Gynecologic Oncology 135 (2014) 487–494

Contents lists available at ScienceDirect

Gynecologic Oncology

journal homepage: www.elsevier.com/locate/ygyno

Self-sampling experiences among non-attendees to cervical screening

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HIGHLIGHTS

- Non-attendees to screening had mainly good experiences with self-sampled HPV-tests
- Insecurity, fear or anxiety during self-sampling were more common among immigrants
- Both practical and emotional barriers to screening can be overcome with self-sampling

ARTICLE INFO

Article history:
Received 16 July 2014
Accepted 19 September 2014
Available online 2 October 2014

Keywords:
Cervical screening
Self-sampling
HPV
Acceptability
Non-attendance

ABSTRACT

Objective. High coverage and attendance is essential to positive cervical cancer screening results. Offering self-sampling for HPV-testing to the non-attendees of the program may improve attendance rates. Information on women's perceptions and experiences with self-sampling (acceptability) is needed to further optimize attendance by this method.

Methods. A questionnaire study focusing on women's experiences on the screening method was embedded in a trial investigating the effects and feasibility of self-sampling among non-attendees of cervical screening in 31 Finnish municipalities in 2011–2012 (n = 4688). Reasons for non-attendance in routine screening were also surveyed.

Results. Response rate to the questionnaire was 98.8% (909/920) among women who performed self-sampling. Self-sampling participants reported mainly good experiences. Negative experiences (difficulties in sample taking, pain, fear, anxiety, insecurity) were reported rarely, but more commonly among women with a mother tongue other than Finnish or Swedish (immigrants). Most common reason for non-attendance in routine screening was a recent Pap-smear elsewhere (opportunistic screening). Practical reasons (pregnancy, scheduling difficulties) were reported by 42%, emotional or attitudinal reasons by 17%, and 16% forgot to take part. Response yield to questionnaire was unsatisfactory among those women who declined the self-sampling option.

Conclusions. Optimizing the practical aspects of screening and offering a self-sampling option to non-attendees can help to overcome a large variety of both practical and emotional barriers to traditional screening. More research is needed among the non-attendees to routine screening who decline also the self-sampling option.

Introduction

High coverage and attendance is essential for effective cervical cancer screening. Personal invitations to screening, pre-booked appointments in invitation letters and reminders sent to non-attendees increase screening attendance [1–10]. Self-sampling for high risk human papillomavirus (hrHPV) DNA testing helps to further increase attendance among women who are not reached by the routine screening program [9–16]. Information on self-sampling experiences is needed to further optimize attendance by this method.

Acceptability of self-sampling, in the meaning of women's experience of the procedure, not solely response rate, has been previously studied by focus group discussions and questionnaires with self-sampling being introduced but not necessarily used by the participants [17–24], and in comparison to a Pap-smear among screening participants or patients at a clinic [25–28]. In countries with existing and functional screening programs, however, the current role of self-sampling would be to provide an alternative for women reluctant to participate in clinic-based screening. For this purpose, acceptability should be studied in the actual target group, i.e. among non-attendees to the current program. Some studies have gathered information on non-attending women's preferences for self-collection or clinician-collection and the reasons for their preference [15,29,30]. Only previous one study thus

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http://dx.doi.org/10.1016/j.ygyno.2014.09.019
0090-8258/

far has explored the aspects of user-friendliness of a self-sampling procedure in a population-based setting among non-attendees [31].

We studied women's experiences and perceptions on self-sampling based screening among non-attendees to cervical screening in a diverse set of Finnish municipalities. We further studied how demographic factors such as age, mother tongue and education level affect the self-sampling experience. In order to explore what kind of barriers to traditional screening can be overcome with the self-sampling option, women's reasons for non-attendance to routine screening were also studied.

Material and methods

In the Finnish program, all women aged 30–60 years are invited to screening by their home municipalities with personal invitations in 5-year intervals. The study population consisted of women who received two invitations to screening (primary invitation and a reminder letter) in 31 municipalities in years 2011 or 2012 and did not attend. These non-attendees were included in a clinical trial on the effects and feasibility of self-sampling described in detail elsewhere [32]. The women were offered a self-sampling option to be performed at home and asked to complete questionnaire relating to test acceptability and reasons on previous non-attendance; the results of the questionnaire study are the focus of this paper. The self-sampling device used was Delphi Screened (Delphi Bioscience BV, Scherpenzeel, The Netherlands) which produces a lavage type sample. Self-sampling was offered with an opt-out option and those that declined were sent only the questionnaire. In total, the questionnaire was sent to 3836 women with a self-sampling kit and 852 women without one. The exact flow of women in the questionnaire study is showed in Fig. 1.

The questionnaire was developed based on a previous pilot study and previous literature [9,10,21,25,26,28]. All questions were pretested by an external group of women to ensure clarity. The women gave their written consent to link their answers to screening data.

Women's experience of self-sampling was measured using a 16 item scale, 13 on test acceptability and sampling experiences and three on the clarity of the user instruction. There was also space for further open feedback. Responses to the 16 items were on a five point Likert-type scale from “totally agree” to “totally disagree” and a “cannot say” option. For analysis, some of the answers were reversed from the original, so that “totally agree” would represent maximal acceptability (positive experience) for each of the items.

Responses to the 13 questions on test acceptability were further examined by socio-demographic characteristics; age, mother tongue, municipality type, education level and marital status. To avoid small frequencies and asymmetry in cross-tabulations for this purpose, the responses were grouped into three categories, “agree” (totally and somewhat agree), “neither agree nor disagree” and “disagree” (totally and somewhat disagree). Women who answered “cannot say” or did not answer at all were excluded from the tabulations. Fisher's exact test was applied to test the independence of socio-demographic and response variables. The p value is the probability for the observed association and more extreme interactions between the variables. The problem of multiple comparisons was approached by Holm–Bonferroni method [33]. Significance level was set at 0.05. For each socio-demographic variable there was a family of 13 hypotheses (questions on test acceptability) of independent association between the socio-demographic characteristic and a response variable. Fisher's exact test p-values related to the 13 hypotheses were arranged in the increasing order. If the smallest p value was smaller than 0.05/13, the corresponding hypothesis was rejected and the second smallest p value was compared to 0.05/12. If not, the hypothesis was not rejected, and testing algorithm ended. The table cell/cells contributing most to the observed interactions were detected with Pearson residuals and their squares, i.e. contributions to the Pearson chi-square statistic. The statistical analyses were conducted using Stata 12.0 (StataCorp LP, College Station, Texas), and Pearson residuals were calculated with a Stata ado file, tabchi, written by Nicholas J. Cox.

Women's reasons for not taking part in screening with self-sampling were enquired with a question with seven ready-made answer options and an open-ended “Other reason, what?”. Multiple answers were allowed.

Women's reasons for previous non-attendance to screening were enquired with a question with 10 ready-made answer options and an open-ended “Other reason, what?”. Some of the questions could also be completed with text. For analysis, the open answers were grouped. All reasons were divided to four categories, “Attended elsewhere”, “Practical reasons”, “Emotional/attitudinal reasons” and “Forgot”. Forgetting to attend was treated as a separate group as it can be due to both practical reasons (too busy) of emotional reasons (not high enough priority). Multiple answers were allowed.

Reasons for previous non-attendance were examined separately for those women, who stated that their previous Pap-smear, including also tests outside the organized program (i.e. opportunistic testing) was ≥5 years ago or never. According to the 5-year screening interval in Finland, this latter group can be regarded truly as underscreened.

The study was approved by the Ethical Committee of the Hospital District of Helsinki and Uusimaa (79/13/03/03/2011) and National Institute for Health and Welfare (THL/1465/6.02.00/2013).

Results

Response rate and characteristics of the responders

In total, 1326 originally non-attending women returned the questionnaire, 28% of all recipients of the questionnaire. 909 (68.6%) of the

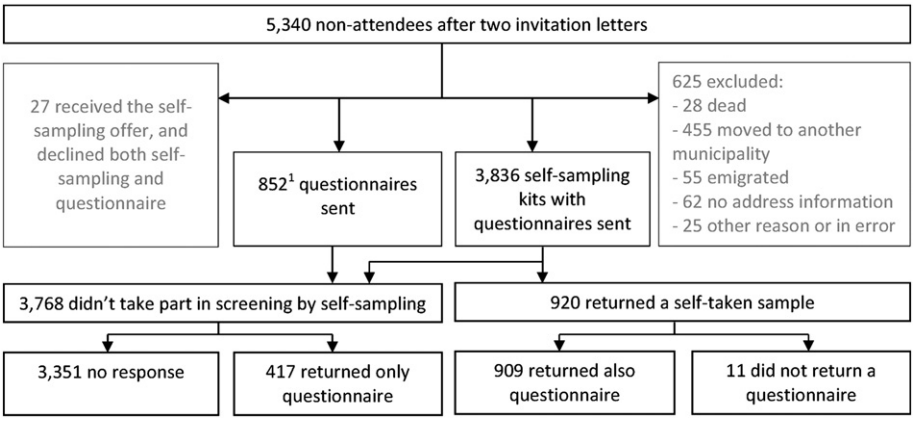

Fig. 1. Flow of study population in the questionnaire study. [1]179 women declined screening altogether after reminder letter (reason for cancelation “I do not want to take part in mass screening”) and were thus excluded from the self-sampling offer, but not the questionnaire; 673 opted out from self-sampling and thus received only the questionnaire.