 FSM National Standards on Breast and Cervical Cancer Screening [9].

Yap State has demonstrated ability to mobilize women from the main and outer islands to tailor cervical cancer education materials, build local capacity for and provide screening, and has been expanding their local capacity for rigorous evaluation of public health programs and policies as part of their partnership with Center for Disease Control and Prevention (CDC) sponsored program with the University of Hawai'i (UH). Although resource limited, Yap has capacity for appropriate follow-up and treatment of abnormal Pap or VIA and can treat Stage 1 cervical cancers on island. Yap State has a well-organized Wa'ab Community Health Center network that provides most primary care services on the main island and has outer island health assistants trained to provide cervical cancer screening. Annually since 2008, the Yap Cancer Program has been able to recruit in just one week over 200 women from the outer islands and main island for Women's Health Week cervical cancer screening.

Non-invasive, self-collected sampling methods for HPV DNA detection in women, which are reliable, efficient, and acceptable have the potential to address current barriers to cervical cancer screening in underserved communities, including low middle income countries (LMIC) such as the FSM. Hernandez et al. demonstrated that – self-collection for detection of penile HPV was preferable to clinician-collection among U.S. males [10]. CDC-funded projects in the USAPI have shown high preference for alternatives to traditional cytology based screening [11]. Nonetheless, urine based HPV testing has not been rigorously evaluated in clinical trials. The primary objective of this pilot study was to determine the acceptability and feasibility of culturally- and health workforce-appropriate cervical cancer screening methods, recently published American College of Obstetricians and Gynecologists Committee Opinion 624 [12].

1.2. Community based participatory research

A secondary objective of this pilot study was to examine the community based participatory research (CBPR) used in the study, how this approach contributed to study completion and fidelity, and the extent HPV screening tests are feasible and preferred. CBPR is an approach in health promotion research that especially addresses health disparities through the engagement and partnership of researchers and community members in all phases of the research [13]. This collaboration has the potential to be transformative for all those involved wherein partners (e.g. researchers, community residents and service providers) participate in multiple aspects of research, from determining goals to developing methods and procedures to disseminating results [14].

Pinto et al., developed and described the International Participatory Research Framework (IPRF) to advance CBPR. The IPRF presents steps and actions to improve the abilities of researchers and practitioners worldwide to systematize the development of research partnerships and which can facilitate participatory research in myriad international settings. The CBPR literature lacks specificity regarding how to initiate, employ and sustain participation when working with partners internationally in developing countries [14]. The IPRF serves as a relevant CBPR project framework because the IPRF describes the international participatory processes that the collaborative team demonstrated, contextualized to the host country, Yap State, FSM.

2. Materials and methods

2.1. Study design

Women undergoing Pap smear screening in Yap State in the FSM were randomly assigned to one of two arms: (1) urine collection followed by clinician cervical sampling; or (2) clinician cervical sampling followed by urine collection. Measures included patient- and provider acceptability of the sample collection procedures and qualitative data collection to gauge readiness for scale-up of HPV DNA testing as the primary screening method as well as participation in formal cancer research.

CBPR was included in this study to tailor the randomized control trial methodology to be more feasible and meaningful to the communities and researchers. Pinto et al's IPRF comprises four recursive steps: (i) contextualizing the host country; (ii) identifying collaborators in the host country; (iii) seeking advice and endorsement from gatekeepers, and (iv) matching partners' expertise, needs and interests [14]. Using this CBPR framework, these steps were operationalized in the current HPV CBPR trial. This manuscript reports on the CBPR methods and results to ultimately address the acceptability and feasibility of cervical vs. urine sample for study participants and project stakeholders (Results of the urine versus pap detection of HPV are reported elsewhere.)

Collaborations between the academic researchers and Yap spanning a decade has provided best practices on successful collaborations involving community feedback and shared decision making used in this project. CBPR was operationalized through a project steering committee (SC) in Yap [15] that included members integrally involved in improving cervical cancer screening and who have a 10-year history of engagement with the academic collaborators. Members of the Yap SC developed the pilot project proposal with the project investigators. Monthly calls and frequent reporting were conducted to evaluate the project's process, progress, intended and unintended impact on the health system in Yap, and any needed changes were discussed and addressed. The Yap SC contributed to all project activities including dissemination. Research protocols and materials were approved by the Western Institutional Review Board.

2.2. Recruitment and randomization

The SC and outreach staff recruited 217 Yapese women and as many outer island women as feasible. Eligible subjects were women aged 21–65, who had not had a hysterectomy and were not currently pregnant, and who had not had cervical cancer screening within the past three years or who had had abnormal screening results within the past three years. –This population was targeted in order to yield higher numbers of HPV DNA+ women than would be derived from a previously screened population. Additionally, targeting these women provided tremendous benefit to Yap and appropriately directed resources toward the population at highest risk for cervical cancer.

Trained staff met with potential study participants, obtained written informed consent and ensured completion of the exit survey after specimen collection was completed. Study subjects were randomized into cervical cell or urine collection groups. Upon conclusion of the study visit, subjects were provided with an incentive worth approximately $15 (i.e., project logo-printed multi-purpose bag).

Cervical cell specimens were collected by a trained clinician using liquid based cytology (ThinPrep). Up to 30 mL of first catch urine specimens were collected by the participant in the restroom using a labeled sterile collection cup. Specimens were stored in the