Introduction
Cervical cancer is the second most common cancer disease in women worldwide (1). In Sweden 440 women were diagnosed with cervical cancer in 2006 (2) and 136 died from the disease in 2005 (3). The decrease of morbidity and mortality in cervical cancer in the western world has been related to effective screening programmes using the Pap smear to discover cervical cancer during early, non-invasive, asymptomatic stages. The Pap smear was developed by Papanicolaou in 1943 and has been used in screening programs and opportunistic screening (that is, Pap smears taken outside screening programmes and without sign or suspicion of a medical problem) for many years. Population-based cervical cancer screening in Sweden has existed since the 1960s and differs from those in many other countries, as it is a population-based outreach program (PCCSP), coordinated by six regional Oncologic Centers (OC).

In the last few years a shift in scientific knowledge has occurred, with evidence implicating a virus, human papilloma virus (HPV) as a necessary precursor of cervical cancer (4). HPV is the most common sexually transmitted disease in both sexes, particularly among adolescents and young adults (5). There are many types of HPV, with approximately 15 types classified as ‘high risk’ due to their association with cervical cancer (5). Most HPV-infections resolve spontaneously, but persistent HPV-infections can lead to pre-cancerous dysplasias (5). A HPV-vaccine has been developed and marketed, first in the US in 2006 and in Sweden in 2007. The HPV-vaccine is described as effective for 70% of the HPV-types, and since is most effective for those who have not been HPV-infected, vaccination programs will still need to be combined with continued cervical cancer screening for best prevention of cervical cancer. These rapid scientific and technological developments emphasize new challenges in relation to the existing cervical cancer screening programmes. Most of the research in this area to date has focused on factors that impact on women’s attendance in cervical cancer screening and interventions to increase the compliance in the screening programmes. There is a need for more knowledge about women’s experiences and reasoning about cervical cancer screening and about the link between HPV and cervical cancer, as well as about the HPV-vaccine.

My PhD research is an expansion of a larger multidisciplinary research project with Professor of Nursing Carol Tishelman as project leader and main scientific supervisor and in collaboration with Dr Catarina Widmark, who is a midwife and Dr Anette Forss, a nurse and anthropologist. Several studies have been previously published by the research group (6-12) about cervical cancer screening, based on different research questions and different stakeholder perspectives. The overall aim for my studies is to explore how women experience and reason about cervical cancer, its causes and prevention, such as cervical cancer screening and HPV-vaccines.

Women’s experiences and reasoning about screening for cervical cancer
In the literature, women who do not take Pap smears are often referred to as one reason that cervical cancer has not been successfully eliminated (13-14). Despite this there is a lack of knowledge about how the women who choose not to attend screening or at all take a Pap smear reason about their decision. Through analysis of interviews and fax messages* by women who had actively chosen not to participate in PCCSP, it became apparent that women could reason somewhat differently about their decision (15). There was a common theme in their reasoning, as tensions between the private and public spheres were salient. The participating women distinguished between what they saw as belonging to the private arena respectively the public domain. Women spoke of a division between the individual and society which they felt existed with regard to responsibility for health maintenance. There was also a difference in manner in which women described being able to ‘know’ one’s own body as opposed to more public, professional knowledge. Women often described believing that a healthy lifestyle protects one from cancer and the Pap smear could therefore be seen as unnecessary. The women’s descriptions also included previous negative experiences of health-care system and the PCCSP, for example a feeling of distrust, or previous encounters with health care staff that were described as disrespectful. Some of these women expressed a strong view that the screening program represents an undesired societal control of private issues. The PCCSP was spoken of by some women as "Big Brother"; these women also highlighted issues related to moral aspects of the PCCSP, such as self-determination versus a feeling of implicit coercion to participate. On the other hand, some women showed a willingness to share private aspects of their private life to the PCCSP, for example sending fax messages about private aspects of their personal lives to the anonymous fax number of the screening program.

As a result of the PCCSP, some women receive an abnormal or unclear Pap smear result and are therefore called for further medical follow-up, including examinations and treatments. This follow-up is often described in the existing literature and in clinical practice as an ‘unproblematic’ intervention for prevention of cervical cancer. In our study, which is based on unstructured, repeated interviews with thirty women who had received some type of abnormal Pap smear result after attending PCCSP, we interpreted the period of medical follow-up as involving strongly embodied experiences for these women (16). These experiences can also be seen in relation to aspects of the private and public spheres. Women’s descriptions of their bodies were found to involve experiences which changed over time, of both “having” and “being” a body. Two overarching, integrated processes were found to be important. One process involved the change from a taken-for-granted body experienced as ‘silent’, healthy, and asymptomatic to a body which becomes ‘heard’ through pain, vaginal discharges, and bleeding experienced after professional mediation and treatment. These women’s reasoning was also related to what was believed to be ‘normal’ or ‘abnormal’ experiences during follow-up. For example pain related to the biopsy was described as unexpected and could lead to women questioning if they were oversensitive to pain and if this could be interpreted as a sign of weakness.

The other process involved how women’s conceptualization of their bodily boundaries appeared to change. These changes could be catalyzed through professional mediation, for example as a...
result of visualization of the cervix, a previously unfamiliar area of the body for most women, as well as through pain, vaginal discharge and bleeding which often could result from professional treatments. In addition, women seemed to move from conceptualizing their own risk for cervical cancer as related to their individual body and private life, to begin to relate their risk for cervical cancer to the bodies and diseases of women in their extended families through the generations.

Issues related to the private and public spheres were also raised through focus group discussions (FGDs) with 30-year old women, which we held to investigate their reasoning about PCCSP. Preliminary analysis of the FGDs indicates the importance of the complex context in which these women live, in their reasoning regarding cervical cancer and screening. These women described the public spheres as having access to knowledge which the women describe themselves as not having. The women expressed uncertainty about a wide array of issues related to the PCCS and cervical cancer, e.g. if, when, and by whom the Pap test had been taken; what could screening detect; and the extent and nature of any information received. Few women described being aware of any relationship between HPV and cervical cancer. A "healthy lifestyle" was described as protective against cervical cancer, with perceived risk factors for cervical cancer varying from air pollution to vague notions about sexually transmitted infections. A salient finding was women’s strong expressions of surprise when the link between sexuality and cervical cancer was brought up by the moderators in the FGDs.

**Discussion and future implications for research and practice**

These different studies highlight women’s experiences and reasoning of different aspects of the PCCSP. The manner in which women conceptualized the roles and responsibilities of the private and public spheres appeared essential in their reasoning about screening for cervical cancer. Women’s ways of conceptualizing health, illness and risk for disease in general was also seen to impact on their decision-making about participation in PCCSP (12, 15). Tensions between the public and private spheres were also related to perspectives of knowledge, for example, what knowledge about women’s bodies is relevant, how it can be obtained and who ‘owns’ such knowledge. These issues are also important in light of the discourse in the contemporary culture regarding the responsibility of the individual for her health maintenance and disease prevention (12). This was apparent in both in the women’s reasoning about their decision not to participate in PCCSP but as well as women’s descriptions of their bodily experiences of the medical follow-up of an abnormal Pap smear (15-16).

Women’s view of the PCCSP as an integrated and comprehensive system suggests a need for increased collaboration around direct and indirect encounters with potential participants, among professionals involved in different stages of the programme. An additional consideration is the tension that exists between the needs of the individual and societal needs, in efforts to improve public health (see also CW’s article reference 6, for a similar discussion in relation to the role of the midwife in screening).

As a HPV vaccine was licensed after the FGDs with 30-year old women were conducted, new data is needed how these developments are understood by young women in Sweden. We therefore continue data collection with the same population. Knowledge about young women’s understandings of the PCCS and related areas are increasingly important, as HPV-vaccination programs are being discussed as an option in several countries. These 30-year old women may also be in the position of determining whether or not their children should receive future HPV-vaccines. In the existing literature the risk for stigmatization is emphasized, due to the link between HPV, a sexually transmitted disease, and cervical cancer. This, in addition to the rapid scientific and technological developments raises new challenges for the individual woman, partners, families and the society. The results of these studies can therefore hopefully add knowledge which can be used for optimizing the cervical cancer screening program, future HPV-vaccination programs, and information to better meet the needs of women.

**References**


At the time for data collection for this study, women who did not want to participate in PCCSP were asked to return the invitation to OC with an explanation for their choice.

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