



Women's experiences of abnormal Pap smear results – A qualitative study



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ARTICLE INFO

Article history:

Received 10 August 2016

Accepted 2 January 2017

Keywords:

Abnormal Pap smears
Cervical cancer screening
Experience
Content analysis

ABSTRACT

Objectives: To describe women's experiences of abnormal Pap smear result.

Methods: Ten women were recruited from a women's health clinic. Qualitative interviews based on six open-ended questions were conducted, transcribed verbatim, and analyzed by content analysis.

Results: The women believed that their abnormal Pap smear result was indicative of having cancer. This created anxiety in the women, which resulted in the need for emotional support and information. Testing positive with human papillomavirus (HPV) also meant consequences for the relatives as well as concerns about the sexually transmitted nature of the virus. Finally, the women had a need to be treated with respect by the healthcare professionals in order to reduce feelings of being abused.

Conclusions: In general, women have a low level of awareness of HPV and its relation to abnormal Pap smear results. Women who receive abnormal Pap smear results need oral information, based on the individual women's situation, and delivered at the time the women receive the test result. It is also essential that a good emotional contact be established between the women and the healthcare professionals.

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Introduction

Cervical cancer is the fourth most common forms of cancer affecting women, worldwide [1]. This cancer develops as cells change from precancerous cells into cancer, which usually takes ten to twelve years. These precancerous cells can be detected and treated before they become cancerous, via a Papanicolaou (Pap) smear test, which can be organized in a cervical cancer screening program (CCSP) [2].

Sweden introduced a CCSP in the 1960s, and since then the incidence of cervical cancer has declined by 67% and mortality by 63% [3]. The Swedish CCSP program is organized regionally in each county based on the national guidelines. These guidelines recommend women to undergo a Pap smear test at three-year screening intervals between the ages of 23–50 and then every fifth year until age 60. It is important to have a high coverage, since among women who have not undergone a Pap smear test within these recommended intervals or not at all, the incidence rate and mortal-

ity from cervical cancer is higher, than among women who have [4]. The national average for coverage in the Swedish CCSP in 2015 was 82%. This resulted in 486,954 Pap smear tests, where 19,770 cases showed either a low-grade cervical intraepithelial neoplasia (CIN 1) or a high-grade cervical intraepithelial neoplasia (CIN 2/3) [5].

The major cause, >99% of cervical cancer, is the sexually transmitted infection human papillomavirus (HPV). Thereby, HPV DNA testing has an important role in the CCSP [6]. In Sweden, new recommendations are on its way with HPV DNA testing as a primary test for women aged 30–64 [7]. These days, the HPV DNA test is already used in the CCSP, as a triage tool on low-grade abnormalities. Sweden has also introduced a HPV vaccination program in 2012.

Worldwide, there have been several studies [8–10] on women's experience of abnormal Pap smear results. Initial psychological consequences such as fear of cancer and worries about fertility were highlighted, and awareness of HPV added blame and anger [11] as well as stigmatizations such as negative self-image e.g., feelings of being contaminated or unclean [12,13]. However, in Sweden, the recent studies of women's experiences of abnormal Pap smear results have focused on women with CIN 1 [14], had data collected in the late 1990s [15], or had a quantitative design [16]. These studies were performed when Swedish women

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generally were unaware of HPV and its connection to an abnormal Pap smear result [16]. We assumed that Swedish women's awareness of HPV had increased, due to the introduction of the HPV vaccination program as well as the great attention paid in the previous year to HPV and its connection to abnormal Pap smear result and cervical cancer. Increased awareness, in turn, might affect women's experiences of an abnormal Pap smear result. Therefore, this study aims to describe women's experiences of abnormal Pap smear result.

Methods

Context

The study was performed at a women's health clinic in south-eastern Sweden. Midwives perform the Pap smear test and at the same time they also give the women written general information about possible outcomes of the test results. In 2014, as part of the CCSP, 289 women were diagnosed with CIN 1, 2, or 3, which required further investigation. These women received a letter from a physician, including the test result and information about further investigations.

Participants and recruitment

A purposive sample was used to ensure maximum variation [17] in age, marital status, and grade of CIN. Criteria for inclusion in the study were diagnosed CIN 1 with high-risk strains of HPV or CIN 2/3, being 23 – 65-years-old, Swedish-speaking, and not diagnosed with cervical cancer. In total, 38 women were consecutively invited to participate in the study, of which 10 women participated (see Table 1 for the women's characteristics). A coordinator at the clinic sent the women an information letter about the study, together with a referral to the clinic. Women who were interested in participating contacted the coordinator who informed the first author; thereafter, a time and place for the interview was booked in consultation with the women.

The study was approved by the Regional Ethics Committee for Human Research, Faculty of Health Sciences Linköping University, Sweden (Dnr 2013/233-31), and performed in accordance with the Declaration of Helsinki [18]. Written informed consent was obtained from the women at the time when the interviews were provided.

Table 1
The women's characteristics ($n = 10$).

Characteristics	n
<i>Age (years)</i>	
Mean (range)	37 (29–53)
<i>Diagnosis</i>	
CIN 1	2
CIN 2	5
CIN 3	3
<i>Marital status</i>	
Single	4
Partners	6
<i>Occupation</i>	
Employed	7
Unemployed	1
Parental leave	1
Disability pension	1
<i>Previous abnormal Pap smear result</i>	
Yes	2
No	8

Table 2
The interview guide for the individual interviews.

Open-ended questions
Can you please tell me...
– About your experiences of receiving an abnormal Pap smear result?
– How it has been since you found out?
– How you have managed since you found out?
– How your daily life has been affected since you found out?
– About your experiences of human papillomavirus?
– What healthcare professionals could have done to optimize the situation for you?

Data collection

Individual interviews were conducted by the first author, using an interview guide consisting of six open-ended questions (Table 2), together with follow-up questions. The interview guide was created based on findings from previous studies [13,14] and the authors' clinical knowledge about the research topic. Pilot-interviews were conducted with two women (included in the study), where the interview questions were confirmed to be adequate. The interviews were conducted, either in the women's home (eight) or by Skype (two), within two weeks after the women had visited the women's health clinic. After seven interviews, no new information was generated, and to confirm this, three more interviews were conducted, according to Patton [17]. The interviews lasted between 20 and 70 min, were recorded, and transcribed verbatim (97 pages), and collected between December 2014 and June 2015.

Data analysis

The interviews were analyzed using a qualitative content analysis, described by Burnard et al. [19]. Initially, the researchers wanted to get a sense of the whole by reading the transcribed interview text several times. Open coding was conducted by making notes and headings in the margins of the transcripts, in order to sum up the content of each highlighted sentences. The open coding resulted in a number of headings, which were then compared and combined with each other in order to be reduced. The remaining headings with similar meanings were brought together into subcategories. The subcategories were then analyzed together with the transcribed interviews, and findings in the transcripts were grouped under respective subcategories. Finally, the subcategories were compared and contrasted, and those with similar content were interpreted in a higher level of abstraction into main categories. (See Table 3 for examples of the steps in the analysis).

Table 3
Examples of the steps in the analysis.

Transcript	Headings	Subcategories	Categories
"You go there and do the Pap smear test, and there has never been anything before so you don't think that there might be something now". (W:5)	Expected a normal test result	Getting an unexpected answer	Losing control
"The more you talk to others around you, the more you realize that people have had cellular changes and that is calming". (W:7)	Others experiences are calming	Need to have support from loved ones	Need to gain control
"I read much on the Internet ...". (W:3)	Searched for information on the Internet	Need for information	Need to gain control

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