

Les jeunes femmes et le dépistage du cancer du col utérin : quels sont les obstacles qui persistent?

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Une réduction du taux de participation au dépistage du cancer du col utérin des femmes âgées de 20 à 24 ans dans la province canadienne de la Colombie-Britannique a conduit à cette étude évaluant les connaissances des jeunes femmes du dépistage du cancer du col utérin et identifiant les obstacles et les facteurs incitant au dépistage. Les chercheuses ont eu recours à une conception qualitative et tenu des groupes de discussion auxquels ont participé un total de 80 femmes. La difficulté à trouver des fournisseurs de soins de santé et le caractère invasif du test de Papanicolaou figurent parmi les obstacles à la participation au dépistage qui ont été mentionnés. Parmi les facteurs susceptibles de faciliter la participation figurent l'aide à la recherche d'un fournisseur de soins de santé, la disponibilité de fournisseurs de soins féminins, des relations établies avec un professionnel de la santé ou une clinique, et l'éducation sur le test de Papanicolaou. L'éducation sur l'importance du dépistage du cancer du col utérin et l'aide à la recherche d'un fournisseur de soins de santé sont des facteurs clés qui favorisent la participation des jeunes femmes au dépistage.

Mots clés : dépistage du cancer du col utérin, test de Papanicolaou

Young Women and Cervical Cancer Screening: What Barriers Persist?

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A reduction in participation rates for cervical cancer screening (CCS) by women aged 20 to 24 in the Canadian province of British Columbia led to this study evaluating young women's knowledge of CCS and identifying barriers to and facilitators of participation in CCS. A qualitative design was used and focus groups were held with a total of 80 women. Barriers to participation in CCS included difficulty finding health-care providers and the invasiveness of the Pap test. Facilitators included assistance with finding a health-care provider, availability of female providers, established relationship with a provider or clinic, and education about Pap tests. Education about the importance of CCS and assistance with finding health-care providers are key factors in increasing young women's participation in screening.

Keywords: cervical cancer screening, Pap tests, young women's health

Introduction

Cervical cancer incidence in Canada has declined from 6.5 per 100,000 women in 1972 to 2 per 100,000 in 2001, while mortality rates over the same period dropped from 18 to just over 7 — decreases that are due in large part to the widespread availability of the Pap test (Public Health Agency of Canada, 2011). The province of British Columbia is home to the world's first population-based screening program for cervical cancer (BC Cancer Agency, 2009). Efforts by the BC Cancer Agency's Cervical Cancer Screening Program (CCSP) and other provincial cancer screening programs have led to an overall cervical cancer screening (CCS) participation rate of almost 80% (BC Cancer Agency, 2010).

In spite of the widespread availability of CCS, and a health-care system that covers all of its costs, between 1995 and 2004 there was a 12% reduction in the rate of participation in CCS by women in British Columbia aged 20 to 24 (BC Cancer Agency, 2005). A decrease in participation was also seen in women aged 19 to 39 who were new to screening, implying that the decrease in recruitment of women in their twenties is part of a trend of younger women failing to incorporate CCS into their health care (BC Cancer Agency, 2005). Since 2005, the rate of CCS participation by women aged 20 to 24 in British Columbia has stabilized and begun to gradually increase (BC Cancer Agency, 2010).

Previous research has found the following predictors for under-utilization of CCS services: lower education, non-English-speaking, single marital status, and poor preventive health behaviours (Maxwell, Bancej, Snider, & Vik, 2001), as well as obesity (Mitchell, Padwal, Chuck, & Klarenbach, 2008). Additional characteristics of under-screened women include poverty, rural address, immigrant status, and Aboriginal status (Black, Yamada, & Mann, 2002), while cultural origin has also been identified as a factor (Woltman & Newbold, 2007). When asked in a survey why they had not had a recent Pap test, 53% of women responded that they did not think it necessary, and this response was especially common among younger women (Maxwell et al., 2001).

The purpose of this study was to explore factors that encourage or discourage CCS participation among young women in British Columbia. Understanding the barriers can lead to strategies for encouraging participation in CCS among young women, thus reducing morbidity from cervical dysplasia, the precursor of cervical cancer, and reducing mortality due to cervical cancer.

Methods

Study Design

This project involved exploratory research, using focus groups as the qualitative research tool to encourage free expression of ideas and opinions and to enable researchers to better understand how young women talk about CCS (Berg, 2001; Neuman, 2006). The interpretation of interview results was facilitated by recording focus group sessions and later analyzing the transcriptions (Neuman, 2006).

Sampling

Focus group host organizations were located in three geographical areas of British Columbia. Seven different towns and cities were identified through purposive sampling. The recruitment strategy consisted of contacting staff at university health clinics, human resources staff at shopping centres, and staff at community centres serving young women, asking their permission to hold a focus group at their site and requesting assistance in recruiting young women from among their clientele for participation in the focus group. The university health clinics and community centres provided large convenience samples of young women who could be invited to participate. To be eligible, the women had to be aged 20 to 29 at the time of the focus group session. Interested young women were asked to confirm that they fit this age range; some of those wishing to participate were excluded because they failed to meet the age criterion.

Our objective was to complete 10 focus groups, with the goal of having a total of 100 participants. We believed this number would allow

for diversity among participants as well as saturation of themes. By hosting a large number of focus groups at a wide variety of venues, we hoped to recruit participants from different ethnic and racial backgrounds, from different educational and employment backgrounds, living in both small towns and urban settings, as well as young women who were parents and those who were not.

Study Sites

Ten focus groups were held, ranging in size from 4 to 12 participants with a median of 9 participants. A total of 80 women participated, 78 of whom were in the target age range of 20 to 29 years. Five focus groups were held at colleges or universities, two at clinics, two at or near shopping centres, and one at an Aboriginal community centre. One of the two clinic groups met at an urban community centre targeting at-risk and homeless clients. The focus group at the Aboriginal community centre comprised young mothers, our hope being to include the perspectives of both young mothers and Aboriginal women. The settings for the focus groups were the British Columbia towns or cities of New Westminster, Surrey, Burnaby, Coquitlam, Victoria, Vancouver, and Kelowna. Existing contacts at colleges, clinics, and shopping centres were used to facilitate the organization of the focus groups. In some cases, contact was made at preferred locations using information readily available on the Internet.

Recruitment

Participants were recruited with assistance from the contact person at each site. For three of the five focus groups held at universities and colleges, the site contact advertised the focus group to young women through an e-mail distribution list. The e-mail recruitment strategy generated between 15 and 40 e-mail responses from potential participants, resulting in focus groups of between 10 and 12 women. At the other two university sites, recruitment was facilitated by the fact that many women in the target age range lived in close proximity to each other. Placing posters in high-traffic locations was adequate to recruit 10 participants for each group. Two focus groups were advertised to young women working at shopping centres, to attract women who were working rather than attending college or university.

Data Collection

During the focus groups, participants were asked to complete an anonymous demographic form and then participate in a discussion. The demographic form elicited the following information: age, ethnicity, parenting status, employment status, education status, and first three characters of

postal code. The focus group guide included open-ended questions about knowledge of the Pap test and barriers to and facilitators of participation in CCS. Saturation of themes was noted by the end of the last focus group and repeated themes emerged in the last two or three focus groups.

Procedures

The recruitment poster and e-mails asked young women interested in participating in the focus groups to respond by e-mail or telephone to a contact person at the CCSP. A toll-free phone number was offered for those outside the Vancouver metropolitan area. Included also was the information that \$25 would be paid to compensate the participant for her time and travel costs.

The principal researcher handled the responses, confirmed the age of the women, answered questions, and scheduled their attendance at a focus group. At the beginning of each focus group, the consent form and the demographic form were reviewed and questions were answered. Participants were also asked to sign a receipt for the \$25 cash to be paid at the end of the session.

Data Analysis

Transcripts of focus groups were thematically coded to identify knowledge of Pap tests and barriers to and facilitators of participation in CCS. Open coding was performed by highlighting different themes identified in the transcripts. Highlighted themes were analyzed for the performance of axial coding, which further organized themes emerging from the transcripts (Neuman, 2006). The qualitative data were analyzed using standard iterative and interpretative qualitative methods; three of the researchers (AB, AM, and RM) reviewed all of the transcripts and identified themes. Transcripts and field notes were reviewed in an iterative manner to ensure that all emergent themes were captured. Representative quotes were selected from the transcripts to illustrate the main themes identified.

Ethical Considerations

Ethics approval for the study was obtained from the University of British Columbia/BC Cancer Agency Research Ethics Board prior to the scheduling of the first focus group. Confidentiality was ensured by keeping the names of participants separate from the recording and transcript of the focus group in which they took part. No attempt was made to link the demographics of participants with their voices in the focus groups. Participants were given a consent form to read and sign prior to taking part in the focus group. The consent form assured the women of

confidentiality and requested them to refrain from discussing individual responses to focus group questions outside of the focus group. The consent form clearly indicated that the participant could decline to respond to any question and could withdraw from the focus group at any time.

Results

Analysis of the demographic forms showed that the focus groups were made up of 66% Caucasian, 17% Asian, 13% Aboriginal, and 2% Latina women. Seventy-two percent of participants were college or university students, almost 13% were parents, and 89% were employed. The women represented 43 different areas of British Columbia, as measured by the first three characters of their postal code; 6% of participants lived in rural areas of the province, as determined by postal code analysis.

Six categories emerged from the data, as follows: (1) existing knowledge about Pap tests, (2) opinions about why women participate in Pap screening, (3) where young women get Pap tests, (4) facilitators of participation in Pap screening, (5) barriers to participation in Pap screening, and (6) opinions about Pap reminders and methods for receiving health information.

Existing Knowledge About Pap Tests

Most participants accurately defined a Pap test as a test for cervical cancer, although many expressed the misperception that Pap tests include screening for multiple sexually transmitted infections (STIs). One woman said, “I kind of thought of the Pap test as sort of maintenance, like taking your car into the shop to check for any abnormalities — it’s routine.” Most believed that Pap screening should begin within a year of a young woman’s becoming sexually active.

Why Young Women Participate in Pap Screening

Many of the participants stated that they took part in Pap screening because they were reminded to by a relative or a health-care provider: “My mom said it was just part of being grown up, so I just do it.” Others said that they had participated in Pap screening because they were pregnant ($n = 3$) or while they were incarcerated ($n = 1$) and had been prompted by a health professional. The most common answer to the question of what prompts a young woman to participate in CCS was that renewal of her prescription for oral contraceptives was linked to annual CCS.

Where Young Women Get Pap Tests

Many of the participants reported that they had initiated CCS with their family physician in their hometown but since moving away from home

for work, university, or other reasons they had not established care with a provider or clinic. Some women had used walk-in clinics and were satisfied with the care they received, while others were unaware that Pap tests were available at walk-in clinics and still others were dissatisfied with walk-in clinics. Among those who reported dissatisfaction, a typical response was, "I find that when I go to a walk-in clinic for anything . . . the doctors don't even sit down; they stand at the door and . . . you're in and out in 5 minutes."

Facilitators of Participation in Pap Screening

The first question we asked about facilitators of CCS was, "What things would help you get a Pap test?" The responses are grouped into several themes.

Assistance with finding physician/health-care provider. The majority of participants agreed that they would be encouraged to get a Pap test if they were given assistance in locating a clinic or health-care provider nearby: "That would make a big difference . . . for the general population of our age . . . because I've been here for almost 4 years and I've been bounced around through walk-in clinics and cannot find a family doctor — it's crazy."

Having an established relationship with a health-care provider or clinic. In every focus group, women stated that they were more likely to participate in CCS if they had an established relationship with a physician, nurse practitioner, or clinic. The following comment is typical: "Then you get more regular Paps, because you've got an established relationship, and they have your history on file, too, which makes a huge difference."

Education about Pap tests. Many participants said that educating women about the importance of Pap testing and what it entails would be a good way to encourage regular participation in CCS: "Education in high school would make a difference" . . . "Just, you know, finding out more of what is actually entailed. I think there's a lot of fear surrounding it the first time. When they actually find out what it is, it's not so scary."

Availability of testing by a female provider. Many participants expressed a preference for having their Pap test performed by a female provider: "Most women want to go to women; they don't like to go to men . . . it's just more comfortable" . . . "Maybe not for the second one, but if you're going for the first one, it does make it a lot more comfortable."

A small minority of participants stated a preference for male physicians ($n = 4$) or said that the gender of the provider made no difference to them.

“Pap Day” or “Pap Week.” The young women were asked if they would be more likely to participate in CCS if there were an occasion dedicated to it, such as a Pap Day or Pap Week. Many responded enthusiastically and several mentioned having heard of or participated in the Papalooza event in Vancouver, a festive Pap Day held in the Downtown Eastside, a low-income neighbourhood where street outreach nurses perform Pap tests. Participants seemed particularly interested in taking part in a Pap Day/Week held in a familiar location such as their community or campus health clinic. However, some participants remarked that Pap Week sounded like an event that would involve a large number of women and a lot of waiting in line. For this reason, some women indicated that an event such as Pap Week would not encourage them to take part in CCS.

Other facilitators. Several women felt that there would be greater participation in CCS by young women if it were made more convenient: “Having a clinic on campus makes it easier” . . . “having a day where there’s no appointment required” . . . “no travel time at all is best, easy to get to.” Others explained that “girlfriends remind each other, and it’s like, ‘Well, you should go,’ and, you know, then you get on each other’s case.”

Barriers to Participation in Pap Screening

The women were asked what they saw as the barriers keeping them or other young women from regularly participating in CCS. Their responses are grouped into four categories: difficulty finding a health-care provider, especially a female provider; fear and discomfort; amount of time required; and general procrastination.

Difficulty finding a health-care provider, especially a female provider. Many participants felt that the primary barrier to CCS participation was lack of a regular health-care provider: “I don’t have a family doctor. . . . he retired a couple of years ago and it’s so hard to find a . . . family doctor” . . . “It’s pretty hard, especially with the female doctor not taking new patients — that’s a bit of a challenge, that I have to . . . wait to get a female doctor, and I prefer to go to a female doctor for a Pap.”

Fear and discomfort. Several participants noted that fear and discomfort keep women from getting a Pap test. Many felt that girls are not well educated, in either primary or secondary school, about what is involved in getting a Pap test or why testing is important: “I think they’re . . . not totally educated about it and they’re scared . . . they don’t know what’s going to happen” . . . “I think maybe for a girl [who] is very sexually active and [has] never had [a Pap test] just out of fear . . . and then, you know, she’s had so many partners and is aware that she’s at risk and thinks that if she goes she might have something to deal with . . . she’d rather

just not know” . . . “A lot of people are scared to go because they’re scared to find out there’s something wrong with them” . . . “I’ve [had a Pap test] a bunch of times, and it’s not scary for me or anything but it doesn’t make it any less uncomfortable.”

Other participants stated that the Pap test was “too invasive” or “just very private.” One woman said, “Sometimes it’s intimidating for young girls . . . they get embarrassed.”

Amount of time required. Several participants stated that they postponed scheduling a Pap test because of the amount of time required. One woman said, “My schedule is really packed . . . it’s hard to commit to going to the doctor for 45 minutes to have . . . a breast exam and Pap done.” Many young women mentioned that the Pap test is “just one of those things you procrastinate on.” One participant said, “It’s kind of always in the back of your head, you know, you don’t really think about it . . . being all that important.” Another response was, “It’s always been something I’ve kind of put on the back burner.”

Other barriers. We asked the participants whether transportation was a barrier to their taking part in Pap screening, and for the majority it was not. Some young women on rural college campuses explained that not owning a car made them less likely to participate in screening. We also asked about child care, but since 88% of the participants were not parents, this did not represent a barrier. Those who were parents said that Pap tests available at a familiar clinic, with child care provided, would be the most convenient option.

Opinions About Pap Reminders and Communication Methods

The participants were asked whether reminders about Pap testing was an effective method for promoting participation in CCS, and the overwhelming response was yes. When asked for their preferred method of communication, the vast majority of participants responded that they would prefer to receive reminders by e-mail and stated that it would make no difference whether the e-mail came from a cancer screening program or their health-care provider.

Discussion

While previous studies have reported several barriers to women’s participation in CCS, such as a belief that the Pap test is unnecessary (Maxwell et al., 2001), this study found that lack of access to health-care providers, or lack of an established relationship with a provider, presents an additional and significant barrier to young women’s participation in CCS. Cervical cancer screening is available in Canada at no charge; however, the present findings illustrate that even when the barrier of cost is

removed, a significant barrier still exists if young women are unable to locate or establish a relationship with a health-care provider who offers Pap tests.

To our knowledge, this is the first study to ask young women for their opinions about receiving e-mail reminders when they are due for a Pap test. Their interest in receiving e-mail reminders suggests that this method may be key to improving screening rates among this population.

The young women who took part in the study were well educated about the importance of the Pap test, and they understood that the test is essential for women who are sexually active. However, there remained some confusion about Pap tests and STI screening, with many young women mistakenly assuming that they were being tested for all STIs when they participated in CCS.

There is a need for more education of young women, especially at an early age, about the importance of the Pap test. Education about CCS may help to overcome the barriers of fear and discomfort identified by the focus group participants, and may normalize the Pap test as part of routine health care. Participants also felt that education about CCS would encourage women to have their first Pap test.

Many participants had not established a relationship with a health-care provider or clinic. Assistance with locating a provider or clinic nearby was identified as a facilitator of participation in CCS, and the lack of a relationship with a provider or clinic was identified as a strong barrier. One attempt to overcome this barrier is the Web site developed by the CCSP, which shows women which clinics and providers in their community offer CCS.

For those young women who are sexually active and use oral contraceptives, the connection made by clinics and health-care providers between annual renewal of contraceptive prescriptions and CCS is an effective tool for promoting participation in CCS. However, those women who use birth-control methods that do not require a prescription or who do not practise birth control may not receive an annual reminder.

Many participants noted that they were encouraged to participate in CCS by health-care providers or by relatives and believed that these reminders were effective. Health-care providers should continue to educate young women about the importance of the Pap test and encourage them to participate regularly in CCS.

Many women indicated that they would participate in Pap Week and Pap Day events if these were available. Organization of such activities should be expanded, and consideration should be given to offering convenient appointment times, as a key non-compliance factor identified by women is inconvenient appointment times (Olowokure, Caswell, &

Duggal, 2006). Female providers should be used whenever possible; many young women expressed a preference for female providers of CCS. The findings of other studies confirm this preference (Webb, Richardson, & Pickles, 2004), with one study suggesting that revealing the gender of the Pap tester in invitation letters to women may increase the uptake of screening (Gannon & Dowling, 2008). The use of nurse practitioners (the majority of whom are female) should be explored as one option for meeting this need.

Our study found that e-mail was the most successful strategy for recruiting young women for the focus groups. By recruiting through a variety of venues, we were able to ensure that the sample represented diversity with respect to ethnicity, geography, employment status, and parenting status.

The focus groups were all facilitated by one researcher (AB). While attempts were made to recruit 10 participants for each group, this was not always possible. In most focus groups, participants needed encouragement to fully engage in the discussion. This could be because the subject matter was of a sensitive nature. Encouragement was offered by holding the focus groups in rooms that were private and by providing snacks and comfortable seating. At times participants seemed embarrassed or slightly uncomfortable with the discussion about Pap tests. Prompts were used, such as empathetic listening and verbal prompts (e.g., *Could you say more about that? Is there anyone who hasn't spoken yet who would like to add an opinion?*). The two smallest focus groups, with 4 participants each, were the most difficult to conduct, as the women voiced their opinions only briefly and the follow-up prompts did not elicit much further conversation. This is consistent with the literature, which suggests an optimal size for focus groups of between 6 and 12 participants (Neuman, 2006).

Limitations

Opinions voiced in this study were limited to the 80 women who participated in the focus groups. The focus groups represented significant numbers of Caucasian, Asian, and Aboriginal women, which are the three most numerous ethnicities in British Columbia. However, only two Latina women were included, and no women of African descent. Additionally, all focus groups were conducted in English, limiting participation to those fluent in English. The results therefore may not represent the opinions of African or non-English-speaking women.

Seventy-two percent of participants were college or university students, while the figure for British Columbia women aged 20 to 29 attending college or university is approximately 50% (Statistics Canada, 2009). Therefore our results over-represent the opinions of this demo-

graphic. Focus groups were conducted primarily in urban areas and 94% of participants listed urban addresses, so the views of women residing in rural British Columbia are limited in the analysis.

It was difficult to recruit women who were employed at the shopping centres; therefore the knowledge, barriers, and facilitators for young women who are employees rather than students may be under-represented in the results.

Recommendations

Educate women about the importance of Pap testing and what it entails. CCS education should emphasize the fact that cervical cancer is curable when diagnosed early. Cancer screening programs can partner with health educators in schools to include components on CCS.

Offer assistance with locating providers or clinics where new patients are accepted and Pap tests are offered. Public health Web sites with links to help women locate clinics and health-care providers who perform Pap tests should be more widely promoted among young women, as a way to address the barrier of lack of established relationships with health-care providers or clinics. Regional cancer screening programs should consider partnering with nursing and nurse practitioner organizations or medical associations to develop resources for helping women to find health-care providers.

Encourage providers to continue promoting young women's regular participation in CCS. Partnerships with family physicians, nurses, and nurse practitioners can be established or strengthened to encourage these providers to continue educating women about the importance of CCS.

Continue and expand Pap Day and Pap Week events, using female providers whenever possible. The use of nurse practitioners (the majority of whom are female) should be explored as one option for addressing the need for more female providers of CCS.

Send e-mail reminders to women who are due for a Pap test. This idea was well received by participants and could increase CCS rates among young women.

Future Research Directions

Future research should explore rates of CCS participation and cervical cancer mortality among rural women. Future researchers could also design an intervention and evaluation study to measure CCS rates in different models of care, in order to explore whether rates differ significantly in different health-care delivery models.

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