

CERVICAL CANCER SCREENING

Knowledge, attitudes and experiences among women and midwives

Akademisk avhandling

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av

Monica Ideström
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Avhandlingen baseras på följande delarbeten:

- I. **Knowledge and Attitudes about the Pap-smear program:
a population-based study of women aged 20-59 years.**
Ideström M, Milsom I, Andersson-Ellström A
Acta Obstet Gynecol Scand 2002;81:962-7.
- II. **Women's experience of coping with a positive Pap-smear.
A registrar based study of women with two consecutive Pap
smears reported as CIN 1.**
Ideström M, Milsom I, Andersson-Ellström A
Acta Obstet Gynecol Scand 2003;82:756-761.
- III. **Cervical Cancer Screening – ‘for Better or Worse’**
Women's experience of screening when stricken by cancer
Ideström M, Milsom I, Andersson-Ellström A, Athlin E.
Submitted for publication
- IV. **The Cervical Cancer Screening Program from a Midwife Perspective.**
Ideström M, Milsom I, Andersson-Ellström A.
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Fakultetsopponent
Professor Viveca Odland
Institutionen för Kvinnors och Barns hälsa
Uppsala Universitet

Cervical Cancer Screening Knowledge, Attitudes and Experiences among Women and Midwives

Monica Ideström, RM, MSc, Department of Obstetrics and Gynaecology
Sahlgrenska Academy at Göteborg University, Göteborg, Sweden

Population based cervical cancer screening (CCS), performed by midwives, to detect cellular atypia before it develops into cancer, has been in force in Sweden since the 1970s. The positive effects of the subsequent decline in morbidity and mortality due to cervix cancer are well documented but does screening also have negative consequences?

Aims: To investigate knowledge about, attitudes to and experience of CCS (i) among women in general, (ii) among women with experience of two mildly atypical Pap smears, (iii) among women diagnosed with cervical cancer and (iv) among midwives who manage CCS.

Populations and methods: *Paper I, II and IV;* A questionnaire was constructed comprising of structured and open questions. *Paper I* was mailed to 400 women, 23–59 years old, randomly selected using the National population register. *Paper II;* A questionnaire was mailed to women (n = 329) who according to the Department of Clinical Pathology five years earlier had two consecutive atypical Pap smears interpreted as CIN 1. For *Paper III* an open-ended interview, inspired by Grounded Theory was performed with eleven women, who had been diagnosed with cervical cancer two years earlier. *Paper IV;* A questionnaire was mailed to 201 midwives working in primary health care managing the programme.

Results: *Paper I:* Sixty-two percent of the women could indicate the site of the cancer the screening actually examined. Only a few women connected cellular atypias with sexually transmitted infections and were aware of the partly protective effect of a condom. Women's knowledge and experiences were age dependant. *Paper II:* Memories of initial worry and anxiety when women were told about the atypical smear were reported by 59%. Most women did not report any signs of anxiety five years later, but 8% reported a persistent negative influence on their sexual life. *Paper III:* Screening 'for better or worse' was identified as the core category around which the categories 'unawareness', 'trust', 'search for understanding' and 'making the invisible, visible' was integrated and on which the conceptual model was built. In all the above studies, most women felt well taken care of by health care professionals and they wanted to participate. Personal communication with midwives and doctors was reported as the most important source of information about CCS. Even the women treated for cancer had a positive attitude to CCS, but they were negatively influenced by their unawareness. Most women looked upon further Pap smears with a sense of security and had trust in health care. *Paper IV:* Midwives lacked guidance when informing about CCS and cytological atypias but most of them did not report a lack of theoretical knowledge. Midwives saw themselves as the main informant about CCS but nevertheless they perceived women to lack knowledge about it.

Conclusions: Women had a positive attitude to screening and wanted to attend. As long as they were confirmed as healthy they did not engage themselves in information. The midwives had difficulties with evidence based explanations concerning screening and cervical cytological atypias. The information given did not seem to reach women. A more empowering meeting where both midwives and women are more deeply engaged may improve the quality of communication. We propose the introduction of an initial, longer scheduled meeting, within the screening programme as a new approach to enhance knowledge and motivation.

Keywords: *cervical cancer screening; cervical cancer; Papanicolaou smear; knowledge, attitude, experience; coping; dysplasia; cervical intraepithelial neoplasia (CIN); midwife; information; Grounded Theory.*

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