**Title: Engaging Community Members as Health Advocates in a Peer Driven Intervention – A Cervical Cancer Prevention Pilot in Punjab, India**

**Abstract (150 words)**

*Purpose:* In India, cervical cancer is the 2nd leading cause of cancer related death in women. We piloted a peer-driven intervention (PDI) called Cervical Health Action and Intervention (CHAI), a curriculum based educational workshop for women in Punjab, India. *Methods*: Sixty eight women (18-50 years) were recruited to attend a workshop with pre-post evaluation. Women from Workshop 1 referred others for Workshop 2. *Results*: Workshop 1 attendees (n=35) referred 33 other women for Workshop 2, confirming the feasibility of PDI. Mean age was 29.48 (SD=8.2). Paired T-tests showed increases in knowledge (19.41 vs 29.25, p<.001), and confidence (2.67 vs 3.70, p<.001) in imparting information. *Conclusions:* This PDI is a feasible, culturally specific approach that leverages personal networks to reach at-risk women, and successfully improve knowledge and confidence in discussing cervical cancer prevention with others in the community with low cost and minimal resources needed for implementation.

**Introduction/Purpose**

In most developing countries, the incidence of cervical cancer and its related mortality has declined significantly through Pap testing and newer screening methods such as Human Papillomavirus (HPV) typing, However, in India, cervical cancer is responsible for 23% of deaths in women from all cancers (Kawana, Yasugi, & Taketani, 2009) and remains a major public health concern despite cervical cancer being preventable and the availability of HPV vaccination and Pap testing. The Indian government is implementing several strategies to raise awareness and prevent cervical cancer, including Pap testing, HPV typing and HPV vaccines (Cervarix and Gardasil), all of which are available at low or no cost. Recent studies have reported that immunization of young girls in India is becoming acceptable among the more educated (Akoijam, Oinam, Rushitha, & Sougaijam, 2016; Rashid, Labani, & Das, 2016), however, uptake among less educated Indians lags far due to lack of knowledge and awareness regarding prevention of cervical cancer (Akoijam et al., 2016; Chatterjee, Chattopadhyay, Samanta, & Panigrahi, 2016; Rashid et al., 2016; Sreedevi, Javed, & Dinesh, 2015).

In India, cervical cancer is the second leading cause of death from cancer in women aged 18-44 (Bruni et al., 2015), contributes 14% of all cancers in the country (Chatterjee et al., 2016) and accounts for 25.9% of all new cancer cases (Kawana et al., 2009). Risk factors for cervical cancer are older age, low social economic status (SES), early marriage, lower education; a higher number of children (Sreedevi et al., 2015), tobacco use and use of oral contraceptives (Bahmanyar et al., 2012; Chatterjee et al., 2016; Schabath et al., 2012). Of great concern is that screening for cervical cancer is generally low in these populations and they are at highest risk of presenting with advanced and late stage disease (Sreedevi et al., 2015).

Based on the success of our community focused cervical cancer prevention program in the Bronx, New York (R. Chhabra, Rivera-Edwards, & Bauman, 2016; R. Chhabra et al., 2015) researchers from Albert Einstein College of Medicine collaborated with two universities in northern India (Himachal Pradesh University in Shimla, HP and Punjabi University in Patiala, Punjab) to pilot the feasibility and acceptability of a community-based intervention called Cervical Health Action and Intervention (CHAI) that combines cervical cancer awareness and knowledge to encourage women to seek preventative services. To improve the adaptation of the Bronx, New York intervention to India, we conducted a needs assessment in Patiala (Sharma-Uppal & Chhabra, 2016), which consisted of four focus groups (FGs) with local women in the University (n=30). We stratified attendance of each focus group to include college educated career women, college students, and women who worked as domestic help and had not attended college. Of the FG attendees, all had heard about cervical cancer. However, only 10% (n=3) knew about Pap testing; 20% (n=6) had ever heard about HPV, and none of the women knew about the HPV vaccine. All women reported that they had no routine testing or provider visits to a gynecologist; women went for a test or examination only during pregnancy and/or childbirth. All women were interested in accessing the HPV vaccine for their children but only 15% thought it important to get a Pap test for themselves. FG participants identified the need for education about cervical cancer prevention and promotion of HPV vaccination for women at the community level (schools, community centers and clinics/hospitals). They also recommended that the HPV vaccine be endorsed by providers, policy makers, media, celebrities and religious leaders to increase acceptability (Sharma-Uppal & Chhabra, 2016).

Our original program, Cervical Health in the Community (CHIC), (R. Chhabra et al., 2016; R. Chhabra et al., 2015) developed a culturally specific health promotion strategy that uses women’s social networks to increase awareness and knowledge of cervical cancer and HPV vaccination, and to increase intention to receive a Pap test and/or HPV vaccine (Chhabra et al., 2016; Chhabra et al., 2015). Women were trained to talk about cervical cancer prevention with other women in their social network and to encourage them to engage in preventive activities using the strength of personal connection. Utilizing similar principals, this pilot study implemented a cervical cancer prevention workshop intervention in two states in India. The purpose was to assess the feasibility, acceptability, efficacy, and referral potential of a peer driven intervention in which women referred their friends, family and peers to attend an educational workshop. The workshop was designed to increase awareness and knowledge of cervical cancer screening, HPV and HPV vaccination. For this paper, the analysis used data from the two workshops completed in the Women’s’ Studies Centre of Punjabi University (in Patiala, India). The study was approved by Population Research Centre (PRC) of H.P. University Shimla, through letter No. PRC/HPU (IRB)-2016 and received approval from the Women’s Study Centre of Punjabi University

**Literature Review**

In 2012, the annual incidence of cervical cancer in India was 122,844, which accounts for almost 23% of all cervical cancer patients globally (Nandakumar, Ramnath, & Chaturvedi, 2009). The estimated prevalence of HPV is 7.5% to 16.9% among women without cervical cancer and is much higher among commercial sex workers (25%) and around 41.7% to 56% for HIV positive women (Kamalesh, Reshmi, Baishali, Bibhuti, & Subhasish, 2011; Sahasrabuddhe et al., 2010; Sreedevi et al., 2015). Implementing prevention through HPV vaccines and Pap testing at the population level in India is challenging given the geographical distribution. About two-thirds (70%) of India’s population lives in rural areas and faces significant financial and logistic access barriers to general health care; this is compounded for women accessing sexual and reproductive health care or cancer care, due to limited health care options financially and logistically.

Cervical cancer preventive interventions need to be scaled up to reach a population of 436.76 million women over the age of 15 years, most of whom live in rural underserved areas. These interventions also must be designed to fit the standards of cancer care in each Indian state, which differ significantly in culture, geography, education attainment, economic status, and accessibility to health care. The National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS), initiated in 2010, advocates for comprehensive cancer care in district-level care centers. However, there is a noticeable absence of nationwide screening programs, which results in wide disparities in screening, cancer treatment and mortality (Chatterjee et al., 2016; Sreedevi et al., 2015).

 Recent research demonstrates that removing structural barriers to accessing care for hard to reach, low-income populations (e.g. access to providers and medical centers) is necessary but not sufficient (Han et al., 2010). It is also essential to address individual-level barriers (Baron et al., 2008; Dietrich et al., 2006; Dietrich et al., 2007; Paskett et al., 1999; Taylor et al., 2002) such as low motivation, lack of intention, fear, embarrassment, lack of knowledge about accessing preventive services, and how to ask questions about reproductive health (Ackerson & Gretebeck, 2007; Breitkopf, Pearson, & Breitkopf, 2005; Byrd, Chavez, & Wilson, 2007; Byrd, Peterson, Chavez, & Heckert, 2004; Carter, Park, Moadel, Cleary, & Morgan, 2002; Erwin et al., 2007). Most strategies to accomplish significant individual-level behavior change in India rely on media campaigns and community outreach. However, when the health behavior is private, embarrassing and low priority, peer educators from one’s community and/or social network strategies are better for increasing motivation and intention to engage in health prevention (Kelly, 2004).

Many successful behavioral interventions utilize peer pressure and persuasion to affect group norms.(Heckathorn, Broadhead, Anthony, & Weakliem, 1999) The theory of Peer Driven Intervention (PDI), based on sociological theories of group mediated social control (Heckathorn, 1990), suggests that the likelihood of adoption of positive behaviors (e.g., taking care of oneself) strengthens as social network members share experiences, knowledge and encourage each other. PDIs are ideally suited for populations that are not well connected to care and have strong community and individual level privacy concerns (Broadhead et al., 2002; Broadhead et al., 1998; Valente, 1996; Valente, 2010). Our PDI focused not only on educating women about cervical cancer prevention but also on encouraging women to refer their own family and friends to learn about the importance of Pap testing and HPV vaccination.

**Method**

*Study Design and Sample*: The pilot was conducted in a rural northern Indian university town, Patiala, in southeastern Punjab. Eligibility criteria were aged 18-50 years, female, speaks English or Punjabi (the local language), and reads at a fifth-grade level. Recruitment was conducted over two days at Punjabi University through recruitment flyers posted at women’s university residential halls. The flyer invited women to attend an interactive workshop called CHAI “Cervical Health and Intervention” to learn about the importance of cervical cancer screening and HPV vaccination and it encouraged women to share the workshop information with other women. The two 2-hour workshops used a standardized curriculum and was developed by Dr. Chhabra and Albert Einstein Team for Project CHIC (Chhabra et al., 2015). The curriculum included was facilitated by two trained facilitators (the Co-PIs). Participants that completed Workshop 1 were asked to refer friends and family that meet the eligibility criteria to attend Workshop 2 being held the following day. Guided by our existing 'train-the-trainer' (TOT) model for peer-focused education programs (Chhabra, Springer, Leu, Ghosh, Sharma, Rapkin, 2010; Chhabra, Springer, Rapkin, Merchant, 2008), the workshop engaged attendees to ask questions about cervical cancer, Pap testing, and HPV infection and vaccination. The workshop curriculum is culturally adaptable in that it uses questions from the audience to guide the discussions and provides opportunity to address cultural/social norms and beliefs that can hinder sexual health interventions. However, workshop content about cervical cancer, Pap testing and HPV was standardized. In addition, the workshop provided training on effective communication skills, including how to talk to peers about sensitive topics and how to ask and answer questions in a non-judgmental manner, so they would be able to share information and motivate their peers to engage in cervical cancer prevention services. Prior to each workshop, research staff answered study inquiries and obtained informed consent from the women.

*Data Collection Tools:* A self-report questionnaire, administered pre-and post-workshop included measures of knowledge about HPV, cervical cancer, and pap testing; subjective norms about HPV and cervical cancer screenings; health practices history; opinions and beliefs about vaccines; demographics; and an assessment of the workshop and suggestions for improvement. The pre-test had 8 scales (70 multiple choice items) and took10-15 minutes to complete. The post-test had 6 scales (45 items) and took 10 minutes to complete. Data were collected anonymously; an identification number was assigned to each participant and listed on the questionnaires. Participants were told not to write their names on the data collection tools.

*Measures*: Knowledge of HPV, reproductive system, and cervical cancer was measured using a 35-item scalethat was validated in India by Montgomery and his associates in Kerala, (Montgomery, Dune, Shetty, & Shetty, 2015). Knowledge of Pap testing was measured with 12 items adapted from a scale by Fernandez et al. (2009). Subjective norms about cervical cancer screening, HPV, and HPV vaccination was measured with a 9-item scale adapted from a survey by Khanna and his associates (Khanna et al., 2015). Self-Efficacy was measured by a 10-item well-validated scale that assesses general ability to cope with life challenges and situations (α =.88) (Schwarzer & Jerusalem, 1995); it was adapted to measure efficacy talking about cervical cancer with other women. Health Practices History was measured with 15 items on health insurance status; availability and accessibility of health care; and specific health practices regarding doctor’s visits, procedures specific to cervical cancer prevention and logistics to maintain health (Montgomery et al., 2015).TheSocial Network Referral measure asked participants to describe women they knew between the ages of 18-50 who they might ask to participate in the same cervical cancer prevention workshop they had just attended. Demographic questions included age, education, employment, income, marital status, and household composition.

A total of 68 women attended the two workshops. Workshop 1 was held in the evening and 35 women attended. Workshop 2 was held the following day in the afternoon and 33 women attended; all were referred by Workshop 1 participants. However, group facilitators observed that more than 40 additional women showed up after the workshop had started and stayed in the back of the balcony (standing room only) to hear the information and discussion. The enrolled Workshop 2 participants were given a choice to keep the door closed to other non-enrolled participants but they opted to keep it open so that others could benefit. Non-enrolled spectators were given a chance to ask questions after the workshop. Within four days, the study recruited and enrolled 68 participants and implemented 2 workshop interventions. The research activities were conducted with limited staff, resources, and minimal recruitment effort (i.e., posted flyers and word of mouth). The interest demonstrated by the 68 enrolled women and the additional 40 observers attests to the feasibility and acceptability of the workshop and PDI intervention strategy.

Results

Participant demographic characteristics are presented in Table -1 (n=68). The mean age was 29.48 years (SD=8.20); half were 18-26 years. Most (94%) were college graduates; 24% were currently employed and 32% were married. A quarter of the women (25.4%) reported ‘ever’ being pregnant.

**INSERT TABLE 1**

Only 17% reported ever having had a Pap test. And few (17%) had ever been encouraged to get a Pap test by their provider; almost all of those who were encouraged reported having had a Pap test. More than a third (39%) reported knowing about the cervical cancer vaccine and 50% had heard about HPV before attending the workshop. One-third of the women (31.2%) worried what their medical provider would think of them if they asked for a Pap test. Only 21% of (n=33) of women age eligible (i.e. 9-26 years of age) for the HPV vaccine were encouraged by their medical provider to get the vaccine. Only two women had at least one of the three required HPV shots.

Paired T-tests were used to analyze the pre-and-post test data. Attending the workshop significantly increased knowledge of cervical cancer, HPV, HPV vaccine, a Pap test, and reproductive health (19.41 vs 29.25, p<.001); confidence in one’s ability to talk to friends and family about cervical cancer prevention (2.67 vs 3.70, p<.001); confidence in one’s knowledge about HPV vaccine, Pap and cervical cancer (.57 vs 2.70, p<.001); and increased positive opinions and beliefs regarding the HPV vaccine efficacy and safety.

Participants were asked on the pre-test how many women they knew between the ages of 18-50 and on the post-test how many women they intended to talk to about cervical cancer screening, HPV and the HPV vaccine. Thirty percent of the women skipped answering these questions. Of the 70% of women who answered these questions, one in three reported knowing over 50 women in their social network between the ages of 18-50 years who they could possibly talk to about getting a Pap test and about HPV vaccine who were age appropriate (Table 2).

**INSERT TABLE 2**

Some women associated sexual behavior with obtaining the HPV vaccine. The workshop openly discussed and answered questions about sexual health, which is in serious contrast with many of the social, religious and cultural values in the Indian population. Participants that completed the workshop were more likely to view the HPV vaccine more acceptable and use on children and adults more positively. Even though 85% of women in our sample agreed that ‘it is acceptable to have a vaccine against an STI’, at pre-test less than half of participants found it acceptable to use the HPV vaccine with young girls 9-14 years of age (47%) and with young boys 9-14 years of age (42%). After attending the workshop acceptability of using the HPV vaccine with children almost doubled for girls and was more than double for boys (90% vs. 92% respectively) and the acceptability of using the HPV vaccine in women increased pre and post from 77% to 96% and 63% to 90% for men. There was no difference between women who had children and those who did not, in their opinion about the age at which the HPV vaccine should be given.

**Discussion**

Cervical cancer prevention is a public health priority in India. We piloted a PDI intervention strategy combined with a professionally-led educational interactive workshop. The data showed that it is a low cost feasible approach to educate women at risk about cervical cancer, and to reach deep into women’s existing personal networks to reach other women. The approach is acceptable and well received and was immediately oversubscribed.

The findings supported the hypothesis that women would be effective at recruiting other women from their social network. Interventions are frequently derailed due to enrollment failure with the concomitant lack of power to demonstrate efficacy and feasibility. The PDI model had demonstrated feasibility with the added benefit of low cost and use of minimal resources to recruit and implement. The pilot also demonstrated that women were able to reach out to social network members to share sexual health information.

There were some limitations of this study. One methodological limitation was that the study relied on self-report in gathering information from the participants. Participants were given a choice to not answer any questions they did not want to, as a result, some of the questions were missing answers. The social network referral measure was missing almost 30% of the responses. We cannot conclude if this was an inadvertent mistake or intentional. Secondly, the pilot was in a university town with a rural highly educated population. We cannot extrapolate the results of the pilot to urban women or to those who are less highly educated.

**Conclusion**

This pilot study found that women in India, an especially vulnerable group for cervical cancer, are eager for information about cervical health, and significantly benefit in terms of information and self-efficacy from attending a two-hour interactive workshop. Given the incidence of cervical cancer and HPV prevalence in the country, there is an urgent need for community-level interventions to increase knowledge and addressing misconceptions about HPV and cervical cancer. The PDI/Workshop model is a promising way to reach women and educate them about cervical cancer prevention.

The results of the pilot warrant further research to test the PDI/Workshop model further. In future studies, we plan to test the intervention in less educated populations, in different Indian states and in different cultures. We will also test whether women are effective in influencing their peers’ access to and actual use of reproductive health services, and whether workshop attendees actually act upon the information and obtain a Pap test and/or the HPV vaccine for themselves. We also plan to test whether involving parents of adolescents and community gatekeepers in the interventions might affect awareness, improve perceptions regarding HPV vaccine, and encourage preventive behavior.

One issue needs to be addressed in order to fully scale up and test this intervention approach in other populations. The HPV vaccine is not universally available at low or no cost. It is not always readily available at government funded hospitals or agencies, and the cost of the vaccine privately is about $60 (Rs.4000) for each dose, which is not affordable for the general population, particularly for most young women who do not have their own health insurance. Most women do not access regular preventive care for themselves, and have no idea where to go or whom to ask about the vaccine. This makes this preventative, optional, irregularly available and expensive vaccine a low priority. Thus, a system-level intervention to increase accessibility of the HPV vaccine would be a useful addition to this individual-level intervention.

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