Discussions about self-obtained samples for HPV testing as an alternative for cervical cancer prevention

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Abstract
Objectives. Patient-collected samples for human papillomavirus (HPV) testing have shown promise, thus opening up a new possibility for cervical cancer screening. The purpose of this study was to explore women’s beliefs about collecting their own samples for HPV testing instead of participating in conventional Pap testing.

Methods. Three focus groups were conducted in diverse cities in Ontario, Canada. One group included women from a small under-serviced northern city, one included culturally diverse women from a large urban city, and one included culturally diverse women from a medium sized under-serviced city. Transcripts were coded using open and axial coding as well as focused coding procedures and were organized using qualitative software. The Health Belief Model (HBM) was used as a framework for designing the focus group guide and interpreting the results.

Results. Six overriding themes were identified in the analysis: (1) need (and desire) for information about cervical cancer and HPV, (2) concerns about self-sampling, (3) perceived potential of self-sampling, (4) logistics remain unanswered, (5) need for education and promotion of self-sampling, and (6) need for options.

Conclusion. The six themes were connected to some or all of the HBM components. In particular, self-sampling provides a different benefits-minus-barriers equation, which might make it a preferred screening option for some women.

Keywords: HPV self-sampling, cervical cancer prevention, women’s beliefs, health belief model, Pap testing

Introduction
The advent of HPV-DNA testing gives rise to the possibility of having women collect their own samples for HPV testing as opposed to having clinicians collect samples for Papanicolaou (Pap) testing. Self-sampling for Pap testing has been evaluated, but a recent review suggests that it is not an effective substitute for conventional cytology screening, whereas, the same review concludes that self-sampling for HPV testing shows potential [1]. It should be made clear that HPV DNA testing does not necessarily preclude Pap testing. Research on HPV-DNA testing suggests that it has the potential to improve cervical cancer prevention programs by being incorporated into cytology screening [2] or by superseding cytology as a primary preventative tool [3]. HPV testing is not diagnostic and follow-up with Pap testing and or colposcopy is necessary when the results are positive. Unlike the Pap test, which necessarily involves obtaining cells that are sufficient for cytologic evaluation, self-sampling for HPV testing involves collecting samples that are then tested for the presence or absence of high risk HPV DNA and thus an adequate sample is easier to collect.

A recent systematic review of the literature on self-collected samples for HPV-DNA testing concluded that there is currently insufficient evidence to make conclusions for or against self-sampling for HPV-DNA testing, but that it is a promising development for cervical cancer screening [4]. It is therefore especially important to examine women’s opinions about HPV self-sampling because it may be the determining factor in whether or not HPV self-sampling is a viable cervical screening alternative for some women.

A number of studies have shown that women find self-sampling for HPV testing acceptable [5–7], but fewer have explored what might influence acceptability. Additionally, only one study [7] has surveyed...
women who have not performed self-sampling. Thus the barriers for self-sampling have not been well documented. In contrast there are documented barriers to Pap testing which include: accessibility [8], time constraints [9], knowing about Pap testing [10], forgetting to schedule a Pap test [11], embarrassment [11], social anxiety [12], and relationship with physician [13]. It is possible that women who have not taken part in Pap testing because of these barriers might take part in self-sampling for HPV testing. An essential first step is to understand women's beliefs about HPV self-sampling as a cervical screening option.

In the Health Belief Model (HBM) there are four main beliefs that contribute to a person's readiness to perform a health action: (a) perceived susceptibility to the illness; (b) perceived seriousness of the illness; (c) perceived benefits of taking action; and (d) perceived barriers to taking action [14]. Perceived ability to take action, that is, self-efficacy was later added to the model [15]. In addition, the model supposes that cues to action are needed to trigger health behavior. Within cervical cancer screening, the model has successfully predicted women's intentions to have a Pap test [16,17] and their actual Pap test history [18].

The purpose of the present study was to examine the range of women's beliefs about self-sampling for HPV-DNA testing as an alternative to conventional cervical screening within the HBM framework. A direct comparison with Pap testing was deemed important because substantial gain can be made in cervical cancer screening if women who are currently not being screened by any method begin performing self-sampling for HPV testing.

**Methods**

Sample size was guided by recommended methods for focus groups [19], although some groups were larger than expected because of a lot of interest in our sessions. We followed the qualitative recruitment strategy of maximum diversity [20] with respect to city location, ethnicity, and access to primary health care. The three focus groups locations in Ontario, Canada were chosen to maximize representation of hard-to-reach women and diversity between groups. They included two under-serviced cities as designated by the Ontario Minister of Health and Long-Term Care (Thunder Bay and Windsor). Thunder Bay is Northern and semi-rural, Windsor is medium-sized and multicultural, and Toronto is a large and multicultural. Women 18 years of age or older were eligible to participate regardless of cervical screening history. We used the “known sponsor” [21] approach to recruitment. A service provider in each of the three cities recruited the participants with posters and letters (that we provided) and arranged a location for the focus group.

**Materials**

The topic guide was developed according to the HBM theoretical framework. The questions began by establishing baseline knowledge about cervical cancer, Pap testing, and HPV. The remaining questions dealt with participants’ beliefs about self-sampling for HPV testing compared to Pap testing.

Three 5 to 10 minute educational presentations, adapted from evidence-based literature, provided information about cervical cancer, Pap testing, the link between HPV and cervical cancer, and HPV self-sampling procedures. In addition, all of the participants’ questions were answered before moving onto the next sections of the focus group. In total approximately half of the focus group time was spend on the educational presentation and on answering participants’ questions. The two self-sampling procedures described involved inserting a swab or tampon into the vagina for a short time, removing it, and placing it in tube with preservative liquid. Both the topic guide and the educational presentations were pilot-tested with four women and revised slightly before they were used in the focus groups.

A one-page questionnaire sought basic demographic and health information.

**Procedure**

The study was reviewed and approved by an institutional research ethics board at a large research university and participants read and signed a consent form before participating. The same experienced moderator guided the discussion of each focus group; a second moderator took notes and provided a final summary. Each session was double audio taped and lasted between 1½ to 2½ hours. The baseline questions were asked first, followed by the educational presentations, and then the questions regarding self-sampling. Participants received $20 as remuneration.

**Participants**

Participants’ demographics/characteristics appear in Table I. The three groups were comparable in terms of age, education, and perceived health status; however, there were other important differences. The Thunder Bay group was primarily white and English speaking, while the Toronto and Windsor groups represented a variety of ethnicities as indicated by the language they spoke most often at home (n in parentheses): Albanian (2); Arabic (5); Cantonese (1); 1 Chinese (1); Czech (1); English (15); Gujarati (1); Hausa (1); Hindi (1); Italian (1); Kanada (2); Punjabi (1); Romanian (1); Somali (1); Spanish (5); Tagalog (2); Twi (1); Urdu (1); Vietnamese (1). There were also differences between
the groups with respect to Pap test history and access to a family physician.

Analysis

A professional transcriber prepared the transcripts from the audiotapes. The primary research analyst, who was also the focus group moderator and a member of the research team, verified the transcripts and corrected or expanded as needed. The transcripts were micro-analysed using both open and axial coding procedures as described by Strauss and Corbin [22]. The research analyst took notes as needed and created categories concerning the topics discussed. Using these categories as a starting point, she next used focused coding procedures [23] to code each transcript using the software program QSR NUD*IST, version six. This procedure involved collapsing and expanding categories when appropriate as the analyst developed more complex connections between codes. As the analysis progressed the research team met as whole on a number of occasions and reached consensus on the final themes.

Results

Need (and desire) for information about cervical cancer and HPV

The first theme identified a need for basic information. Women expressed confusion about the purpose of the Pap test, the link between sexual activity and cervical cancer, and the fact that cancer could be caused by a virus. Gaining some information about cervical cancer and HPV through participation spawned a need for much more information. Women were especially surprised to learn that cervical cancer was linked to a sexually transmitted virus.

P1: I have no idea. The cancer is caused by virus . . . the cancer was caused by a virus. I had no idea.

P2: I never heard about it (all talking at once). . . .

P3: Cancer cannot be, cancer can be sexually transmitted? You know? (T)*

Concerns about self-sampling

Participants identified a number of concerns about HPV self-sampling. For instance, women spoke of losing the benefit of a yearly appointment with a physician and the tests that are often done in conjunction with the Pap. Women discussed potential barriers that could also be problematic with Pap testing such as, not doing the test regularly, loss to follow-up, and limited awareness and acceptability of the test in marginalized and low literacy women. Sometimes the barrier was clearly seen as more troublesome in HPV self-sampling. “The Pap test, you have to go every year or every two years. And you don’t forget. But this you can forget” (T). HPV self-sampling was also thought to introduce new barriers. For instance, some women believed the actual procedures involved in self-sampling were unsafe (i.e., losing the tampon or pieces of the swab inside the body; triggering an infection, or painfully poking the cervix). Some women expressed concern that

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Thunder Bay</th>
<th>Toronto</th>
<th>Windsor</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>10</td>
<td>14</td>
<td>20</td>
<td>44</td>
</tr>
<tr>
<td>Age: mean (range)</td>
<td>37 (19–64)</td>
<td>40 (25–58)</td>
<td>40 (21–64)</td>
<td>39 (19–64)</td>
</tr>
<tr>
<td>Has a Family Physician: n (%)</td>
<td>6 (60%)</td>
<td>11 (79%)</td>
<td>12 (60%)</td>
<td>29 (66%)</td>
</tr>
<tr>
<td>Had Pap in Past 24 Months: n (%)</td>
<td>7 (70%)</td>
<td>5 (36%)</td>
<td>14 (70%)*</td>
<td>26 (59%)</td>
</tr>
<tr>
<td>Number of Different Languages</td>
<td>2</td>
<td>11</td>
<td>10</td>
<td>19</td>
</tr>
<tr>
<td>Spoken Most Often at Home: n</td>
<td>9</td>
<td>1</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>English is Spoken Most Often: n (%)</td>
<td>4 (40%)</td>
<td>3 (21%)</td>
<td>6 (30%)</td>
<td>13 (30%)</td>
</tr>
<tr>
<td>Perceived Health Status: n (%)</td>
<td>5 (50%)</td>
<td>8 (57%)</td>
<td>11 (55%)</td>
<td>24 (55%)</td>
</tr>
<tr>
<td>Poor</td>
<td>0 (0%)</td>
<td>1 (7%)</td>
<td>1 (5%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Education Level: n (%)</td>
<td>0 (0%)</td>
<td>2 (14%)</td>
<td>3 (15%)</td>
<td>10 (23%)</td>
</tr>
<tr>
<td>High-school Diploma</td>
<td>1 (10%)</td>
<td>2 (14%)</td>
<td>5 (25%)</td>
<td>8 (18%)</td>
</tr>
<tr>
<td>College, Technical Diploma</td>
<td>4 (40%)</td>
<td>3 (21%)</td>
<td>3 (15%)</td>
<td>10 (23%)</td>
</tr>
<tr>
<td>University Degree</td>
<td>4 (40%)</td>
<td>9 (64%)</td>
<td>10 (50%)</td>
<td>23 (52%)</td>
</tr>
<tr>
<td>Post-graduate</td>
<td>1 (10%)</td>
<td>0 (0%)</td>
<td>1 (5%)</td>
<td>2 (5%)</td>
</tr>
</tbody>
</table>

*The women’s centre in Windsor where the focus group took place had organized an in-house Pap test clinic the previous year.

*The three focus group locations are identified as follows, Thunder Bay “TB”, Windsor “W”, and Toronto “T.”
doctors would not accept self-sampling and would later blame women who developed cervical cancer. By far the most widely discussed concern was that HPV self-sampling would not be as accurate as Pap testing. Some women assumed that Pap testing was very accurate; self-sampling seemed “primitive” by comparison. Some women said that they would not feel confident in doing the test and would worry that they had done it incorrectly. “But I am always going to have that in my mind, I did it right? It has been three years I have been doing it on my own. How do I know that I did it right?” (W).

**Perceived potential of self-sampling**

Some women indicated that they would begin cervical cancer screening if given the option to self-sample for HPV and other women said that would prefer HPV self-sampling to Pap testing. Participants pointed out a number of barriers to Pap testing and explained how HPV self-sampling could reduce those barriers (e.g., time commitment and inconvenience, cultural taboos, forgetting etc.). In addition, reduced discomfort and embarrassment by avoiding the gynecological exam was a dominant topic.

I think it’s so uncomfortable. Just being in the waiting room. I’m just shaking for half hour, the day before, the week before the appointment. It’s so uncomfortable. I’d rather not go. I mean, I’ve been going, but it is so uncomfortable. So if I can avoid all the hassle and do it myself, and the results are the same, definitely I would do it. (T)

Some noted that self-sampling might be an option for women who are not screened regularly because of barriers. In particular, it was mentioned as an option for adult offenders, women in isolated areas, and women on Aboriginal reserves who have difficulty accessing healthcare, as well as immigrant women who may object to exposing their genitalia.

Participants noted unique benefits that were specific to self-sampling. For instance, in a discussion about accuracy, some women said self-sampling would be more accurate because one would not be rushed like doctors and would take sufficient time to follow procedures. Other perceived benefits included the simplicity of the test and the relief of knowing that the actual virus was not there or was now gone.

An unexpected finding was that self-sampling may be valuable because women would learn more, take more control of their own health, and necessarily become more familiar and comfortable with their genitalia, “I think, for me and for many women, it would give them more control of their own bodies. (umm hmms from another participant) More of a sense of knowing that they take their own health under control” (W). Although this idea of empowerment through the procedure was not discussed at length, it did arise in all three focus groups.

**Logistic remain unanswered**

This theme emerged from specific discussions about what self-sampling would look like and from participants many logistical questions. For instance, a particularly controversial question was whether self-sampling would be provided without cost to the patient (Pap testing is currently covered by Canada’s universal health plan). Some women were adamant that something as important as cervical screening should not be charged to the patient, whereas others saw paying for self-sampling kits as convenient, much like the availability of pregnancy tests.

Fortunately, participants also provided suggestions for implementation, sometimes in response to other participants’ logistical questions. For instance, participants wanted to know how they would obtain a self-sampling kit and warned that most women would not even know to look for these kits. In response to this, the idea of offering self-sampling in the doctor’s office was suggested, which was such a popular idea that the moderator raised it in the other two groups. Some women liked this option because it gave them access to a physician, alleviated concerns about collecting the sample incorrectly, and served as a convenient prompt for regular screening.

**Need for education and promotion of self-sampling**

This theme dealt with participants’ perceived need for education and promotion of self-sampling as a cervical screening option because both the reasoning behind the test and the procedure for acquiring a sample would be unfamiliar. Participants also provided a number of suggestions about what educational resources should look like and what should be considered. For instance, they noted that the materials would have to be accessible to women with low literacy and be available in many languages. They suggested multiple media including: pamphlets, workshops, videos, clear diagrams, and websites.

**Need for options**

The final theme makes it clear that if self-sampling were to be implemented, it should be optional. Some women clearly felt more comfortable with physician-collected samples and other women expressed mixed feelings or endorsed self-sampling as an option.

So if this was to replace the Pap test, . . .I think that would be a problem. If [it] were to be added to
your list of options I think for most people that is positive because then they could choose to choose it versus, “Oh now I have to do this thing at home or it doesn’t happen”. That would be very alienating. (TB)

Discussion

The HBM

The focus group themes are listed in Table II and linked to the components of the HBM. The need and desire for basic information was particularly important because the HBM is based on perceived beliefs, so consequently changing knowledge about cervical cancer, Pap testing, and HPV inevitably impacts all the HBM components. This suggests that when women first learn about HPV, they will have many more questions and will need time to make sense of this newly acquired information before deciding to participate in self-sampling.

The present study provided insight into how self-sampling might complement conventional screening by changing the benefits-minus-barriers equation of the HBM. This is not to say that the benefits-minus-barriers equation is better for HPV self-sampling than it is for Pap testing—it is simply different. This difference might make it more favorable for some women and lead them to initiate cervical screening. Participants talked about how documented structural barriers (e.g., accessibility [8] and time constraints [9]) and psychological barriers (embarrassment [11] and intimidating or uncomfortable relationship with physicians [13]) could be effectively reduced by self-sampling.

For some participants the benefits-minus-barriers equation was more favorable for Pap testing. Pap testing has some unique benefits that were perceived as lost through HPV self-sampling. In particular, the idea that it may discourage a regular gynecological exam, which often includes other tests, was seen as a serious problem. In addition, self-sampling was perceived to heighten some recognized Pap barriers (e.g., knowledge about the test [10] and forgetting to do the test [11]). It also produced a few new barriers (e.g., fear of injuring oneself).

The self-efficacy component of the HBM highlights a particularly interesting finding. The most common concern expressed about self-sampling was that women would not collect the sample properly, which has also been identified as a concern in other studies [7]. In contrast to this, however, some women talked about self-sampling as having the potential to empower them to take control of their own health. This suggests that self-sampling might actually increase self-efficacy for some women.

Self-sampling for HPV testing poses some challenges for the cues to action component of the HBM. Participants wondered how women would find out about HPV self-sampling and provided some suggestions. A particularly popular suggestion was to provide access to HPV self-sampling at the doctor’s office. What the participants have made clear is that the successful implementation of HPV self-sampling,

<table>
<thead>
<tr>
<th>Table II. Major Themes and the Health Belief Model (HBM).</th>
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<tbody>
<tr>
<td><strong>HBM Components</strong></td>
</tr>
<tr>
<td>All: (susceptibility, seriousness, benefits, barriers, self-efficacy, and cues to action)</td>
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<tr>
<td>• Increased knowledge create more questions</td>
</tr>
<tr>
<td>• Increased knowledge changes perceptions of cervical cancer prevention</td>
</tr>
<tr>
<td><strong>(2) Concerns About Self-sampling</strong></td>
</tr>
<tr>
<td>Benefits Barriers</td>
</tr>
<tr>
<td>• Some Pap benefits might be lost</td>
</tr>
<tr>
<td>• Some Pap barriers heightened</td>
</tr>
<tr>
<td>• Some new barriers recognized</td>
</tr>
<tr>
<td>Self-efficacy</td>
</tr>
<tr>
<td>• Fear of doing self-sampling wrong (accuracy)</td>
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<tr>
<td><strong>(4) Logistics Remain Unanswered</strong></td>
</tr>
<tr>
<td>Cues to action</td>
</tr>
<tr>
<td>• Decisions about implementation</td>
</tr>
<tr>
<td><strong>(6) Need for Options (Intentions)</strong></td>
</tr>
<tr>
<td>• Mixed feelings and want options</td>
</tr>
<tr>
<td>• Preference for self-sampling</td>
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especially if it is to target women who have not participated in Pap testing, will require the development of creative strategies that not only provide the necessary basic and promotional information, but also serve as cues to action.

Implications

Participants’ information needs about cervical cancer and HPV were extensive, but were not entirely unexpected. Others have also shown that women know little about the link between cervical cancer and HPV [24]. However, what health care providers may be unprepared for is the shock that many women feel at learning this information and they should be cognizant of the fact that it can change women’s thinking about cervical cancer and cervical cancer prevention.

Future research should be particularly concerned with the needs and opinions of women who have not participated in regular screening because they potentially have the most to gain from HPV self-sampling. A recent study in the Netherlands has found that self-sampling is an effective alternative for women who have not participated in regular cervical screening programs in the past and does not markedly increase costs per detected CIN2+ lesion [25]. This outcome is encouraging but there were still a large percentage (66%) of women that did not respond. Future trials should consider providing women with the option of doing self-sampling at home or at the doctor’s office given the popularity of this option in our focus groups. Additionally, the present study outlines the kind of information women in such trials would want when being introduced to the concept of self-sampling and emphasizes the importance of alleviating women’s concerns about collecting the sample correctly.

Strengths and limitations

The strength of the methodology used in this study is that it generated extensive dialogue about self-sampling because women were able to follow-up on each other’s ideas. This provided a large amount of data and many varied opinions about self-sampling. The focus group design was invaluable in allowing us to answer women’s questions as they arose in order to obtain an informed opinion about self-sampling. Not only were we able to document their information needs, but the method allowed women to digest and understand the material as the focus group progressed.

The methodology used does not allow conclusions to be made about how many women would actually participate in self-sampling. The nonrandom recruitment method also limits the generalizability of the results; however there was a substantial amount of overlap between the three focus groups and each of the themes described emerged in all three groups. Although we included both women who had and had not had a Pap in the previous 24 months, we did not stratify the focus groups by this criterion, so we are limited in the conclusions we can make about previously under screened women.

The overall results of this study are nicely summed up by the last theme, “Need for Options”. There is no question that Pap testing has been a success story, but there is room for improvement. The current study provides some information about how HPV self-sampling might be perceived by women if it were given as an alternative option for cervical screening. The information needs, potential and challenges of this option were outlined and should be especially useful to others who are exploring this cervical screening alternative.

Acknowledgements

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References

Current knowledge on the subject

- Pap testing has dramatically reduced cervical cancer rates for women who participate in regular screening.
- There are many structural and psychosocial barriers to Pap testing such as accessibility, embarrassment, and relationship with physician.
- HPV self-sampling provides a promising alternative for cervical cancer prevention.

What this study adds

- Perspectives from a diverse group of women on the barriers and benefits of self-sampling for HPV testing compared to those of Pap testing.
- A better understanding of how HPV self-sampling can complement Pap testing.
- A broader perspective on how HPV self-sampling could be implemented in cervical cancer prevention programs and direction for future research in this area.