Women receiving notification of an abnormal Pap smear result

– experiences and impact on health-related quality of life
WOMEN RECEIVING NOTIFICATION
OF AN ABNORMAL PAP SMEAR RESULT
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MARIE RASK
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LINNAEUS UNIVERSITY PRESS
Abstract


Aim: The aim of this thesis was to investigate experiences of receiving notification of an abnormal Pap smear result and its impact on women's health-related quality of life as well as to investigate women's awareness of human papillomavirus.

Methods: In total, 176 women and 20 health care professionals participated. Data were collected through individual interviews (I, II) and a questionnaire (IV) including the instrument Functional Assessment of Chronic Illness Therapy – Cervical Dysplasia (FACIT-CD) and Hospital Anxiety and Depression Scale (HADS). For the translation and cross-cultural adaptation of the FACIT-CD, and for evaluation of its linguistic validity and reliability, cognitive debriefing interviews and a questionnaire consisting of the Swedish instrument FACIT-CD was used. Data were analysed by content analysis (I, II) and by using statistical analysis (III, IV), while one part (III) was analysed according to FACIT translation methodology.

Results: Women receiving notification of an abnormal Pap smear result have good overall HRQoL; they become anxious but not depressed. Reasons for anxiety were mainly that women misinterpreted the result as cancer, which could lead to lower attendance for further investigation, treatment and follow-up. To cope with the anxiety, women sought emotional support and information. They primarily used the Internet for information but also turned to healthcare professionals for information needs. Moreover, women had low awareness of HPV, its sexually transmitted nature, and its relationship to abnormal Pap smear results and cervical cancer. An awareness of HPV as a sexually transmitted infection did not lead to higher level of anxiety or more depression symptoms or worse HRQoL, compared to not being aware. Finally, the Swedish FACIT-CD is equivalent to the English version and linguistically valid and exhibited good internal consistency reliability.

Conclusion: Women have low awareness of HPV and abnormal Pap smear results, whereupon they misinterpret their test result as cancer. It is of importance that women understand their test result, in order to minimise anxiety as well as to maintain high attendance for investigation, treatment and follow-up of abnormalities.

Keywords: Abnormal Pap smear, human papillomavirus (HPV), cervical cancer screening, health-related quality of life (HRQoL), anxiety, depression, HADS, FACIT-CD, translation.
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To Rebecka and William
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The thesis is based on the following papers, referred to in the text by their Roman numerals.


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ABBREVIATIONS

ANHC          Antenatal health clinic
ASC-US        Atypical squamous cells of undetermined significance
CCSP          Cervical cancer screening programme
CIN           Cervical intraepithelial neoplasia
CPS           Conventional cytology
EU            European Union
FACIT-CD      Functional Assessment of Chronic Illness Therapy – Cervical Dysplasia
HADS          Hospital Anxiety and Depression Scale
HCP           Healthcare professional
HPV           Human papillomavirus
HR-HPV        High-risk human papillomavirus
HRQoL         Health-related quality of life
HSIL          High-grade squamous intraepithelial lesion
IMS           Item mean substitution
LBC           Liquid-based cytology
LEEP          Loop electrosurgical excision procedure
LR-HPV        Low-risk human papillomavirus
LSIL          Low-grade squamous intraepithelial lesion
Pap           Papanicolaou
PCC           Person-centred care
PIF  Patient Interview Form
PMS  Person mean substitution
RCT  Randomised controlled trial
STI  Sexually transmitted infection
SWE IH Swedish item history
TBS  The Bethesda system
QoL  Quality of life
WHO  World health organization

Name abbreviations

GL  Gunnel Lindell
KS  Katarina Swahnberg
MO  Marie Oscarsson
MR  Marie Rask
PREFACE

In my work as a nurse, I have always endeavour to develop and shape the care in accordance with the patients’ needs and demands. However, optimal care is not static; instead, it is changeable. Society has changed and contributed to the fact that today’s patients are not the same as ten years ago. Today, the patient is generally more information seeking and active in his or her own care. Moreover, in gynaecological care, there have been major changes since detection of the sexually transmitted infection, human papillomavirus and its relation to abnormal Pap smear results as well as cervical cancer. The Swedish national cervical cancer screening programme is changing as well as the general view of abnormal Pap smear results. Based on these changes, I began to reflect more on how an abnormal Pap smear result affects women’s lives, and if care is adapted to women’s needs and demands. The thesis focuses on women’s experiences of receiving notification of an abnormal Pap smear result as well as the healthcare professionals’ experiences in caring for these women. Both perspectives have been chosen; the perspective of women because they are experts in their own life situation, and the healthcare professionals’ perspective as they conduct and develop the care and come into contact daily with women with an abnormal Pap smear result. Healthcare professionals’ experiences may be consistent with the women’s and/or contradictions. By investigating both perspectives my hope is to adopt a holistic perspective on the studied topic. In Sweden, since the focus has been drawn to the relation between human papillomavirus and abnormal Pap smear results as well as with cervical cancer, research on experiences of receiving notification of an abnormal Pap smear result as well as women’s awareness of HPV is limited. My hope with this thesis is to contribute with knowledge that can be helpful in improving the cervical cancer screening programme.
INTRODUCTION

In Sweden, in 1960s, a cervical cancer screening programme (CCSP) was introduced. Since then, the incidence and mortality of cervical cancer has declined (1). The major cause of cervical cancer is the sexually transmitted infection (STI) human papillomavirus (HPV), which occurs in >99% of the cancer cases (2). Cervical cancer develops from precancerous lesions, which can be detected and treated before they develop into cancer. A Papanicolaou (Pap) smear test (3) can be used to detect the precancerous lesions, and performed in the CCSP. In CCSP, approximately, 490,000 Pap smear tests are performed annually, where 10% result in abnormalities (4). Receiving an abnormal Pap smear result has shown to evoke wide range of initial negative emotions in women, such as anxiety, fear of cancer, and worries about fertility (5-8), whereupon, HPV awareness increased the anxiety (9, 10). The anxiety, in turn, has been shown to hinder adherence to screening (11-16), and further investigation and treatment (17). A high level of coverage and adherence to CCSP is required to be able to have an effect on both incidence and mortality rates in cervical cancer. It is of importance that healthcare considers how to best adapt the CCSP to women’s needs and wishes, in order to reduce the negative impact of an abnormal Pap smear result on women as well as to maintain high level of coverage and adherence. Furthermore, many Swedish women have previously reported to be unaware of HPV and its relation to abnormal Pap smear results (9, 18). An awareness of HPV is important, as new recommendations in the Swedish CCSP are on its way, which include the HPV DNA testing as a primary test for women aged 30–64, (19), and as the HPV vaccination is part of the organised school-based vaccination programme for girls (20). From a caring science perspective, this thesis aims to investigate experiences of receiving notification of an abnormal Pap smear result and its impact on women’s health-related quality of life (HRQoL) as well as to investigate women’s awareness of HPV.
BACKGROUND

Cervical cancer

Burden of cervical cancer
Worldwide, cervical cancer is the fourth most common cancer that affects women, with an estimated 528,000 new cases and 266,000 deaths annually, representing 7.5% of all cancer deaths in women, in 2012. The mortality rate in cervical cancer varies between countries, ranging from less than 2 per 100,000 in Western Europe, Australia/New Zealand and Western Asia to more than 27 in Eastern Africa. Almost 9 out of 10 (87%) of the cervical cancer cases occur in developing countries (21). This was also the case in many European countries, such as Denmark and Germany, and in North America, before the introduction of a CCSP (22). In Sweden, the introduction of the CCSP has led to a decrease in incidence of cervical cancer by 67% and mortality by 63%; still, there is an estimated incidence of 560 and an annual mortality of 120 cases (1).

HPV as a cause of cervical cancer

HPV transmission and risk factors
HPV is the most common STI among women and men worldwide (23, 24). The virus is transmitted through skin-to-skin contact and via skin-to-mucosa (25). Approximately 80% of all sexually active individuals have been infected by HPV during their lifetime (26). The peak incidence of HPV infection occurs at a young age, in late adolescence or in young adulthood (24). Several risk factors are associated with HPV-related disease and cervical cancer. Age at first sexual intercourse, number of sexual partners and partner’s sexual behaviour are associated with increased risk of HPV infection (27, 28). Smoking, long-term use of oral contraceptives (>5 years), high parity (>5 children), and comorbidity with other STIs, such as HIV, chlamydia and herpes simplex type 2, are also associated with increased risk (29, 30).
HPV characteristics
There are over 200 HPV genotypes identified (25), whereof about 40 are known to infect the anogenital tract (31). The HPV types are categorised as low-risk human papillomavirus (LR-HPV) and high-risk human papillomavirus (HR-HPV). Most of the HPV infection is asymptomatic, and approximately 90% clear within one to two years, but persistent infections can cause cancer (26, 32-34) in the vulva, anus, penis, vagina and oropharynx (35). Persistent infection of HR-HPV is a prerequisite for precancerous lesions and cervical cancer, detected in >99% of the cancer cases (2, 36). HPV-16 and HPV-18 are the causative agents of about 70% of cervical cancers; other well-known HR-HPV types include 31, 33, 35, 39, 45, 51, 52, 56, 58, 59 and 68 (37). Progression from HPV infection to invasive cervical cancer is usually a slow process, taking 10 to 12 years, (38); consequently, changes can be detected and treated at an early stage (39).

Prevention of cervical cancer
For the prevention of cervical cancer, there are two complementary approaches: primary prevention through HPV vaccination to prevent infection, and secondary prevention through cervical cancer screening to detect and treat precancerous lesions before they develop into invasive cancer (40). Noteworthy, consistent use of condoms among sexually active individuals as form of prevention, which if not elimination can at least mean reduction in risk of HPV transmission (41, 42).

HPV vaccination
Characteristic of the HPV vaccines
The primary prevention of cervical cancer is the HPV vaccines, which have been licensed since 2006, 2007 (43) and 2015 (44, 45). Three prophylactic HPV vaccines are available. The bivalent/2vHPV (Cervarix®) protects against HPV 16 and 18; the quadrivalent/4vHPV (Gardasil®) protects against HPV 6, 11, 16 and 18; and the 9-valent/9vHPV (Gardasil 9®) protects against HPV 6, 11, 16, 18, 31, 33, 45, 52 and 58 (45). The 2vHPV and the 4vHPV vaccines prevent approximately 70% of all cervical cancer incidents (46), while the 9vHPV prevents more than 96% (47). In 2015, the 9vHPV vaccine was approved in the European Union (EU) (48).
HPV vaccination programme

Many western countries and most European countries have implemented national HPV vaccination programme (49-51). The HPV vaccination is recommended for routine vaccination at age 11 or 12 years (44), administered in a 2-dose schedule, 6 to 12 months apart (52). For best protection, the vaccines should be administered before the individual has been exposed to an HPV infection (53). In Sweden, HPV vaccination (these days, with Gardasil®) has been part of the organised school-based vaccination programme for girls since 2012 (20). However, the HPV vaccination does not eliminate the need for cervical cancer screening (54).

Cervical cancer screening

Principals of screening

The basic idea of screening differs from that of traditional medicine in which an individual seeks healthcare for a problem or a disease. In screening, the initiative comes for the society, and refers to the use of tests across a healthy population to identify them who have disease, but do not yet have symptoms (55). This means that a large group of people are offered medical examination for a disease that they normally are not aware of. The tensions between these two approaches are obvious. Introduction of screening programmes are not without controversies, as there might be a conflict between public health and the ethical aspects of screening. On the one hand, it is possible to prevent a major health problem by screening a population and then treating people at risk. On the other hand, people might receive unclear statements about their health, which may lead to anxiety and concerns as they subsequently undergo unnecessary examinations and treatments. The flip side of this is that others may yet be lulled into a sense of false security that they are completely healthy when they are not (56).

World health organization (WHO) has guidelines for conditions that would be suitable for screening based on the classic criteria set by Wilson and Jungner (57), which are as follows. 1. The condition sought should be an important health problem, 2. There should be an accepted treatment for patients with a recognized disease, 3. Facilities for diagnosis and treatment should be available, 4. There should be a recognizable latent or early symptomatic stage, 5. There should be a suitable test or examination, 6. The test should be acceptable to the population, 7. The natural history of the condition, including development from latent to declared disease, should be adequately understood, 8. There should be an agreed policy on whom to treat as patients, 9. The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on
medical care as a whole, and 10. Case-finding should be a continuing process and not a “once and for all” project.

**Organised population-based cervical cancer screening programme**

CCSP aims to detect precancerous lesions, which, untreated, may develop into cervical cancer (58). Organised CCSP have been shown to reduce the number of new cervical cancer cases and enhance cancer survival (59, 60). In most countries with CCSP, the majority of cervical cancers occur in women who do not participate in regular screening (60, 61). Instead, a regular participation in the CCSP reduces life-threatening risk of cervical cancer by 88% (62). The EU had recommended an overall coverage, regarding participation in CCSP, of 85% (63) which also had been embraced in Sweden (64). In the EU, 22 out of 28 member states have a population-based CCSP that is ongoing, piloted or planned. In the world, some of the longest ongoing population-based CCSP is in the EU countries e.g. Sweden and Finland (63).

**Cervical cancer screening in Sweden**

In Sweden, a population-based CCSP was introduced in the 1960s and fully implemented in each county in 1977 (1, 65). The CCSP is based on guidelines outlined by the National Board of Health and Welfare, and is organised regionally in each county, where practical differences in the CCSP are found. The first national guideline was outlined in 1967, and gradually altered since then with respect to target groups and screening intervals. The national guidelines outlined in 1998 recommended that the screening should have a 3-year interval between ages 23–50 and then every fifth year until age 60 (66). In 2015, National Board of Health and Welfare came up with new guidelines, which include HPV DNA test as the primary test. These new guidelines are the biggest changes in the Swedish CCSP since its introduction in the 1960s. The new guidelines include Pap smear test with cytology analysis at interval of 3 years between ages 23–29, HPV analysis at interval of 3 years between ages 30–49 (complemented with a cytology analysis at age 41) and at interval of 7 years between ages 50–64. Pap smear tests that are positive for HPV are complemented by a cytological analysis. A normal as well as abnormal Pap smear result is communicated to the women by standardised letter (19, 40). The Swedish guidelines are in accordance with the EU’s guidelines on cervical cancer screening (67).

In the Swedish CCSP, in 2016, approximately 490,000 Pap smear tests were performed, resulting in an average coverage across the country of 82.4% in the age group 23–60-years-old (4).
Abnormal Pap smear results

Atypical squamous cells of undetermined significance and cervical intraepithelial lesion

The most common abnormal Pap smear results are cell changes in the epithelium; atypical squamous cells of undetermined significance (ASC-US) and cervical intraepithelial neoplasia (CIN) (4). ASC-US is slightly abnormal cells in the cervix, which are commonly caused by noncancerous conditions, such as inflammations or infections. The se abnormal cells mostly return to normal appearance with time, if not caused by HR-HPV. CIN, also called cervical dysplasia, is a precancerous lesion of the cervix, and divided into grades: CIN 1, 2 and 3. The grades indicate how much of the cervix is affected by abnormal cells. CIN 1 indicates mild changes, that is, one-third of the basal layers of the epithelium. CIN 2 indicates moderate changes affecting two-thirds of the total thickness of the epithelium. The last grade, CIN 3, indicates severe changes affecting the whole thickness of the epithelium. Cervical cancer arises as a consequence of progression from mild dysplasia through severe dysplasia to carcinoma-in-situ and carcinoma (79). For the natural behaviour of the abnormal Pap smear results, see Table 1.

Table 1. Natural behaviour of abnormal Pap smear results (80-82)

<table>
<thead>
<tr>
<th>Abnormal Pap smear result</th>
<th>Regress</th>
<th>Progress to CIN 2</th>
<th>Progress to CIN 3</th>
<th>Progress to invasive cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>CIN 1</td>
<td>60–80%</td>
<td>6–12%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CIN 2</td>
<td>40–43%</td>
<td>-</td>
<td>35%</td>
<td>5%</td>
</tr>
<tr>
<td>CIN 3</td>
<td>30–32%</td>
<td>-</td>
<td>-</td>
<td>14–31%</td>
</tr>
</tbody>
</table>

CIN, Cervical intraepithelial neoplasia.

In the Swedish CCSP, in 2016, of the 490,000 Pap smear tests, 10% showed abnormalities. The most common abnormal Pap smear results were ASC-US (4.90%) and CIN 1 (2.80%) followed by CIN 2 (0.90%) and CIN 3 (0.50%) (4).

Classification system of abnormal Pap smear results

The classification system (Table 2) for abnormal Pap smear results had changed several times. In the past, CIN terminology was the most commonly used classification system, based on the different grades of CIN, 1 to 3 (83). Nowadays, the Bethesda system (TBS) is widely used and consists of two nomenclature: Low-grade squamous intraepithelial lesion (LSIL) and High-grade squamous intraepithelial lesion (HSIL) (84-86). The EU guidelines

Types of screening

There are two types of screening: screening by cytology, which includes conventional cytology (CPS) (Pap smear) and liquid-based cytology (LBC), or screening by HPV DNA testing. Nowadays, worldwide, LBC is more common than CPS (3, 58). In Sweden, the HPV DNA test is used as a triage tool on low-grade abnormalities, until new guidelines will be applied (3). Even though techniques for screening have changed over the years, this thesis uses the term Pap smear as it is applied internationally.

Screening by cytology: For these tests, cells are collected from the surface of the uterine cervix and the cervical canal using a plastic spatula or brush. The entire transformation zone should be sampled, as false negative tests could occur. The sample is either smeared on a glass slide (CPS) or immersed in a container with preservative solution (LBC) and then sent to a cytological laboratory for analysis under a microscope. CPS has a sensitivity range from 38% to 84%, and a specificity of >90% (58). Regarding sensitivity of LBC, divergent results are reported. A Dutch randomised controlled trial (RCT) (68) showed no increase in sensitivity, while a Swedish RCT (69) showed 40% increase compared with CPS. The LBC technique has several advantages, such as the residual material allows for ancillary testing such as reflex HPV DNA testing (70).

Screening by HPV DNA testing: This test does not require a pelvic examination or a visualisation of the cervix; instead, a swab or small brush is inserted deep into the vagina to collect a sample of cells. The cells are then placed in a container with preservative solution and sent to a cytological laboratory to be analysed for the presence of HPV DNA (58). Compared to cytology, HPV DNA testing has less specificity but higher sensitivity and reproducibility with increase predictive values for the detection of severe abnormalities (71-75). A combination of cytology and HPV DNA testing (dual or co-testing) attains very high sensitivity and negative predictive values (76). An important aspect of HPV DNA testing is the availability of self-sampling, which has the potential to increase the coverage of cervical cancer screening among women that would otherwise not be screened (61, 77). In addition, compared to cytology screening programme, a HPV-based screening can be more efficient with fewer screening-related harms (78), but in turn, carries a risk of unnecessary colposcopies, psychological distress and possible over diagnosis (4).
Abnormal Pap smear results

Atypical squamous cells of undetermined significance and cervical intraepithelial lesion

The most common abnormal Pap smear results are cell changes in the epithelium; atypical squamous cells of undetermined significance (ASC-US) and cervical intraepithelial neoplasia (CIN) (4). ASC-US is slightly abnormal cells in the cervix, which are commonly caused by noncancerous conditions, such as inflammations or infections. These abnormal cells mostly return to normal appearance with time, if not caused by HR-HPV. CIN, also called cervical dysplasia, is a precancerous lesion of the cervix, and divided into grades: CIN 1, 2 and 3. The grades indicate how much of the cervix is affected by abnormal cells. CIN 1 indicates mild changes, that is, one-third of the basal layers of the epithelium. CIN 2 indicates moderate changes affecting two-thirds of the total thickness of the epithelium. The last grade, CIN 3, indicates severe changes affecting the whole thickness of the epithelium. Cervical cancer arises as a consequence of progression from mild dysplasia through severe dysplasia to carcinoma-in-situ and carcinoma (79). For the natural behaviour of the abnormal Pap smear results, see Table 1.

Table 1. Natural behaviour of abnormal Pap smear results (80-82)

<table>
<thead>
<tr>
<th>Abnormal Pap smear result</th>
<th>Regress</th>
<th>Progress to CIN 2</th>
<th>Progress to CIN 3</th>
<th>Progress to invasive cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>CIN 1</td>
<td>60–80%</td>
<td>6–12%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CIN 2</td>
<td>40–43%</td>
<td>-</td>
<td>35%</td>
<td>5%</td>
</tr>
<tr>
<td>CIN 3</td>
<td>30–32%</td>
<td>-</td>
<td>-</td>
<td>14–31%</td>
</tr>
</tbody>
</table>

CIN, Cervical intraepithelial neoplasia.

In the Swedish CCSP, in 2016, of the 490,000 Pap smear tests, 10% showed abnormalities. The most common abnormal Pap smear results were ASC-US (4.90%) and CIN 1 (2.80%) followed by CIN 2 (0.90%) and CIN 3 (0.50%) (4).

Classification system of abnormal Pap smear results

The classification system (Table 2) for abnormal Pap smear results had changed several times. In the past, CIN terminology was the most commonly used classification system, based on the different grades of CIN, 1 to 3 (83). Nowadays, the Bethesda system (TBS) is widely used and consists of two nomenclature: Low-grade squamous intraepithelial lesion (LSIL) and High-grade squamous intraepithelial lesion (HSIL) (84-86). The EU guidelines
recommended that all classification systems should be translatable into TBS (87). In 2017, TBS was introduced in Sweden (85).

<table>
<thead>
<tr>
<th>WHO</th>
<th>CIN</th>
<th>TBS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atypia</td>
<td>Atypia</td>
<td>ASC-US</td>
</tr>
<tr>
<td>Mild dysplasia</td>
<td>CIN 1</td>
<td>LSIL</td>
</tr>
<tr>
<td>Moderate dysplasia</td>
<td>CIN 2</td>
<td>HSIL</td>
</tr>
<tr>
<td>Severe dysplasia</td>
<td>CIN 3</td>
<td>HSIL</td>
</tr>
<tr>
<td>Carcinoma-in-situ</td>
<td>CIS</td>
<td>HSIL</td>
</tr>
<tr>
<td>Invasive carcinoma</td>
<td>Invasive carcinoma</td>
<td>Invasive carcinoma</td>
</tr>
</tbody>
</table>

ASC-US, Atypical squamous cells of undetermined significance; CIN, Cervical intraepithelial neoplasia; CIS, Carcinoma-in-situ; LSIL, Low-grade squamous intraepithelial lesion, HSIL, High-grade squamous intraepithelial lesion.

**Detection and treatment of abnormal Pap smear results**

Abnormal Pap smear results need additional investigations to confirm or reject abnormalities. Cytological and HPV DNA test surveillance is general recommended management of ASC-US and LSIL, as these abnormalities very likely regress spontaneously (40, 58). Otherwise, colposcopy, biopsy and endocervical curettage are commonly used diagnostic tests, after an abnormal Pap smear result. In cases where treatment are needed, some common options are loop electrosurgical excision procedure (LEEP), cold knife conisation and cryotherapy. Treatment is safe, often non-destructive and usually curative (58). However, women treated for HSIL have increased long-term risk of cervical cancer for at least 20–25 years (89). After treatment, follow-up is performed in order to exclude residual dysplasia and HPV infections as well as to detect newly acquired dysplasia. Detection and treatment as well as follow-up after treatment are outlined in management algorithms, whereupon, the Swedish national managements are available at: http://www.cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptakt/gynekologisk-cellprovskontroll/vardprogram/nvp-cervixcancerprevention-170119.pdf (40).
Previous research related to women receiving notification of an abnormal Pap smear result and HPV awareness

Women’s experiences of receiving notification of an abnormal Pap smear result and impact on HRQoL

Previous research (5-7, 90-96) has shown that receiving notification of an abnormal Pap smear result evokes a wide range of negative psychological responses in women, which in turn hinders adherence to screening (12-16, 97-99) and further investigation and treatment (17). Juraskova et al. (92) found anxiety, fear and shock as common initial psychological responses to the test result, among women with varying degrees of CIN. Similar results are also found in quantitative research with women receiving notification of abnormal Pap smear result, undertaken among women in France, Spain and Portugal (100), Canada (6), the Netherlands (101) and Germany (7). The anxiety has been described to be mostly related to fear of cancer followed by further reproductive problems (92, 102-105), and not depended on the severity of the abnormalities (8, 92, 94, 96). This contradicts research among Canadian women undertaken by Drolet et al. (6), which reported that women with HSIL had higher levels of anxiety after receiving notification of an abnormal Pap smear result than women with LSIL or ASC-US. Higher levels of anxiety was also found to be associated with lower income, smoking, higher perceived risk for developing cervical cancer and lack of understanding of the Pap smear result (6).

Previous studies (6, 8, 95, 96) have reported that anxiety persists in women for some time after notification of an abnormal Pap smear result. Drolet et al. (6) found that the anxiety persisted for 12 months after notification of the result. Hellsten et al. (95, 96) found that 6-months after notification, the overall HRQoL was no longer affected and the level of anxiety was lower and further decreased over the following 24 months, but the mental health was still affected. An observational study conducted among Finnish women by Heinonen et al. (8) reported that anxiety decreased over time for the majority of women, but 35% of 492 women still had clinically meaningful anxiety 12 weeks after notification.

Previous research (18) among Swedish women referred for diagnostic colposcopy found that an abnormal Pap smear result had negative impact on women’s sexual function, such as lower spontaneous interest in sex and decrease in frequency of intercourse. Blomberg et al. (106) investigated in a Swedish context, and in relation to how women experience their bodies over time, during the medical follow-up of their abnormal Pap smear. The result showed that women’s conceptualisation of bodily boundaries appeared to
change (106) and that women objectified their body and did not have trust in it. Thangarajah et al. (7) found a moderate impact on family life, professional life and relationship, among a German cohort of women who were referred to a special clinic for evaluation of an abnormal Pap smear result.

Moreover, studies with different approaches and context (10, 107-113) had shown that an awareness of HPV infection increases the negative responses evoked by the abnormal Pap smear result, as well as added other negative responses. Qualitative research with women testing HPV-positive undertaken in the US (114) and Ireland (115) found stigma, fear, self-blame, embarrassment, powerlessness, guilt and anger as well as reactions of stress, confusion, shock and isolation as common responses. In addition, O’Conner et al. (115) found that women who expressed negative emotions were more concerned over the abnormal test result, had greater HPV knowledge and awareness of HPV as sexually transmitted infection, had low awareness of the high prevalence of HPV infection, and high HPV information needs.

**Healthcare professional’s experiences in caring for women with abnormal Pap smear results**

Healthcare professional’s (HCP’s) experience in caring for women with abnormal Pap smear results is poorly studied. Ideström et al. (116) investigated Swedish midwives’ experience of the CCSP and their apprehension of women’s knowledge about Pap smear screening. The results showed that midwives experienced that women had limited knowledge of cellular changes not being the same as cancer and were not aware of what followed an abnormal Pap smear result. Chew-Graham et al. (117) interviewed 27 English HCPs and found that they do not prepare women for an abnormal Pap smear result when taking the tests. This was also highlighted in a study by Sarkadi et al. (118) involving gynaecologists. The results also showed that the gynaecologists were aware of the anxiety an abnormal Pap smear result can evoke, whereupon, most of the gynaecologists expressed the need to be available by phone or write a personal letter informing of the abnormal result. Murff et al. (119) conducted a cross-sectional survey among primary care physicians where the results showed that the majority of care physicians were not satisfied with their method for notifying women of their abnormal Pap smear result.

**HPV awareness**

Previous research (18, 120-123) indicated that awareness of HPV was lower before the introduction of HPV vaccination than after. A large population-based cross-sectional Swedish study (122) found that 23% of young women,
13% of young men, 29% of female parents and 17% of male parents had heard of HPV. Similar results are also found in studies undertaken in the US (120, 121), which found that approximately one-third had heard of HPV. In a longitudinal study among 100 Swedish women attending a follow-up after a colposcopy, only a small number of women (19%) had any knowledge about the relation between HPV and an abnormal Pap smear result (18). A review based on European studies to ascertain the level of HPV knowledge among European adolescents found that the adolescents had poor understanding of basic HPV knowledge. Awareness of HPV varied between studies, where the lowest study reported that 5% had heard of HPV and the highest reported 92% (124).

After the introduction of HPV vaccination, several studies (125-128) have indicated that the awareness and knowledge of HPV has increased. A large population-based post vaccination survey among Scandinavian women found that in all countries (Sweden, Denmark and Norway) the awareness of HPV had increased after introduction of the HPV vaccination, and varied between 62.4%–75.8% (127). A high awareness of HPV has also being reported in US (125, 126) and UK (129), where the awareness varied between 75%–90%; however, only a little understanding of HPV as a cause of cervical cancer was reported (126, 129). In contrast, previous studies (128, 130) among respondents from nationally representative sample of US adults found that 44%–68% of the adults were aware of HPV. Low awareness about HPV was reported among Swedish parents of 11–12-years-old girls (131), and among immigrant women in Sweden (132). Factors that have been found to be associated with greater HPV awareness and knowledge include: being female (124, 125, 128, 130), not in a relationship (128), being below the age of 65, (128, 130), higher education (124, 128, 130), being vaccinated (124) and having previous sexual experience (124, 127). Factors associated with lower HPV awareness and knowledge include: never having used condoms, non-use of contraception at first intercourse, and daily smoking (127).

**Significant concepts**

In this section, three significant concepts for this thesis will be described, which are as follows: health, quality of life (QoL) and HRQoL.

**Health**

Health is a multidimensional concept and understood in different ways depending on the disciplinary perspective (133). In the perspective of caring sciences, health is understood in relation to life and to the life circumstances in
which persons are living. The person actively and consciously influences their health with the health choices they make. Health is expressed through feelings, attitudes, actions and achievements (134). Throughout the years, health has been defined in various way; some definitions are based on what health is, while others on how health occurs and what leads to health (135). There is no general definition of health that means the same for all people, even if health often is discussed in such a way (136). The most commonly used definition of health is the one stated in 1948 by the WHO, ‘Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity’ (137, p. 100). The limitation in this definition in relation to the caring science is the lack of a fourth dimension, the spiritual well-being. This dimension is included in the concept QoL, which is a concept that health often is related to (135); thus, it will also be included in this thesis.

Quality of life and health-related quality of life
One of the earliest definitions of QoL derives back to Nichomachean Ethics where Aristotles (384–322 BC) stated: ‘both the multitude and persons of refinement ...conceive “the good life” or “doing well” to be the same thing as “being happy”. Although, Aristotle did not use the term QoL, it was first during the early twentieth century the term QoL was coined (138). In the 1980s within medical literature and research studies, the term QoL was more often referred to as HRQoL (139). This was so in order to distinguish from the broader meaning of QoL (138), as well as to exclude influences on QoL such as cultural and political factors less directly influenced by health-care; however, to differentiate health-related factors from other factors, can be difficult (140). QoL and HRQoL are complex and multidimensional concepts, and include several domains. The most frequent domains are the physical well-being, psychological well-being, social concerns and spiritual well-being (133). Neither QoL or HRQoL had a universal accepted definition (133, 138), resulting in that they often are implicitly defined by the way the investigator measures them (141). However, one internationally well-known definition of QoL is the one outlined by the Constitution of the WHO. The concept QoL is defined as ‘individuals’ perceptions of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns. It is a broad ranging concept, affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment’ (142, p. 1404). In addition, HRQoL can be defined as ‘those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment’ (143, p. 646). QoL and HRQoL reflects an individual’s subjective sense of their life and well-being, are always changing and dynamic’ (144) and influenced by several factors. Example of factors that influence include: age, diagnosis, beliefs, personal experiences and
factors that influence include: age, diagnosis, beliefs, personal experiences and changing and dynamic' (144) and influenced by several factors. Example of an individual's subjective sense of their life and well-being, are always the presence of disease or treatment' 'those aspects of self-perceived well-being that are related to or affected by their environment' independence, social relationships, and their relationship to salient features of in a complex way by the person's physical health, psychological state, level of expectations, standards, and concerns. It is a broad ranging concept, affected the culture and value system in which they live, and in relation to their goals, defined as QoL is the one outlined by the Constitution of the WHO. The concept QoL is measures them (141). However, one internationally well-known definition of well-being, psychological well-being, social concerns and spiritual well-being and include several domains. The most frequent domains are the physical, mental, and social well-being and not merely the absence of disease health is the one stated in 1948 by the WHO, often is discussed in such a way (136). The most commonly used definition of general definition of health that means the same for all people, even if health while others on how health occurs and what leads to health (135). There is no been defined in various way; some definitions are based on what health is, attitudes, actions and achievements (134). Throughout the years, health has refinement …conceive “the good life” or “doing well” to be the same thing as dimension is included in the concept QoL, which is a concept that health often cultural and political factors less directly influenced by health-care; “being happy'. Although, Aristotle did not use the term QoL, it was first One of the earliest definitions of QoL derives back to Nichomachean Ethics (135); thus, it will also be included in this thesis. Why measure health-related quality of life? Conventional clinical outcomes have previously shown to poorly correlate with patient’s assessment of HRQoL (138), which is an important benchmark in nursing. In addition, HRQoL is one of the primary patient-reported outcomes in order to provide the patient’s perspective on the effects of a disease or condition and treatment (146). Measurements of HRQoL might provide important information to HCPs that can be helpful to improve clinical practice. This can be accomplished by it leading to suggestions for changes in care delivered and/or in treatment (133).

Measurement of health-related quality of life
These days, there are a large number of HRQoL instruments, which can be categorised as generic and specific instruments (condition/disease or dimension specific) (138). In this thesis, the disease specific instrument Functional Assessment of Chronic Illness Therapy – Cervical Dysplasia (FACIT-CD) (147) and the dimension specific instrument Hospital Anxiety and Depression Scale (HADS) (148) has been used (IV).

Generic instruments
Generic instruments are designed to measure the complete dimensions relevant to HRQoL, irrespective of the illness or condition of the patient (133, 138). Advantages with a generic instrument are that they are suitable for use across a broad range of diseases and conditions. They allow for comparisons between treatments for patient with different illness or condition to assess comparative effectiveness. They can also be used within a healthy population in order to generate normative data that can be used to compare different patient groups (149). On the other hand, the disadvantages are that a generic instrument does not focus on problems of a specific disease or condition or simultaneously measure the effect of contemporaneous diseases/conditions. Finally, generic instruments are potentially less responsive to clinically important changes in health (133).

There are two types of generic instruments, health profiles and utility measures. Health profile instruments attempt to measure different domains of QoL and are designed for use in a wide range of diseases and conditions, not focused on one specific (133). Example of these instrument is the Medical Outcomes Study 36-Item Short Form (SF-36) (150). Utility instruments, on the other hand, attempt to measure a single number along a continuum of e.g.
perfect health (10) to death (0). Thus, a typical question is, “How would you rate your overall health today?” (133).

**Disease/condition specific instruments**

Disease/condition specific instruments, e.g. FACIT-CD (147), are designed to measure the patient’s perceptions of a specific disease or condition. Advantages with disease/condition specific instruments are that they focus on the issues of particular concern to a patient with a specific disease or condition (138). They are also more sensitive to detecting clinically important changes in patient’s HRQoL than a generic instrument (151). On the other hand, the disadvantages with disease/condition specific instruments are that they are seldom comprehensive and cannot be used to compare results across diseases or conditions (149).

**Dimension specific instruments**

Dimension specific instruments, e.g. HADS (148), are designed to measure one specific dimension of HRQoL (e.g. psychological well-being) (138). Advantages with a dimension specific instrument are that they measure the specific dimension of HRQoL in greater depth than generic and disease/condition specific instruments (152). On the other hand, the disadvantages with dimension specific instruments are that they do not capture other dimensions of HRQoL that might be of importance. Accordingly, these instruments are used in conjunction with generic or disease/condition specific instruments (138).

**Theoretical framework**

This thesis has been developed from a caring science perspective, with focus on HRQoL and concepts in person-centred care (PCC). In combination, coping is used to improve understanding of coping strategies in women with abnormal Pap smear results.

In the caring science, the human being is the primary object of study (153), and focus is on how human perceive and experience their daily lives, their health, environment, relations, their well-being or suffering. The person/human, health, environment and caring is the core ontological concept, and the patient perspective is the central of perspectives (135). However, a HCP’s perspective does not need to be excluded, since the meaning is to investigate something that it is of importance for the patient’s care (153). The fundamental aim in caring science is to generate knowledge in order to alleviate suffering, preserve and protect life and to promote health (135). This thesis focuses on the ontological concepts of person, health and caring.
Ontological concepts

Person
The person (woman and HCP) is viewed as a subject, which means that it is a multidimensional unit of body, (mind) soul and spirit, which cannot be separated from each other (154, 155). Furthermore, the women’s perspective is the central and through their lived experience they are the expert on their own life-situation (153). This, in how they perceive and experience their daily lives, health, relations, well-being and suffering after becoming notified of an abnormal Pap smear result. The HCP’s perspective can contribute with knowledge that could have importance for the women’s care in the CCSP.

Health
Health is not only to be understood as the absence of `disease` (the abnormal Pap smear); instead the focus is on the well-being and the suffering. The concept health was replaced with QoL, where following dimensions were used: physical well-being, psychological well-being (special focus on anxiety and depression), social well-being and spiritual well-being. In turn, QoL was replaced with HRQoL, in order to distinguish from the broader meaning of QoL. The HRQoL is to be viewed as the women’s subjective perceptions of their life, where the HRQoL changes over time and is affected by them becoming notified of their abnormal Pap smear result. The women’s HRQoL is also affected by the HCP’s action such as in how they communicate and treat the women.

Caring
Caring is to be viewed as a phenomenon that is not tied to a specific HCP but rather refers to the process of intentions, activities, strategies and actions performed by the HCPs. For the caring of the women, the communication and treatment is at focus. Furthermore, the caring is also discussed based on the first component in PCC (the patient’s narratives), notable, not the whole model (156). This component highlights that the HCPs need to know the women behind the patients, as a human being with reason, will, feelings and needs, which can be accomplished by having a dialogue with the women. The goal is to engage the woman to become an active partner in decision-making regarding her care and treatment. The woman’s view about her life situation and condition (the abnormal Pap smear) is at the centre as well as the starting point of the care (156). The focus shifts from the condition (the abnormal Pap smear) to the woman with the condition (needs and resources) (157). Concepts in the PCC that are used in the discussion part are: holistic, individualised, respectful and empowering (158). I hereby, present a simplified explanation of the central concepts. Holistic care is when the HCPs recognises and value the
biological, social, psychological, and spiritual aspects of the women, as well as the interdependence of these aspects (159, 160). Individualised care means that the HCPs consider the individual woman’s unique needs and specific health concerns and based on that provide customised care (161). For this, the HCPs need to understand the woman’s life situation (e.g. having knowledge about beliefs and preferences) as well as the woman’s desire or ability to take control of her care (162). Respectful refers to the woman’s right to be treated with respect, which allows the woman to be viewed as an active healthcare consumer and recognised as competent to make own decisions about her care (163). Empowerment encourages the two important factors, autonomy and self-confidence, which promote self-determination which in turn facilitates the women’s participation in decisions concerning care (164). The HCP could help the women to feel empowered, e.g. by assisting the women to learn and obtain information (165).

**Coping strategies**

Receiving a notification of an abnormal Pap smear result can become a stressful situation, which women need to cope with. Coping is the set of intentional, goal-directed efforts people engage in to manage psychological stress (166, 167). Lazarus and Folkman (167, p. 141) define coping as ‘constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person’. Coping strategies can be classified in many different ways. This thesis use the classification: problem-focused and emotion-focused coping strategies. Problem-focused coping aims to resolve the stressful situation (such as receiving notification of an abnormal Pap smear result) or event or altering the source of the stress. This is done, for example, by taking control of the stress (the anxiety) and/or seeking information in handling the stressful situation (receiving notification of an abnormal Pap smear result) and/or removing oneself from the situation. Instead of changing the stressful situation, the emotion-focused coping aims to manage the emotions associated with the stressful situation (such as receiving notification of an abnormal Pap smear result) (166, 168). This coping strategy is apt to be mainly palliative since it, for example, includes processes such as avoiding, denying, distancing, and taking tranquilizers (166, 169). It is common to use a variety of coping strategies to deal with a stressful situation (170). For the women to cope successfully with their abnormal Pap smear result, it is more important that the coping strategy they choose match the stressful situation than one strategy over another (171).
RATIONALE FOR THIS THESIS

The benefits of the introduction of the CCSP in Sweden in 1960s were that it reduced the incidence and mortality of cervical cancer. Having women confident in CCSP is essential to maintain a high level of coverage both for taking the Pap smear test and follow-up treatment. A high level of coverage and adherence to treatments is required for the screening to be able to have an effect on both incidence as well as mortality rates in cervical cancer (60). The new guidelines in the CCSP, an HPV-based screening, are resulting in more women being notified of an abnormal Pap smear result. Already, there are many anxious women calling the women’s health clinic, with questions about their abnormal Pap smear result. Therefore, it is essential that healthcare address how to best adapt the CCSP to women’s needs and wishes. By developing the CCSP, both medical expenses and women’s concerns can be minimised.

Research within the topic of abnormal Pap smear results from the HCP’s perspective is limited. Previous research had focused on HCP’s role in CCSP (11, 116, 118, 172-175), and not regarding HCP’s experiences of meeting and taking care of women with abnormal Pap smear results. From women’s perspective, there is a range of previous research on this topic. This research had shown that an abnormal Pap smear result elicits a wide range of initial negative emotions in women (5-8), whereupon an awareness of the sexually transmitted nature of HPV infection increases these negative emotions (10, 107-109). In addition, there is also previous research about the impact of an abnormal Pap smear result on women’s HRQoL (7, 96, 109). However, in Sweden, the recent research on women’s experiences of abnormal Pap smear results have focused on women with low-grade abnormalities (103), had data collected in the late 1990s (106), or had a quantitative design, notable, not using disease-specific instruments (18, 91, 95, 96). Since these researches were conducted, there has been more focus on the relation between HPV and abnormal Pap smear result as well as with cervical cancer. This led to changes in the Swedish CCSP regarding diagnosis and treatment of abnormal Pap smear.
smear results, as well as an introduction of HPV DNA test. As a result, more women are going to receive notification of an abnormal Pap smear result. In addition, there has also been an introduction of a HPV vaccination programme. Since attention has been drawn to the HPV infection, little is known about experiences of receiving notification of an abnormal Pap smear result and its impact on women’s HRQoL, as well as women’s caring needs and HPV awareness. Unfortunately, there are no Swedish disease specific instruments to assess the impact of an abnormal Pap smear result on women’s HRQoL. By translating and cross-culturally adapting the English disease specific instrument called the FACIT-CD, women’s HRQoL associated with an abnormal Pap smear result can be assessed (147). By conducting research in this field, knowledge can be generated about HPV awareness, and abnormal Pap smear result’s impact on women’s HRQoL as well as their care needs and wishes.
AIM

Overall aim
The overall aim of this thesis was to investigate experiences of receiving notification of an abnormal Pap smear result and its impact on women’s health-related quality of life as well as to investigate women’s awareness of human papillomavirus.

Specific aims

I. To explore the experiences of healthcare professionals in caring for women with abnormal Pap smear results.

II. To describe women’s experiences of abnormal Pap smear result.

III. To translate and cross-culturally adapt the Functional Assessment of Chronic Illness Therapy – Cervical Dysplasia (FACIT-CD) into a Swedish context, and evaluate the linguistic validity and reliability.

IV. Among women with an abnormal Pap smear result, assess a) women’s awareness of human papillomavirus (HPV), b) women’s health-related quality of life and levels of anxiety and depression, and c) to compare the outcomes between women who are aware of the sexually transmitted nature of the HPV infection and women who are not.
MATERIAL AND METHODS

This thesis is based on four studies, whereupon the findings in study I generated knowledge from the HCP’s perspective where the topic needed to be further investigated from the women’s perspective to get a holistic perspective. Findings from study I were used to create the interview guide in study II. Thereafter, these two studies findings generated hypotheses that guided the research aim and design in study IV. The needs of an instrument in study IV guided the research aim and design in study III. In this section, the material and methods of the studies of this thesis are described. See Table 3 for an overview of the studies. For more descriptions, see respective article.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Participants</th>
<th>Data collection</th>
<th>Analysis</th>
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<tbody>
<tr>
<td>I</td>
<td>Explorative study</td>
<td>HCP(^a) ((n=20))</td>
<td>Individual interviews</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>II</td>
<td>Descriptive study</td>
<td>Women with CIN(^b) ((n=10))</td>
<td>Individual interviews</td>
<td>Qualitative content analysis</td>
</tr>
<tr>
<td>III</td>
<td>Methodological study(^d)</td>
<td>Women with CIN(^b) ((n=10))</td>
<td>Cognitive debriefing interviews</td>
<td>Performed by the FACTT project manager</td>
</tr>
<tr>
<td></td>
<td>Methodological study(^e)</td>
<td>Women with CIN(^b) ((n=34))</td>
<td>Questionnaire</td>
<td>Item analyses</td>
</tr>
<tr>
<td>IV</td>
<td>Cross-sectional and descriptive study</td>
<td>Women with ASC-US(^c) or CIN(^b) ((n=122))</td>
<td>Questionnaire</td>
<td>Student’s t-test, (\chi^2) test, Fisher’s exact test, Mann-Whitney U-test, Fisher-Freeman-Halton exact test</td>
</tr>
</tbody>
</table>

\(^a\)HCP, Healthcare professional; \(^b\)CIN, Cervical intraepithelial neoplasia; \(^c\)ASC-US, Atypical squamous cells of undetermined significance; \(^d\)Pilot test; \(^e\)Evaluation of the reliability.
Design

In the research underlying this thesis, both qualitative (I, II) and quantitative (IV) approaches were applied, from the perspectives of women (II, IV) and HCPs (I). In order to provide answers to the specific aims, different methods for data collection, individual interviews (I, II, III), and questionnaire (III, IV), and different analysis, contents analysis (I, II) and statistical analysis (III, IV), were used. The goal was to establish an enriched understanding and broader perspective of the studied area (176, 177).

Settings

This thesis was conducted at one antenatal health clinic (ANHC) and two women’s health clinics, in rural districts of Sweden. Women participating in the CCSP visited a midwife, who took the Pap smear test at ANHC. Thereafter, women with abnormal Pap smear results were referred to one of the women’s health clinics for further investigation. Gynaecologists, midwives, nurses, enrolled nurses, counsellors, and medical secretaries worked at the women’s health clinics. There were differences between the women’s health clinics in the manner in which they notified the women about their abnormal Pap smear result. At one of the women’s health clinics, the physician notified the women by letter, while at the other, the midwives at the ANHC notified women by phone. The physician at both of the women’s health clinics informed the women by letter about further investigations. The Pap smear tests are performed at ANHC’s which are linked to either the one or the other of the women’s health clinics. Annually, in the CCSP, each of the women’s health clinics performed approximately 8,500 to 11,500 Pap smear tests (coverage 82%) and diagnoses approximately 900 abnormal Pap smear results.

Participants

Study I

A purposive sample was used, with the strategy of maximum variation (heterogeneity) sampling. This was done with the aim to capture central themes that cut across variations (177) in age and professionals. The inclusion criteria were: HCP with ≥ one year experience in meeting and taking care of women with abnormal Pap smear results, Swedish-speaking, and willing to share their experiences with the researcher. In total, 20 HCPs were invited, of which all participated in the study. See Table 4 for the characteristics of the participating HCPs.
Study II
A purposive sample was used, with the strategy of maximum variation (heterogeneity) sampling. This was done with the aim to capture central themes that cut across variations (177) in age, marital status and grade of CIN. The inclusion criteria were: aged 23–65-years-old, diagnosed CIN 1 with HR-HPV or CIN 2/3, Swedish-speaking, and not diagnosed with cervical cancer. In total, 38 women were invited, of which 10 women participated in the study. See Table 4 for the characteristics of the participating women.

Study III
This study comprised two parts, first, the translation and cross-cultural adaptation, which included a pilot test of the Swedish FACIT-CD test version, and secondly, the evaluation of the reliability of the Swedish FACIT-CD (Figure 1). The translation and cross-cultural adaptation has a different kind of sample as the pilot test, therefore, they are presented separately. Instead, the pilot test and the evaluation of the reliability of the Swedish FACIT-CD are presented together.

Figure 1. A description of how the two parts in study III are related.
Translation and cross-cultural adaptation (pilot test excluded)

For the translation and cross-cultural adaptation process, the criteria for persons that needed to be involved were followed (178). In total, seven persons were involved: three forward translators, one reconciler, one back translator, one reviewer/language coordinator (MR) and a FACIT project manager (the latter represents the constructers of the FACIT-CD). Two of the forward translators, the reconciler and the reviewer/language coordinator were native Swedish speakers and HCPs. The FACIT project manager, one of the forward translators and the back translator were native English speakers, whereupon the two latter persons also were authorised translators.

Pilot test of the Swedish FACIT-CD test version and evaluation of the reliability of the Swedish FACIT-CD

According to the FACIT translation methodology, there should be different samples for the pilot test and the evaluation of the reliability (178, 179). Hence, women were consecutively recruited into two different samples. The inclusion criteria for both samples were women: aged ≥18 years, diagnosed with CIN and having Swedish as native language (the latter only for the pilot test). In total, 32 women were invited to participate in the pilot test, before the predetermined number of 10 women was reached. In total, 92 women were invited to participate in the evaluation of the reliability, of which 34 women participated. See Table 4 for the characteristics of the participating women.

Study IV

Women were consecutively invited to participate in the study. The inclusion criteria were: aged 23–65-years-old, receiving an abnormal Pap smear result necessitating further investigation, and not diagnosed with cervical cancer. In total, 231 women were invited to participate in the study, of which 122 women (53%) participated. The responding women were significantly older than the non-responders (m = 35.1 years SD = ±12.2 vs. 28.8 ±7.1; p = 0.000) and more often diagnosed with severe cervical abnormalities: CIN 3 (26.2% vs. 17.4%), a non-significant difference, p = 0.251. See Table 4 for the characteristics of the participating women.
Studies I – IV

The managers at the clinics were contacted and informed about the study (I – IV). Coordinators, designated at the clinic, informed and invited either the HCP (I) or the women (II, III, IV) to participate in the respective study. The HCPs were orally invited at the time they were at work (I). However, the women were invited either by an information letter sent to them together with their abnormal Pap smear result and a referral to the clinic (II, IV), or orally at the time they attended a follow-up visit for their abnormal Pap smear result.
(III). Those who were interested in participating in study I, II, III – the pilot test contacted the coordinator who informed MR; thereafter, a time and place for the interview was booked in consultation with the HCP (I) or the women (II, III). Those who were interested in participating in study III – the evaluation of the reliability, were referred to a nurse at the clinic. Regarding study IV, one of the coordinators at the women’s health clinic forwarded the women’s name and address to MR, for the data collection. Finally, the persons involved in the translation and cross-cultural adaption process (pilot test excluded), except the FACIT project manager, were recruited from a University and a proofreading and translation company in Sweden.

Data collection

Studies I and II

Data were collected with individual interviews using an interview guide, one for the respective study, with open-ended questions (Table 5). The interview guide was created based on co-authors’ (MO and GL) clinical knowledge about the research topic (I, II), and findings from a study by Ideström et al. (103) and study I (II). Pilot-interviews were conducted with two HCPs (I), and two women diagnosed with CIN (II), and included in the respective study. The interview questions were confirmed to be adequate; therefore, no changes were necessary. The open-ended questions were facilitated by follow-up questions such as: “Can you tell me more about that?” or “What did you feel then?”, according to Patton (177). Furthermore, sociodemographic data were collected based on a specially designed questionnaire, for the respective study.

Table 5. The open-ended questions in studies I and II

<table>
<thead>
<tr>
<th>Study</th>
<th>Open-ended question</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Can you please tell me about your experiences of ...</td>
</tr>
<tr>
<td></td>
<td>… meeting women with abnormal Pap smear results?</td>
</tr>
<tr>
<td></td>
<td>… how women’s lives are affected by an abnormal Pap smear result?</td>
</tr>
<tr>
<td>II</td>
<td>Can you please tell me ...</td>
</tr>
<tr>
<td></td>
<td>… about your experiences of receiving an abnormal Pap smear result?</td>
</tr>
<tr>
<td></td>
<td>… how it has been since you found out?</td>
</tr>
<tr>
<td></td>
<td>… how you have managed since you found out?</td>
</tr>
<tr>
<td></td>
<td>… how your daily life has been affected since you found out?</td>
</tr>
<tr>
<td></td>
<td>… about your experiences of human papillomavirus?</td>
</tr>
<tr>
<td></td>
<td>… what HCP could have done to optimise the situation for you?</td>
</tr>
</tbody>
</table>

The interviews were conducted either in a secluded room at the clinics (twenty) (I), or in the women’s home (eight) or by Skype (two) (II). The interviews with the women (II) were conducted within two weeks after they...
had visited the women’s health clinic. After 17 (I) and 7 (II) interviews, no new information was generated, and to confirm this, three more interviews, in the respective studies, were conducted, according to Patton (177). The interviews lasted between 10 and 30 minutes (I), and 20 and 70 minutes (II), were mp3-recorded, transcribed verbatim (116 pages, I; 97 pages, II), and collected between September and November 2013 (I), and December 2014 and June 2015 (II).

Study III
This section starts with a description of the instrument that was used in this study, the FACIT-CD. Thereafter follows a description of the translation and cross-cultural adaptation process, and the data collection for the pilot test and the evaluation of the reliability of the Swedish FACIT-CD. Data for the pilot test were collected through cognitive debriefing interviews, and for the evaluation of the reliability through a questionnaire.

Functional Assessment of Chronic Illness Therapy – Cervical Dysplasia
FACIT-CD is a disease specific instrument that assesses the HRQoL associated with cervical dysplasia, constructed by Rao and colleagues (147). The instrument is self-administered and takes 10–15 minutes to complete. FACIT-CD consists of 36 items divided into five subscales: Physical well-being (8 items), Treatment satisfaction (4 items), General perceptions (7 items), Emotional well-being (11 items) and Relationships (6 items). Each subscale is related on a five-point Likert-type scale, (scores 0–4), with the exception of two items that have response categories Yes/No (Appendix 1). FACIT-CD is scored by adding the items (19 items is reversed scored) in the respective subscale, according to the manual. The subscales are then summed up to create a total score of the FACIT-CD (range 0–136), where higher scores indicate better HRQoL (147). The FACIT-CD is available at: www.facit.org/.

Translation and cross-cultural adaptation
The translation and cross-cultural adaptation of the English FACIT-CD into Swedish was conducted according to the FACIT translation methodology (178, 179). A document called the Swedish Item History (SWE IH) was used to document the steps of the translation and cross-cultural adaptation process as well as the results of every step. The process is summarised as follows. Three forward translators independently presented translations of the English version into Swedish, with a focus on capturing the meaning of the items. Next, a fourth independent translator reconciled the three forward translations by choosing the better of them and resolving discrepancies between them, using the English version as reference. This reconciled version is then back-
translated blindly by a native English speaking translator fluent in the Swedish language. The FACIT project manager received the SWE IH document for a quality control, wherein the back translations were compared with the original English source, and any comments were expressed. Next, the reviewer/language coordinator analysed all the translations and the comments, and formed a test version of the translation, either by using the reconciled translations or modifying it. The FACIT project manager evaluated the completed reviewer assessments and the test version of the translation, and communicated any concerns to the reviewer/language coordinator. The resolution resulted in a proofread test version. The test version was pilot tested through cognitive debriefing interviews (further described below, in the section pilot test), with Swedish speaking women diagnosed cervical dysplasia. The analyses of these interviews resulted in a pilot test report, which was used to create a linguistically validated Swedish FACIT-CD. The translation and cross-cultural adaptation of the FACIT-CD occurred between January and October 2015.

**Pilot test of the Swedish FACIT-CD test version**

Data were collected through cognitive debriefing interviews, which were performed using a test packet, one for each woman. The test packets were distributed by the FACIT project manager, and included a Swedish test version of the FACIT-CD and a semi-structured patient interview form (PIF). The PIF consisted of socio-demographic questions, and general questions about the Swedish test version of the FACIT-CD, as well as questions on each item. The data collection started with the women receiving the Swedish test version and being asked to complete it. After completion, individual face-to-face, semi-structured cognitive debriefing interviews were performed using the PIF. In the interviews, the women went back to the Swedish test version, whereupon the interview technique was both think-aloud and verbal probing, according to Willis (180). The cognitive debriefing interviews lasted between 43 and 90 minutes, and nine took place in the women’s home while one was at a university. All interviews were mp3-recorded and typed into the PIF in Swedish, but also in English as translated by MR. The PIFs were then sent in a secure file to the FACIT project manager for further analyses. Data were collected in June 2015.

**Evaluation of the reliability of the Swedish FACIT-CD**

Data were collected using a questionnaire, which consisted of six socio-demographic questions and the Swedish FACIT-CD (For the Swedish FACIT-CD, see Appendix 2). The coordinator at the women’s health clinic responsible for the data collection asked the women to complete the questionnaire. All of the women completed the questionnaire anonymously in
a secluded place at the women’s health clinic while they attended a follow-up appointment for their abnormal Pap smear result. The completed questionnaire was then retrieved by MR. Data were collected between October 2015 and January 2016.

Study IV
Data were collected through a posted self-administrated questionnaire, which was sent to the women within a week after they received their abnormal Pap smear result. The questionnaire was provided with stamped addressed return envelopes. Up to two reminders were sent to the women, within 10 and 20 days. Data were collected between January and October 2016.

The questionnaire was created based on MR and co-authors’ (MO and KS) theoretical and clinical knowledge about the research topic, as well as on findings from studies I and II. The questionnaire included; 1) socio-demographic characteristics (age, country of birth, pregnancy, children, marital status, and education level); 2) three items regarding awareness of HPV, “Have you heard about HPV?” “Is HPV sexually transmitted?” “Can HPV cause cervical cancer?” These items were answered by checking the box, explaining either yes, no or do not know; 3) three items regarding how to cope with the Pap smear result, “Have you called the healthcare services in association with your abnormal Pap smear result?” “Have you searched for information on the Internet in association with your abnormal Pap smear result?” “Have you consulted relatives or friends in association with your abnormal Pap smear result?” These questions were answered by checking the box, with either a yes or a no; a yes response was followed up with a question requesting: the number of times the healthcare services was called, which sites on the Internet were visited, or who they had consulted; 4) the Swedish FACIT-CD (147); and, 5) the HADS (148).

Functional Assessment of Chronic Illness Therapy – Cervical Dysplasia
FACIT-CD has been previously described, see the data collection (III). Since the participating women (IV) had not attended any further investigations for their abnormal Pap smear result, the subscale Treatment was not used. This resulted in the total maximum sum score for the Swedish FACIT-CD being 120. The Swedish FACIT-CD exhibited good internal consistency reliability (III, IV), except the subscale Relationships (III). The total scale of the FACIT-CD α = 0.84 (III), α = 0.89 (IV), subscales; Physical well-being α = 0.71 (III), α = 0.72 (IV), Treatment satisfaction α = 0.81 (III), General perceptions α = 0.74 (III) α = 0.86 (IV), Emotional well-being α = 0.79 (III) α = 0.84 (IV) and Relationships α = 0.67 (III), α = 0.76 (IV).
Hospital Anxiety and Depression Scale

HADS is a generic instrument that assesses the levels of anxiety and depression symptoms among patients in non-psychiatric hospital clinics, constructed by Zigmond and Snaith (148). The instrument is self-administered and takes approximately five minutes to complete. HADS consists of 14 items divided into two subscales, HADS-anxiety (HADS-A) and HADS-depression (HADS-D), seven items respectively, on a four-point Likert scale (scores 0–3). HADS is scored either by adding up the ratings for the 14 items (six is reversed scored) to yield a total score (range 0–42), or adding up each subscale to yield separate scores (range 0–21). For this study, the subscales HADS-A and HADS-D were used separately, not added up to yield a total score. Cut-off scores that were established and applied in this study were between 8–10 for possible cases and ≥11 for probable cases for each subscale score (148, 181). HADS-A and HADS-D has been widely used and exhibited good psychometric properties (181, 182) and also in this study, $\alpha = 0.86$, for respective subscales (IV).

Data analysis

Studies I and II

The transcribed interview text was analysed with qualitative content analysis according to Burnard et al. (183), in order to systematically analyse and make sense of the text (184). An inductive approach was used, where the data itself formed the structure of the analysis (183). Initially, all the transcribed interview text was read (by MR) several times to get a sense of the whole. 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 sentence. The headings in the open coding were discussed and reflected upon together with a co-author (MO) who had read, and made headings in the transcribed interviews. 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, resulting in six subcategories, in the respective study. These subcategories were discussed and reflected upon together with the co-authors (MO and KS). The subcategories were then analysed together with the transcribed interviews, and findings in the transcripts were grouped under respective subcategories, (this should not be interpreted as a deductive approach). In the next step, together with co-author (MO), the subcategories were compared and discussed, and those with similar content were interpreted in a higher level of abstraction into three (I) and two categories (II). Finally, the categories were discussed together with three co-authors (MO, KS and GL), and after a few adjustments, consensus was reached on identifying the categories.
Study III (Pilot test of the Swedish FACIT-CD test version)
The cognitive debriefing interviews were analysed in collaboration between the reviewer/language coordinator (MR) and the FACIT project manager. The analysis determined if the women’s comments in the interviews, regarding the items, were of a conceptual, semantic or stylistic nature. The FACIT project managers concerns regarding the women’s comments in the interviews were presented to the reviewer/language coordinator, in order to provide further input and resolve queries regarding why women may have responded in a certain way. This input was further reviewed by the FACIT project manager, and in some cases investigated further, with new concerns brought to the reviewer/language coordinator. This continued until consensus was reached for each item.

Studies III (Evaluation of the reliability of the Swedish FACIT-CD) and IV
The statistical analysis in both studies is presented, at first, together, secondly, separately.

Studies III and IV
All statistical analyses were performed using SPSS for Windows statistical software version 21 (SPSS, Inc., Chicago, IL, USA). Descriptive statistics as frequencies (n) (III, IV) and percentages (%) (IV) were used to evaluate the categorical data, while median (md), quartiles (q) (IV), range, mean (m) (III, IV), and standard deviation (±SD) (IV) were used to evaluate the continuous data.

Study III
The internal consistency reliability of the total scale as well as of each subscale was estimated by Cronbach’s alpha coefficient. Values ≥0.70 were considered acceptable, ≥0.80 considered good, and ≥0.90 excellent (185). Homogeneity of the items was evaluated by corrected item-total correlations, to identify items with poor correlations with the respective subscale. An acceptable level of the corrected item-total correlations was set to ≥0.20 (178).

Study IV
The FACIT-CD had 131 missing data, which were not replaced at item level. Instead, the subscale scores were estimated, by calculating the sum of the individual item scores, multiplying by the number of items, and dividing by the number of items answered, in the respective subscales. This was performed according to the FACIT-CD scoring guidelines, outlined by the FACIT organisation. The response rate in the total scale of the FACIT-CD
was at least 80%; in the subscales, it varied between at least 50%–91%, which is considered to be an acceptable scale (186). HADS-D had one missing data, which was replaced based on the mean of the remaining six items.

The women were categorised into two subgroups, women who were aware of the sexually transmitted nature of the HPV infection and women who were not, which was based on the variable “Is HPV sexually transmitted?” Comparisons of the socio-demographic characteristics between the two subgroups were performed using the Student’s t-test for continuous variable and Chi-squared tests or Fisher’s exact test, as appropriate, for categorical variables. Comparisons of all the scales (HADS and FACIT-CD) between the two subgroups were performed using Mann-Whitney U-test (depending on the skewed distributed variables) for continuous variables, and in HADS, Chi-squared tests or Fisher-Freeman-Halton exact test, as appropriate, for categorical variables. Prior to the analysis of the frequencies and percentages of the cases, the HADS-A and the HADS-D were recoded into three variables, 0–7 scores = non cases, 8–10 scores = possible cases, and 11–21 scores probable cases. A two-tailed p-value of <0.05 was considered to be statistically significant.

**Pre-understanding**

My clinical experience as a nurse involves having worked in elderly care and in the neonatal intensive care. After working for several years in the neonatal intensive care unit, I became a teacher at a university, teaching nursing students. With this starting point, I became a PhD student, with no clinical experience as a nurse within this thesis research topic. In addition, upon starting to write up the project plan, my theoretical knowledge in the research topic was limited. In my private life, I have encountered the research topic, as I have been invited to attend cervical cancer screening, which I have attended but never received an abnormal Pap smear result. My pre-understanding is that receiving an abnormal Pap smear result as well as other abnormal results creates an anxiety in the individual; moreover, not understanding the result or what is going to happen evokes this anxiety. With this pre-understanding, I started the analysis process in study I. In the analysis process of the studies (I, II), I constantly asked myself whether what I saw in the transcribed interview text derived from the interviews or if it was from my own pre-understanding. My pre-understanding was modified as the studies progressed, whereupon I felt it became more important for me to ask myself the question above in the analysis process in study II. Apart from me, the research group consisted of two members, one who was a midwife (MO), and the other a nurse (KS), both with backgrounds in nurse education, and the midwife also with clinical
experience within the research topic. In studies I and II, another member (GL) participated in the research group; this person was a gynaecologist with clinical experiences within the research topic.

Ethical considerations

The thesis followed the Swedish law concerning the regulation of ethics in research involving humans (187) and was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki (188). The Regional Ethical Review Board in Linköping, Sweden (Dnr 2013/233-31; I, II, III, and Dnr 2015/338-31; IV) approved the studies. The managers at the three clinics gave their approval to conduct the studies as well as to recruit participants from respective clinics (I–IV). A personal data processing notification form was filled out and sent to the personal data representative, at Linnaeus University (IV). The representative’s role was to ensure that personal data was processed in a lawful and proper manner. The thesis is conducted in accordance with the requirements on research, including informed consent, right to self-determination, confidentiality and beneficence.

At the time of recruitment the HCPs and the women received written information. This information consisted of the studies aim, design, as well as any risks and benefits from participating in the study. The information also included confidentiality and informed that participation was voluntary and that they could withdraw at any time without explanation or negative consequences. The researchers’ name and contact details were also included in case of any questions. In relation to the data collection, the participants were informed again orally and in writing (I; II; III), or only in writing (IV). Consent to participate was obtained in writing (I, II), or orally (III); the latter according to instructions from the FACIT project manager or assumed when one filled in and returned the questionnaire (IV).

To preserve the confidentiality of the collected data, the mp3-recordings and transcripts (I, II), the test packet (III) and the questionnaires (IV) were anonymised and coded by number, and separately from the participants’ name and addresses. There was no personal data, such as name or addresses connected to the questionnaire (III), and therefore not coded. All data collected were stored in a locked space, which only the researcher (MR) had access to. However, the coordinator at the clinic (IV) stored the women’s personal identity and the diagnosis at the clinic, in a locked space, which only the coordinator had access to. The diagnosis was coded by number (1–4) and registered directly in SSSP, linked to the code used at the questionnaire. Furthermore, a secure file was used when sending the copies of the
anonymised test packet (III) to the FACIT project manager. Finally, regarding confidentiality, the analysis and presentation of the data were done in a way that did not expose the participants’ identity.

The participants were not dependent on the researchers. Furthermore, we were of the opinion that the data collection did not violate the participants’ integrity. However, there could have been a risk that the data collection had been emotionally demanding for the participants. Accordingly, a counsellor at the women’s health clinic, who was experienced in providing support to women with abnormal Pap smear result was informed about the studies, and allowed for us to refer women to her. The women were informed to contact the counsellor to get support, if needed. However, it is our belief that the benefits of this thesis outweighed any kind of possible risks. The data collected are only used for research.
RESULTS

In this section the results of the four studies of this thesis are briefly described. The section starts with the results from studies I, II and IV, whereupon similar and divergent opinions between the women’s and the HCP’s experiences are presented together. The section ends with study III, which, because of its nature, is presented separately from the other studies. For more complete descriptions of the results from the four studies, see respective article.

Receiving notification of an abnormal Pap smear result (I, II, IV)

Being prepared or not for the test result
HCPs (I) expressed that women become better prepared and find it easier to cope with the test result if they are informed about abnormalities at the time of taking the Pap smear test. There were divergent opinions about how prepared women were to face their abnormal Pap smear results. On the one hand, some of the HCPs (I) expressed that women are well informed; on the other hand, other HCPs (I) and the women (II) expressed a limited understanding. This was due to different reasons. First, a lack of being informed about the possibility of an abnormal Pap smear result or what the concept cellular changes meant (I, II). Secondly, women had repressed, misunderstood or did not take in the information given (I). Furthermore, the women (II) and the HCPs (I) stated that attending the CCSP was a routine for the women, and a normal test result was expected, resulting in that the women were not prepared for the abnormal Pap smear result.

Initial reactions to the test result
The women (II) and the HCPs (I) expressed that women felt upset upon receiving the test results, and feelings of shock, distress, sadness and anxiety were evoked. Anxiety was reported by 48.4% of the women (IV), and the
were evoked. Anxiety was reported by 48.4% of the women (IV), and the receiving the test results, and feelings of shock, distress, sadness and anxiety for the abnormal Pap smear result. Normal test result was expected, resulting in that the women were not prepared for that association such as previous experience of cancer among relatives, and previous non-attendance in the CSSP (II), as well as belief that a Pap smear test is synonymous with a cancer test and that the concept cellular changes (used in the written test result) is associated with cancer. There were different reasons for that association such as previous experience of cancer among relatives, and previous non-attendance in the CSSP (II), as well as belief that a Pap smear test is synonymous with a cancer test and that the concept cellular changes (used in the written test result) is associated with cancer (I). Other reasons for feeling anxious, other than cancer, were questions about whether one’s fertility would be affected by the treatment, especially among younger women (I, II). In addition, a few women (II) were aware of the sexually transmitted nature of HPV infection and discussed feelings of fear that they could infect their partner through intercourse. Of the women (IV), 50% were aware of the HPV and 40.2% were aware of the sexually transmitted nature of HPV, and 45.9% knew that HPV could cause cervical cancer. However, there were no significant differences in the median score on

Due to the anxiety, both the women (II) and the HCPs (I) stated that oral notification of the abnormal Pap smear result was preferred, since this could provide an opportunity to ask questions and to get information from the HCPs. Despite women feeling anxious, the HCPs (I) stated that it was not a severe condition and women did not need to become anxious. Furthermore, the women (II) and the HCPs (I) reported that one reason for women feeling anxious was that the test result was associated with cancer. There were different reasons for that association such as previous experience of cancer among relatives, and previous non-attendance in the CSSP (II), as well as belief that a Pap smear test is synonymous with a cancer test and that the concept cellular changes (used in the written test result) is associated with cancer (I). Other reasons for feeling anxious, other than cancer, were questions about whether one’s fertility would be affected by the treatment, especially among younger women (I, II). In addition, a few women (II) were aware of the sexually transmitted nature of HPV infection and discussed feelings of fear that they could infect their partner through intercourse. Of the women (IV), 50% were aware of the HPV and 40.2% were aware of the sexually transmitted nature of HPV, and 45.9% knew that HPV could cause cervical cancer. However, there were no significant differences in the median score on

Table 6. Outcomes of the HADS and FACIT-CD and comparisons between women with and without awareness of the sexually transmitted nature of the human papillomavirus infection.

<table>
<thead>
<tr>
<th>Scale and cases</th>
<th>All women (n=122)</th>
<th>Women aware (n=49)</th>
<th>Women not aware (n=73)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HADS-A</strong> Md (q1-q3)</td>
<td>7.0 (4.0-10.0)</td>
<td>7.0 (4.0-10.0)</td>
<td>7.0 (3.0-10.0)</td>
<td>0.772†</td>
</tr>
<tr>
<td>Cases of anxiety, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>0.965††</td>
</tr>
<tr>
<td>Non-cases 0-7</td>
<td>63 (51.6)</td>
<td>26 (53.1)</td>
<td>37 (50.7)</td>
<td></td>
</tr>
<tr>
<td>Possible cases 8-10</td>
<td>33 (27.1)</td>
<td>13 (26.5)</td>
<td>20 (27.4)</td>
<td></td>
</tr>
<tr>
<td>Probable cases ≥11</td>
<td>26 (21.3)</td>
<td>10 (20.4)</td>
<td>16 (21.9)</td>
<td></td>
</tr>
<tr>
<td><strong>HADS-D</strong> Md (q1-q3)</td>
<td>3.0 (1.0-5.5)</td>
<td>3.0 (1.0-5.5)</td>
<td>3.0 (1.0-5.5)</td>
<td>0.587†</td>
</tr>
<tr>
<td>Cases of depression, n (%)</td>
<td></td>
<td></td>
<td></td>
<td>0.843†††</td>
</tr>
<tr>
<td>Non-cases 0-7</td>
<td>106 (86.9)</td>
<td>44 (89.8)</td>
<td>62 (84.9)</td>
<td></td>
</tr>
<tr>
<td>Possible cases 8-10</td>
<td>10 (8.2)</td>
<td>3 (6.1)</td>
<td>7 (9.6)</td>
<td></td>
</tr>
<tr>
<td>Probable cases ≥11</td>
<td>6 (4.9)</td>
<td>2 (4.1)</td>
<td>4 (5.5)</td>
<td></td>
</tr>
<tr>
<td><strong>FACIT-CD</strong> Md (q1-q3)</td>
<td>97.6 (81.8-107.0)</td>
<td>98.0 (83.5-106.7)</td>
<td>96.6 (78.4-107.0)</td>
<td>0.469†</td>
</tr>
<tr>
<td>Physical Well-being</td>
<td>29.0 (24.8-31.0)</td>
<td>29.0 (25.1-31.0)</td>
<td>29.0 (24.0-31.0)</td>
<td>0.821†</td>
</tr>
<tr>
<td>General Perceptions</td>
<td>22.0 (18.0-25.3)</td>
<td>22.0 (18.5-25.0)</td>
<td>22.0 (18.0-26.0)</td>
<td>0.840†</td>
</tr>
<tr>
<td>Emotional Well-being</td>
<td>33.0 (27.0-40.0)</td>
<td>34.0 (30.0-39.0)</td>
<td>33.0 (26.0-40.0)</td>
<td>0.520†</td>
</tr>
<tr>
<td>Relationships</td>
<td>14.7 (12.0-16.0)</td>
<td>14.7 (10.3-16.0)</td>
<td>14.7 (12.0-16.0)</td>
<td>0.579†</td>
</tr>
</tbody>
</table>

HADS, Hospital Anxiety and Depression Scale; FACIT-CD, Functional Assessment of Chronic Illness Therapy - Cervical Dysplasia; Score range; 0-21; 0–120; 0–32; 0–28; 0–44 and 0–16; †Mann-Whitney U-test (2-tailed); ††Chi-squared test; †††Fisher-Freeman-Halton Exact Test; Md = median, q = quartile.
FACIT-CD, HADS-A and HADS-D between those who were aware of HPV as sexually transmitted infection, and those who were not (Table 6). This indicated that there were no differences between those women’s (IV) HRQoL, and prevalence of anxiety and depression. Finally, there were divergent opinions about whether the women’s HRQoL was affected. On the one hand, some of the HCPs (I) stated that women’s sleep and sex lives were negatively affected. On the other hand, some HCPs (I) stated they were not negatively affected, and the women (IV), in general, reported a good HRQoL. This was assessed with FACIT-CD; median = 97.6, q1–q3 = 81.8–107.0 (Table 6).

Coping with an abnormal Pap smear result

Women’s strategies for coping with the test result

The women (II) expressed that they coped with their test result by immediately seeking emotional support, mainly from their mothers and partners, but also from relatives, friends and acquaintances. Assessment of the type of support showed that of the women (IV), 61.5% had consulted relatives and/or friends and 97% of those who had a partner consulted them. The HCPs (I) had another opinion than the women, and instead stated that women immediately sought information and used the Internet as the primary information source. However, the women (II, IV) (59.2%, IV) also expressed that they used the Internet as source of information to cope with the test result. Whereupon, significantly more women (IV) who were aware of the sexually transmitted nature of HPV infection than women (IV) who were not aware had used the Internet (77.1% vs. 47.2%; \( p = 0.001 \)). Another source used for information was the HCPs at the women’s health clinic, whom 18% (IV) of the women called within a few days (I, II, IV). The most frequent questions, as expressed by both the women (II) and the HCPs (I) were: Is it cancer? Will it affect my ability to get pregnant? What does cellular change mean? Can cellular changes be transmitted? The women compared the information from the HCPs and other sources to check for consistency (I, II). Furthermore, women (II) who practiced alternative medicine reported that they made lifestyle changes to cope with the test result e.g. stopped eating sugar and started drinking healthy teas. Finally, the HCPs (I) expressed that the majority of women cope with the abnormal Pap smear result by themselves and do not contact healthcare services.

Healthcare professional’s strategies to support the women

The HCP’s (I) primary strategies for supporting the women after notification of the abnormal Pap smear result were to provide information and to answer women’s questions. However, there were divergent opinions about this
information, where the women (II) stated that they did not get the information requested, resulting in further distress. However, HCPs (I) stated that the majority of women were calmed by this information. During the investigation, the women (II) had another opinion about the information. At this time, the women emphasised they were calmed by the information given, but a few were still anxious. Furthermore, there were two different strategies that HCPs (I) used when the women were very anxious because of the notification of the test result; at first, they offered to reschedule the appointment with the physician at an earlier date than planned and second, they referred the women to a counsellor at the clinic. During the investigation and treatment, one strategy to support the women was to hide the gynaecological instruments, as they may be perceived as frightening by the women and might create anxiety. Another strategy was to offer the anxious women analgesics and sedatives, and in some cases using anaesthesia.

Women’s attendance at investigation, treatment and follow-up
The two women’s health clinics (I) had different experiences about women’s attendance at investigation, treatment and follow-ups. At one clinic, the HCPs reported that women, in general, attend. At the other clinic, the HCPs said they failed to attend. HCPs thought that fear of cancer was the reason for both attendance and non-attendance. Apart from fear of cancer, HCPs emphasised that the most common reasons for non-attendance were: fear that the investigation or the treatment would be unpleasant and painful, as well as fear of being altered in the genital area. HCPs also reported practical reasons for women’s non-attendance such as women who were travelling or studying abroad, or just forgetting to attend the follow-up. Finally, the HCPs stated that younger women and women with low-grade abnormalities were more likely to be non-attenders than older women and those with high-grade abnormalities.

Healthcare professional’s approaches towards non-attending women
HCPs (I) expressed either an active or passive approach towards women’s non-attendance. An active approach was chosen for women with high-grade abnormalities, whereupon the physician sent the woman a letter explaining the importance of attendance and that cellular changes can develop into cervical cancer if left untreated. As a result of the letter, the women usually attended. A passive approach was chosen for non-attending women at 6-month and 1-year follow-up after the treatment. Thereafter, the physician allowed the choice of
attending be the women’s own responsibility, but emphasised that it would be regretful if the woman developed cervical cancer due to non-attendance at follow-up.

Translation and cross-cultural adaptation, pilot test and evaluation of the reliability of the Swedish FACIT-CD (III)

The results indicate that the Swedish FACIT-CD is conceptually and semantically equivalent to the English version and linguistically valid; moreover, it has good internal consistency reliability, and the majority of the items exhibited acceptable corrected item-total correlations. This section describes the results from the translation and cross-cultural adaptation, the pilot test as well as the evaluation of the reliability of the Swedish FACIT-CD.

Translation and cross-cultural adaptation

The translation and cross-cultural adaptation went smoothly without any problems, except for the three items that consisted of the term “pelvic area” (CD1, CD2 and CD3). During the translation and cross-cultural adaptation process, the Swedish terms “bäckenområde” and “underliv” were discussed extensively between the FACIT project manager and the reviewer/language coordinator (MR). This resulted in the test version of the Swedish FACIT-CD being finalised with the term “bäckenområde”, but the term “underliv” was used as an alternative translation, discussed in the cognitive debriefing interviews. Additionally, one item (Sp9) changed the source word “spiritual beliefs” in Swedish to use “inre övertygelse”, which could be back translated into English as “inner beliefs”. This change was based on additional review in a separate project from this study, and during the same time period. Finally, the result of the translation and cross-cultural adaptation process suggests that the Swedish FACIT-CD (Appendix 2) is conceptually and semantically equivalent to the English version and linguistically valid.

Pilot test of the Swedish FACIT-CD test version

Results of the cognitive debriefing interviews

The women displayed good understanding of the items, and the responses they selected corresponded with the reasons they provided for choosing those answers. According to the women, all of the items were relevant to their diagnosis, the instructions were easy to understand and the response categories were unambiguous and comprehensive. The women also reported that the Swedish FACIT-CD test version was easy to complete in general.
Results from the cognitive debriefing interviews led to some changes in eight of the items in the Swedish FACIT-CD test version. The items CD1, CD2 and CD3 were changed to use the term “underliv”. One of the items had the Swedish word “information” added in parentheses (CD7). Four of the items had structural changes, where the phrase “if yes” was moved from the question introduction (Q9 and Q10) and placed instead before the respective follow-up questions (CD21 and CD22).

**Evaluation of the reliability of the Swedish FACIT-CD**

**Internal consistency reliability and homogeneity**

The total scale of the Swedish FACIT-CD exhibited good internal consistency reliability with a Cronbach’s alpha coefficient of 0.84. Of the subscales, four out of five exhibited an acceptable to good Cronbach’s alpha coefficient (α = 0.71–0.81). Nevertheless, the subscale Relationships had a Cronbach’s alpha coefficient of 0.67, which is below the acceptable value of ≥0.70. The majority of the items exhibited acceptable corrected item-total correlations, except four items (Tables 7–11).

<table>
<thead>
<tr>
<th>Subscale in English and Swedish, and Item code</th>
<th>α</th>
<th>Corrected item-total correlation</th>
<th>α if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical well-being/Fysiskt välbefinnande</td>
<td>0.71</td>
<td>0.78</td>
<td>0.59</td>
</tr>
<tr>
<td>CD1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD2</td>
<td>0.55</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>CD3</td>
<td>0.46</td>
<td>0.68</td>
<td></td>
</tr>
<tr>
<td>Cx1</td>
<td>0.34</td>
<td>0.71</td>
<td></td>
</tr>
<tr>
<td>GP5</td>
<td>0.11*</td>
<td>0.73</td>
<td></td>
</tr>
<tr>
<td>ES8</td>
<td>0.55</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>CD4</td>
<td>0.42</td>
<td>0.68</td>
<td></td>
</tr>
<tr>
<td>CD5</td>
<td>0.08*</td>
<td>0.75</td>
<td></td>
</tr>
</tbody>
</table>

*Corrected item-total correlation below the acceptable level of ≥0.20.

<table>
<thead>
<tr>
<th>Subscale in English and Swedish, and Item code</th>
<th>α</th>
<th>Corrected item-total correlation</th>
<th>α if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment satisfaction/Tillfredsställelse med behandling</td>
<td>0.81</td>
<td>0.55</td>
<td>0.81</td>
</tr>
<tr>
<td>GR1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD6</td>
<td>0.69</td>
<td>0.74</td>
<td></td>
</tr>
<tr>
<td>CD7</td>
<td>0.79</td>
<td>0.68</td>
<td></td>
</tr>
<tr>
<td>CD8</td>
<td>0.62</td>
<td>0.81</td>
<td></td>
</tr>
</tbody>
</table>
Discussion of findings

The overall aim of this thesis was to investigate experiences of receiving notification of an abnormal Pap smear result and its impact on women's HRQoL of life as well as to investigate women's awareness of HPV. The findings showed that women's HRQoL was not affected by them becoming notified of their abnormal Pap smear result, except for the dimension psychological well-being, as the women became anxious (I, II, IV). This was due to them being unprepared and misinterpreting their test result as cancer, for lack of information. Consequently, the majority of women had a desire to receive oral notification, since that could provide an opportunity to have information from the HCPs and questions answered. Since the women lacked information they coped with their test result by searching from several different sources, such as the Internet and HCPs. Surprising findings were that many women were unaware of the HPV infection (II, IV) and that women who were aware of HPV as sexually transmitted infection had the same level of anxiety and depression symptoms and HRQoL as those who were not aware (IV). The results will be discussed in subsequent sections. First, impact of the abnormal Pap smear results on women's HRQoL will be discussed. Second, the manner in which women are notified of their abnormal Pap smear result will be addressed, followed by women's coping strategies and finally, women's HPV awareness.

Women become anxious upon receiving notification of an abnormal Pap smear result

In this thesis, women's HRQoL does not seem to be affected upon notification of an abnormal Pap smear result except for the HRQoL dimension of psychological well-being. In that case, women become anxious receiving notification of an abnormal Pap smear result (I, II, IV). Anxiety was reported in 48.4% of the women, and the median score for HADS-A was 7.0 (q 1–q3 = 5–10).

Table 9. Cronbach’s alpha coefficient and corrected item-total correlation for the Swedish FACIT-CD subscale general perceptions (n = 34).

<table>
<thead>
<tr>
<th>Subscales in English and Swedish, and Item code</th>
<th>α</th>
<th>Corrected item-total correlation</th>
<th>α if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>General perceptions/Allmänna uppfattningar</td>
<td>0.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GF1</td>
<td>0.13*</td>
<td>0.76</td>
<td></td>
</tr>
<tr>
<td>GF3</td>
<td>0.47</td>
<td>0.72</td>
<td></td>
</tr>
<tr>
<td>HI11</td>
<td>0.62</td>
<td>0.70</td>
<td></td>
</tr>
<tr>
<td>Sp9</td>
<td>0.41</td>
<td>0.75</td>
<td></td>
</tr>
<tr>
<td>GF7</td>
<td>0.57</td>
<td>0.69</td>
<td></td>
</tr>
<tr>
<td>CD9</td>
<td>0.67</td>
<td>0.65</td>
<td></td>
</tr>
<tr>
<td>CD10</td>
<td>0.57</td>
<td>0.68</td>
<td></td>
</tr>
</tbody>
</table>

*Corrected item-total correlation below the acceptable level of ≥0.20.

Table 10. Cronbach’s alpha coefficient and corrected item-total correlation for the Swedish FACIT-CD subscale emotional well-being (n = 34).

<table>
<thead>
<tr>
<th>Subscale in English and Swedish, and Item code</th>
<th>α</th>
<th>Corrected item-total correlation</th>
<th>α if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional well-being/Känslomässigt välbefinnande</td>
<td>0.79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD11</td>
<td>0.39</td>
<td>0.78</td>
<td></td>
</tr>
<tr>
<td>CD12</td>
<td>0.48</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>CD13</td>
<td>0.40</td>
<td>0.78</td>
<td></td>
</tr>
<tr>
<td>BMT18</td>
<td>0.42</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>CD14</td>
<td>0.42</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>CD15</td>
<td>0.65</td>
<td>0.75</td>
<td></td>
</tr>
<tr>
<td>CD16</td>
<td>0.68</td>
<td>0.74</td>
<td></td>
</tr>
<tr>
<td>CD17</td>
<td>0.34</td>
<td>0.78</td>
<td></td>
</tr>
<tr>
<td>CD18</td>
<td>0.36</td>
<td>0.78</td>
<td></td>
</tr>
<tr>
<td>CD19</td>
<td>0.49</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>CD20</td>
<td>0.39</td>
<td>0.78</td>
<td></td>
</tr>
</tbody>
</table>

Table 11. Cronbach’s alpha coefficient and corrected item-total correlation for the Swedish FACIT-CD subscale relationships (n = 34).

<table>
<thead>
<tr>
<th>Subscales in English and Swedish, and Item code</th>
<th>α</th>
<th>Corrected item-total correlation</th>
<th>α if item deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships/Relationer</td>
<td>0.67</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD21</td>
<td>0.66</td>
<td>0.43</td>
<td></td>
</tr>
<tr>
<td>CD22</td>
<td>0.75</td>
<td>0.35</td>
<td></td>
</tr>
<tr>
<td>GS1</td>
<td>0.01*</td>
<td>0.82</td>
<td></td>
</tr>
<tr>
<td>HI3</td>
<td>0.67</td>
<td>0.58</td>
<td></td>
</tr>
</tbody>
</table>

*Corrected item-total correlation below the acceptable level of ≥0.20; ** Cronbach’s alpha coefficient below the acceptable level of ≥0.70.
DISCUSSION

Discussion of findings

The overall aim of this thesis was to investigate experiences of receiving notification of an abnormal Pap smear result and its impact on women’s HRQoL of life as well as to investigate women’s awareness of HPV. The findings showed that women’s HRQoL was not affected by them becoming notified of their abnormal Pap smear result, except for the dimension psychological well-being, as the women became anxious (I, II, IV). This was due to them being unprepared and misinterpreting their test result as cancer, for lack of information. Consequently, the majority of women had a desire to receive oral notification, since that could provide an opportunity to have information from the HCPs and questions answered. Since the women lacked information they coped with their test result by searching from several different sources, such as the Internet and HCPs. Surprising findings were that many women were unaware of the HPV infection (II, IV) and that women who were aware of HPV as sexually transmitted infection had the same level of anxiety and depression symptoms and HRQoL as those who were not aware (IV). The results will be discussed in subsequent sections. First, impact of the abnormal Pap smear results on women’s HRQoL will be discussed. Second, the manner in which women are notified of their abnormal Pap smear result will be addressed, followed by women’s coping strategies and finally, women’s HPV awareness.

Women become anxious upon receiving notification of an abnormal Pap smear result

In this thesis, women’s HRQoL does not seem to be affected upon notification of an abnormal Pap smear result except for the HRQoL dimension of psychological well-being. In that case, women become anxious receiving notification of an abnormal Pap smear result (I, II, IV). Anxiety was reported in 48.4% of the women, and the median score for HADS-A was 7.0 (q1–q3 =
written information does present difficulties to women who are unable to read. They did not understand the written test result and got confused. In addition, preferred rather than written. This is in line with an Australian study (196) that lack of information at the time of taking the Pap smear test was a reason for this interpretation. The HCPs (I) added that women had repressed, misunderstood, and/or forgotten the information that was given (I). According to Langewitz et al. (194), patients remember only 25% of the medical information that is given. In addition, when a Pap smear test is taken, a lot of women feel vulnerable, exposed and nervous, which can lead to difficulties absorbing the information given (12). Another factor that affects the memory for the information given is its perceived importance (195). In this thesis, attending the screening was reported as a routine, and women usually expect to have normal Pap smear results, as they have no symptoms and feel healthy (I, II). Additionally, the information given might not have been of perceived importance, and perhaps women are most susceptible to information when they receive an abnormal Pap smear result, given the anxiety it evokes (102). Unfortunately, not all anxiety can be prevented, but the women’s anxiety must be taken seriously, which should be highlighted to the HCPs. Since HCPs (I) seem to feel that abnormal Pap smear result is less severe condition, they may feel that the women’s anxiety can be overlooked. Finally, it is essential that notification of a test result be developed in a manner that reduces women’s anxiety.

**Women receiving notification of an abnormal Pap smear result in writing vs orally**

The results of this thesis (I, II) show that written strategies to notify women about an abnormal Pap smear result might not be sufficient, as it can evoke anxiety. HCPs (I) as well as the women (II) stated that oral notification is preferred rather than written. This is in line with an Australian study (196) where women did not like to be notified about their test result by letter, since they did not understand the written test result and got confused. In addition, written information does present difficulties to women who are unable to read. The benefits of written information is that it could be read and re-read in a
The benefits of written information is that it could be read and re-read in a private location where it could be easier for women to digest the information of the abnormal Pap smear result (196, 197). In contrast, being notified orally gives the women opportunity to express their concerns and have their questions answered, which could prevent anxiety and/or reduce such stress (I, II). Nowadays, the most common manner to notify women of their abnormal Pap smear result is by standardised letter (198). Even if the letter is formulated with attention to aspects of anxiety, it is still a standardised letter and not individualised. This has been reported by the women (II), where the letter is described as being formally written and having limited information about their personal test result as well as general information about abnormal Pap smear results. When communicating an abnormal Pap smear result, it is essential that the HCP show empathy and respect (199, 200) and provide information based on the individual women’s abnormal Pap smear result, in a clear (e.g. not using medical terminology) and consistent manner. Furthermore, there are some key areas that should be shared such as the relation to HPV infection, its being common, emotional reactions, what cellular changes means, the follow-up process (196, 201) and how fertility is affected, but the most important aspect is to explain that their abnormal Pap smear result is not the same as cancer. However, since the results in this thesis imply that oral notification of abnormal test result is preferable, the CCSP might benefit by developing in a manner that offers women opportunity to be notified of their abnormal Pap smear result orally. The HCPs (I) emphasised that oral notification of a test result might be given by someone whom the woman has already met and has confidence in. For instance, the person who performs the Pap smear test could be the one who notifies the women of their test result (I). Finally, it is vital that HCPs are aware that women have access to their medical records online, according to EU (202). Even if this is not available in all Swedish counties, it will be in the near future. If the purpose is to notify women orally, this should be organised in a manner so they become notified of their abnormal Pap smear result before they get access to their medical record online. Furthermore, the HCPs should be aware of the information women obtain from their medical records regarding their abnormal Pap smear result.

**Women’s strategies for coping with the test result**

**Searching for information on the Internet**

In this thesis, majority of the women used a problem-focused coping strategy, as they searched for information in order to reduce their anxiety (I, II, IV). The problem-focused coping strategy, in turn, leads to an emotion-focused function as it attempts to reduce anxiety. This coping strategy was also found in a previous study (203), where women requested information to limit the emotional impact following notification of an abnormal Pap smear result. In this thesis, women used several different sources from which they searched for
information; two of the sources were the Internet and the HCPs at the women’s health clinic (I, II). The Internet was the primary source (I, II), whereupon 59.2% of the women (IV) reported having used Internet as a coping strategy, which is in line with previous research (90, 204, 205) that investigated women’s need for information. Disadvantages with the Internet, as reported by the women (II) in this thesis, were that this information could be frightening, confusing, and lead to more questions than answers. Instead, the benefits were that information on the Internet is likely to make women more aware of the information they ought to receive from HCPs (206). The fact that women use problem-focused coping strategies has changed their information-seeking behaviour from being passive to active patients (207), which is fundamental in a PCC (156, 200). Unfortunately, this information-seeking behaviour can have different implications. On the one hand, the information from the Internet gives women greater control over their health (203, 205) and empowers them in their encounter with the HCPs (204, 206). This could result in a patient-centred interaction between women and the HCPs (207), which has shown to have a positive effect on adherence to care recommendations (208) (e.g. adherence to follow-up of abnormal Pap smear result), better health outcomes and increased patient satisfaction (156). On the other hand, women who have sought information from the Internet might feel that they have exceeded the established role of a patient, as they become well informed (209). Consequently, the HCPs must be aware of this and encourage women to use the Internet as a complement to the information given by them. To use the Internet as a source of information can be communicated to the women when taking the Pap smear test and/or when providing notification of the test result, and/or when the women call the health clinic. In addition, the HCPs should also support women in finding reliable information and medical links on the Internet as well as help them to filter and analyse information (206). This requires HCPs with competence and knowledge about how reliable information can be obtained and how to filter it. Currently, HCPs commonly recommend women to search information at the website, https://www.1177.se. This website must be developed with more information about abnormal Pap smear result, but it is more important also to include emotional reactions. Finally, the HCPs should also be aware of the benefits as well as their own feelings about a well-informed patient, in order to not be provoked when the power structure becomes more equal.

**Seeking information from the healthcare professionals**

Furthermore, in this thesis, women also sought for information by calling the HCPs at the women’s health clinic (I, II), whereupon 18% of the women (IV) reported using it as coping strategy. Unfortunately, there were divergent opinions between the women (II) and the HCPs (I) regarding how this information met the women’s needs. On the one hand, the HCPs (I) thought
the information they provided helped the women to cope with their anxiety. This is in line with a previous study (210), where HCPs assumed that they know what kind of information patients with cancer need. On the other hand, the women (II) reported that the information provided by the HCPs was insufficient. This is in line with previous studies (211, 212), where physicians did not always know or meet individual information needs and, e.g. provided medical facts instead of commenting on emotional concerns. It has also been shown that the preferred level of detail and content varied between women (209, 213), whereupon too much information could be overwhelming (196). This highlights the importance of PCC, which has been shown to have big impact on the quality of care, since the women feel heard and understood (214). In order to be more person-centred, the HCPs need to be flexible to meet the individual women’s needs, as well as work together with the women to make sure there is good communication and information exchange (215).

To identify the information that women require, HCPs should enter into a dialogue with the women to know the women behind the “patient”, in order to examine the women’s emotional concerns, beliefs and understanding of cervical cancer screening and abnormal Pap smear result, as well as, asking them what information they already received (215, 216). In order to make sure that the women understand the information given, the HCPs should evaluate the women’s comprehension, by letting her state the information in her own words. It is important that HCPs develop their competence in order to be prepared to meet the women’s need for information. HCPs in this theses, stated they provided the information women requested, this contradicts the women’s statement. Consequently, HCPs need to be informed about this misconception, in order to meet the women’s needs. Furthermore, the HCPs (I) stated that the majority of the women cope with the abnormal Pap smear result on their own and do not call the HCPs. These women may have adapted an emotion-focused coping strategy, which, in turn, can affect their attendance at investigation, treatment and follow-up, since they might avoid dealing with their abnormal Pap smear result. This can be a reason as to why many women in this thesis did not attend or delayed attending further investigation of their abnormal Pap smear result. Accordingly, the challenge for the HCP is not only to support women with a problem-focused coping strategy, in coping with their anxiety but also to support these women with an emotion-focused coping strategy. Unfortunately, these women might be more difficult to come into contact with since they do not call the HCPs. However, oral notification of abnormal Pap smear result might be a good way to identify women with an emotion-focused-coping strategy.

**Women’s awareness of HPV**

In this thesis, women reported low awareness of HPV infection (II, IV), where 50% of the women reported to be aware (IV). These findings indicate a higher
HPV awareness than those observed among Swedish women referred for colposcopy (18) among a general population of women aged ≤30 years (122, 123), where these studies reported awareness in 5.4%–23% of the women. Notable, these studies were conducted before the introduction of a HPV vaccination programme (20), which was indicated to increase the HPV awareness (127) observed, for example, among Norwegian, Scandinavian, American, British and Australian women, reporting 53%–76% awareness (127, 217, 218). However, even if awareness has increased, the results indicated that many women, who received an abnormal Pap smear result, were unaware of HPV (II, IV). Since HPV is a STI, a possible explanation might be that the sexual dimension of abnormal Pap smear result and cervical cancer has been underplayed, and STI and CCSP have ostensibly evolved separately. Interestingly, in this thesis the HCPs (I) did not even mention the HPV infection. The relationship between HPV and cervical dysplasia might be one reason that HCPs found it difficult and embarrassing to provide information about HPV (219, 220), as it can cause feelings of shame and stigmatisation (10, 221). Another reason could be that there is no treatment for the HPV infection itself; instead, the treatment focuses on the disease or condition the virus caused, e.g. cellular changes such as with abnormal Pap smear result (222). From the results of this thesis (II, IV), it seems as though women’s awareness of HPV had no impact on their HRQoL. Women who were aware of the HPV being sexually transmitted infection had the same level of anxiety and depression symptoms and HRQoL, as women who were not aware (IV). This is in line with findings from a previous study (218) among Norwegian women, which reported that HPV awareness is not likely to increase anxiety, or reduce screening attendance. However, STIs are personal and a public health issue, and there are several reasons for HCPs to provide HPV information. Specifically, awareness is essential for girls and their parents, as well as for women in general, to make informed choices about HPV vaccination. In addition, HPV awareness seems to lead to higher vaccination coverage (127). The concern is when vaccinated women lack awareness of HPV, and the relationship between HPV infection, abnormal Pap smear results and cervical cancer. Consequently, women think they are vaccinated for all STIs (223) and being fully protected from cervical cancer. In turn, this can decrease their participation in the CCSP and lull them into a false sense of security (224, 225). Another reason to provide HPV information is that the Swedish CCSP is on its way to include HPV test as a primary screening tool, whereupon more women may need follow-up testing and/or treatment. HPV testing might be a sensitive issue for women, and it is essential for them to understand the test result (198), as well as rectify misconceptions about HPV (222). Another reason is the entrenched gender norms and stereotypes associated with HPV, as the women are viewed as being tainted, and as vectors of HPV, who pass their infection on to the men (226). One reason for this stigmatisation is that only girls, not boys, are offered HPV vaccinations
In this thesis, the stigmatisation was present as the women reported they were afraid of infecting their partners through intercourse (II). HPV-related cancers mainly include cervical cancer, vulvar, anal, penile and oropharyngeal cancer (228). Thus, men can also be infected by HPV and HPV-related cancers and in turn infect others (229). This fact, lead to suggestions that also boys should be HVP vaccinated, and not excluded from campaigns and discussion about HPV (230). Clearly, public awareness of HPV could be improved as well as misconceptions could be rectified and feelings of shame and isolation could be reduced. This can be accomplished by providing clear and consistent information about the key features of HPV, such as the high prevalence (112, 222, 231) that the majority of the HPV infections resolve spontaneously (23, 222, 231), how HPV is prevented, transmitted and what it can cause, as well as the fact that both men and women are unlikely to be visibly affected, and finally, the link between HPV and abnormal Pap smear results and cervical cancer as well as with other HPV-related cancers (232).

To provide reliable information and counselling, key persons are suggested, such as the school nurses (131), midwives at the youth clinics and at the local antenatal health clinics (223) and physicians who take the Pap smear tests and/or provide treatment and follow-ups due to the abnormalities (222). These persons were also suggested by the HCPs (I) in this thesis. Disadvantages of making the relation between HPV infection and abnormal Pap smear results explicit is that it can reduce attendance in the CCSP, as it is an STI. Thus, it is vital that key persons are well educated in the area of HPV and can communicate the information in a non-frightening as well as non-judgment manner, which can be challenging. Furthermore, these key persons might also be educated on how reliable information can be obtained and how to filter it (206), as there is so much information available on the Internet, with varying degrees of credibility (231).

Methodological discussion

In this thesis, in order to respond to the aims of the studies, both qualitative and quantitative approaches were used. Combing qualitative and quantitative studies should not be viewed as a problem, as long as each method is well conducted (233, 234). A qualitative approach can provide in-depth understanding of women receiving notification of an abnormal Pap smear result, but cannot be generalised, as with a quantitative approach (177). Moreover, in a qualitative study, hypothesis can be generated, and are attempts to describe rather than to prove (235). Here too, the findings (I, II) generated hypotheses that guided the research aim and design for further study (IV). Despite the fact that qualitative and quantitative approaches have different views of epistemology (236), humans have the ability to reflect and
thus are able to move between different approaches (237). Using different perspectives and approaches in this thesis might hopefully lead to a more complete understanding and knowledge of women receiving notification of an abnormal Pap smear result.

The methodological considerations are discussed, based on the approach of the studies. The qualitative studies (I, II) have been judged according to its trustworthiness, based on Lincoln and Guba’s four criteria: credibility, confirmability, dependability and transferability, (177, 238). In contrast, Burnard et al. (183) explicitly address issues relating to validity; therefore, this is added. Next, the quantitative study (IV) and the methodological study (III), are discussed, in terms of validity, reliability and generalisability, whereupon the latter is excluded for the methodological study (III).

**The qualitative studies (I, II)**

Purposive sampling with a maximum of heterogenic variation (177) in professions (I), age (I, II), marital status and grade of CIN (II) was used. Unfortunately, it was difficult to recruit women (II) due to the lack of research recruiters at the clinic. As a result, after a month, the sampling strategy was changed to be consecutively. The sample (I) comprised of several different professions that come into contact with women in the CCSP in different situations. A wide range of variations in the sample is essential to make the results transferable to a group of individuals similar in characteristics (177). The fact that all participating HCPs (I) were women may influence transferability, as the findings could have been different with men included. Another limitation that may influence transferability is that anxious women (II) are overrepresented since it was voluntary-based, and negative reactions might motivate women to participate. Moreover, the small sample size of 10 women (II) might be a limitation and influence transferability of the findings. However, the interviews were conducted until no more new data were generated, judged by the interviewer/author (MR) and co-authors (MO and KS) after all of them had read and discussed the transcript interviews.

The data were collected through individual interviews using an interview guide for the respective studies, which increased dependability. Disadvantage with an interview guide could be that the interviewer focuses on the guide rather than the conversations with the women, resulting in adherence to the interview being lost and valuable data missed (177). To obtain rich in-depth data to strengthen credibility, the interviewer (MR) maintained flexibility in following up also issues that the women raised. Furthermore, follow-up questions were added, which allowed the participant to speak more freely and to respond to questions in their own words. To ensure that the interview guide concerned issues that answered the aim of the studies, pilot interviews were
conducted (177). The pilot interviews were also used to evaluate the interviewer (MR) and to minimise bias such as the interviewer controlling the women’s response; this increased the confirmability and dependability of the findings. The interviewer was evaluated by co-authors (MO and KS), familiar with conducting interviews, by listening to interviews and discussing them in the research group.

To achieve credibility as an interviewer, it is of great importance to perform in-depth interviews. This can be achieved by showing curiosity and a deep genuine interest in each of the interviews (I, II), as well as building trust in the interview (239). All interviews started with small talk, and there was plenty of time for each interview, as well as time for the participants to receive information and opportunity to ask questions. The same interviewer (MR) conducted all the interviews and transcription, to minimise interview bias and to strengthen dependability of the data analysis.

The interviews were conducted at the HCPs (I) place of work when they were on duty. This could have had impact both on participation, as they might have felt responsibility to participate, and also in the manner in which they responded to the interview questions. This could have occurred if they thought that a spoken statement could result in some consequences. In addition, the stressful situation at the clinic could have resulted in them not taking the time to reflect, which may have limited the depth of the interviews. However, the place for the interviews had the advantage that it was easily accessible for the participants (I, II), which facilitated participation. All the women (II) preferred home interviews without disturbances. Eight interviews were performed face-to-face, while two by Skype, which was the women’s desire. Skype offers a novel interview method, and can provide an equal authenticity level with face-to-face interviews because of the access to verbal and nonverbal cues (240-243). Having both the interviewer (MR) and the women have access to high-speed Internet, good technical equipment, familiarity with online communication, and having digital literacy was crucial as this affected the nature of the interview (242) and influenced the dependability of the findings.

The interviews (I, II) were analysed using a qualitative content analysis, according to Burnard et al. (183). This is a systematic method and suitable for describing the content of the transcript interviews (177). To ensure credibility (238) as well as to validate (183) the analysis process, the interviewer/author (MR) and an experienced co-author (MO) conducted the analysis and established the categories, following discussions between them. Two other experienced co-authors (KS and GL) read some of the transcribed interviews and evaluated the analysis, the contents in the categories, as well as the categorisation, which ended up with a discussion between all of the authors. To avoid the addition of meaning that was not explicit in the interview text, a
pre-understanding of the interviewer/author (MR) and a co-author (MO) was recognised and discussed between them, which strengthened confirmability.

**The quantitative study (IV)**

A randomised sample of women from all counties in Sweden would have been preferable; instead, we had a cluster sampling involving a total sample in one county. This sampling strategy could have had an effect on the validity, as there could be selection bias, which, in turn, affects the results and conclusions provided (244). In addition, the method for collecting data, self-reporting using a questionnaire, cannot rule out self-selection bias (244, 245), as it could be that the most anxious women were attracted to participate. This could have had an effect on the validity and limited the generalisability. However, a previous study (189) with a similar sample had shown the same level of anxiety among the women as in this study (IV). Moreover, the external dropouts might be a limitation, as the response rate was 53%. However, response rates above 50% are established as an acceptable rate in social research postal surveys (246). According to the non-response bias, an analysis of the non-responders was performed. This related to age and diagnosis, since it was not possible to obtain any other characteristics. The mean years showed that responding women were significantly older than non-responders and were more often diagnosed with severe cervical abnormalities, a non-significant difference. This might have affected the generalisability; thus, the results should be generalised to other ages than those represented in the sample, with caution. Having a small subsample ($n=49$ respectively $n=73$) could also have affected the validity and limited the generalisability.

The questionnaire used to collect data comprised of the instruments HADS and FACIT-CD. HADS reported good psychometric properties of the initial test (148), is well established, widely used, and further validated in other studies (181). FACIT-CD is developed using a well established measurement system (186), and translated, cross-culturally adapted and linguistically validated into Swedish (III) using a multi-step rigorous translation methodology (178). FACIT-CD is disease-specific, focuses on the issues of particular concern to the women, and more sensitive to detecting clinically important changes in the women’s HRQoL than a generic instrument (151). However, some items in the FACIT-CD contain the word “infection”, which reflects the HPV infection, which could lead to misunderstandings. Thus, validity could have been affected, as it could have led to missing value, as well as information bias. A statement saying that cellular changes could replace the infection was added in the questionnaire. Infection could not be replaced in the questionnaire, based on a discussion between the author (MR) and the project manager of FACIT-CD, in study III.
The fact that the women received the questionnaire within a week after they became notified of their test result was a difficult balance between ethics and bias. This is because the women could have been anxious and vulnerable. On the other hand, another time point could have affected the validity as there could be recall bias as well as information bias (244). This is because the women could have had contact with healthcare, which could have affected how they responded to the questionnaire. However, one action in relation to the ethics was that the information letter had a statement that a counsellor was available to women who needed.

Usually, participants fail to respond to every item within an instrument (247), resulting in internal dropouts. A commonly used approach replaces the missing value with the mean of the variable, called mean substitution (247, 248). This can be either for the item, item mean substitution (IMS) or for the person, person mean substitution (PMS). In this study, the HADS-A had no missing value, while HADS-D had one, which was replaced using the method PMS. This might not lead to information bias, thus, does not affect the validity or the generalisability. However, FACIT-CD had 131 missing values, which were replaced according to the FACIT-CD scoring guidelines. The majority of the internal dropouts can be attributed to three items, which were not applicable if there was no treatment, any partner/spouse or family members. Moreover, the subscale that included the two items with most missing values consists of four items, with Likert-type response categories. Thus, the missing values had a great impact on the per cent of the response rate, in that subscale. Imputation of values has probably resulted in the variance in the data being changed, as well as the true distribution being distorted. Nonetheless, since at least 50% of the items in respective subscales have been responded to, there might be good representations of the original data (186), which minimises the information bias, and the effect on validity and generalisability.

Cronbach’s alpha coefficient ($\alpha$) was measured in order to show the reliability of this specific sample (249). Internal consistency was good for the FACIT-CD (FACIT-CD, $\alpha = 0.89$, subscales range, $\alpha = 0.72–0.86$), as well as for HADS-A and HADS-D ($\alpha = 0.86$, respectively). None of the scales exceeded alpha values of 0.90, where values above this could reflect redundant items (249, 250). The alpha values were calculated for respective subscales. This, because instruments that have more than one construct, a larger number of items of the whole scale will inevitable inflate the value of alpha (185, 251).

**The methodological study (III)**

This study consisted of two parts: at first, a translation and cross-cultural adaptation of the instrument FACIT-CD. This instrument was considered appropriate as it: (1) is disease-specific for cervical dysplasia; (2) contains a
broad set of domains of HRQoL and (3) was developed using a multi-step rigorous process (147). In addition, the FACIT organisation had over the years developed several instruments to be used in different contexts (available at www.facit.org/). An instrument needs to be systematically translated and cross-culturally adapted into the language of the research (250, 252). For this purpose, the FACIT translation methodology was considered appropriate (178, 179). This methodology is a more rigorous version of the double-back translation method (178). In this study, the FACIT translation methodology was used to produce a Swedish FACIT-CD that is equivalent to the English version (178, 179); however, attaining 100% equivalence is impossible (178). Using this methodology, the goal was to strive to minimise bias and come as close to this level of equivalence as possible. This was facilitated by the FACIT organisation assisting with the help of a project manager, who had experiences in conducting translation using the methodology, as well as had a close relationship with the developer of the FACIT-CD. The project manager was also source of great support for the reviewer/language coordinator (MR) during the translation process.

Validity is a fundamental element in the evaluation of a measurement instrument. Linguistic validation was conducted to ensure that the translation in the Swedish language stated what the original in the English language intended. This validation is the entire process of the translation and cross-cultural adaption, which included a pilot test through cognitive debriefing interviews. A sample size of 10 women for the interviews was predetermined, by the project manager, as it is considered enough for “saturation”, according to the methodology (178). The aim with the interviews was to identify and correct translation reversals and translation errors (179). The result was an identification of difficulties in the FACIT-CD that may otherwise have gone unrecognised. The interviews were performed using a semi-structured interview guide, including both think-aloud and verbal probing technique. Having the interview guide developed by the project manager, experienced in creating this type of interview guides, minimised bias, such as probes are unbiased phrasing (180). According to the FACIT translation methodology, the women should complete the Swedish FACIT-CD prior to the interview, to evaluate the suitability of the instrument for self-administration (178). This approach can be discussed in relation to the think-aloud technique. Moreover, to train the women in this technique, and to minimise potential bias in the women’s information processing tendencies, the interviewer (MR) induced the women to think aloud, with some practice prior to the interview (180). In addition, the interviewer (MR) gained theoretical knowledge on how to conduct interviews with think-aloud and verbal probing technique, in order to minimise bias related to the interviewer. The project manager, experienced in this field, conducted the analysis of the interviews. This might have minimised bias in the analysis process. Moreover, the project manager did not accept the
word disease to be replaced by condition, and the word infection by cellular changes, which might have weakened the Swedish FACIT-CD.

After an instrument has been translated and cross-culturally adapted, it is highly recommended to statistically evaluate that version produced (252). In addition to validity, reliability is a fundamental element for this evaluation. Accordingly, statistical analyses were performed on the Swedish FACIT-CD, in a sample of 34 women. This small sample size could be a limitation; however, according to Eremenco (178), a sample size of 15–30 is sufficient to provide preliminary evidence for the kind of analysis conducted in this study. Data were collected through a questionnaire, which, except the FACIT-CD, also included socio-demographic questions. There were no missing values in the responded FACIT-CD, which minimises bias, since no item needs to be replaced.

Reliability was evaluated in terms of internal consistency reliability, which refers to the degree of different items in the respective subscale of the Swedish FACIT-CD, as well as the total scale, measuring the same characteristic. It is important that the internal consistency reliability be determined before the FACIT-CD is employed for researches to ensure validity since an instrument cannot be valid unless it is reliable. Internal consistency reliability of the total scale as well as for each subscale was estimated by Cronbach’s alpha coefficient. Values ≥0.70 were considered acceptable, ≥0.80 was considered good and ≥0.90 was excellent (185). However, values ≥90 should be taken into account since it could be redundant (249, 250). Nevertheless, no scale in the Swedish FACIT-CD achieved that value. The homogeneity of the items was evaluated by corrected item-total correlations, to identify items with poor correlations with the respective subscale. An acceptable level of the corrected item-total correlations was set at ≥0.20 (178). This could be a limitation since the most common cut-off used in research is ≥0.30 (185). However, the FACIT translations methodology recommendations cut-off was followed (178).

All subscales of the Swedish FACIT-CD demonstrated acceptable (≥0.70) to good (≥0.80) internal consistency reliability, except for the subscale Relationships, which had a somewhat low alpha value of 0.67 (185). Reason for this low value could be that the subscale consists of a few items (185, 249). Another reason is the fact that one item exhibited significantly low corrected item-total correlation of 0.01. Hence, our findings suggest that the subscale Relationships could be improved by deleting that item (deleted α = 0.82), as it did not seem to be measuring the same construct as the others. Furthermore, each of the subscales Physical well-being and General perceptions had at least one item, respectively, which demonstrated significantly low corrected item-total correlation of 0.11 and 0.13, respectively. Nevertheless, of the items
deleted, none of them dramatically increased the respective subscales’ value of alpha. In addition, the subscale Physical well-being also demonstrated a low corrected item-total correlation of 0.08; if the item was deleted, the subscale improved (deleted $\alpha = 0.75$). However, according to the developer of the FACIT-CD, this item should not be deleted, with the explanation that it relates to a physical situation.

Furthermore, the stability of the Swedish FACIT-CD was not evaluated, as no data were collected a second time. This study only evaluated the linguistic validation, no other terms of validity. Further studies are recommended to conclude that the Swedish FACIT-CD is valid and reliable with a larger sample. This is warranted before any decision on whether or not to delete the four items that exhibited corrected item-total correlations below the acceptable level of $\geq 0.20$ (178). To confirm the original factor structure of the Swedish FACIT-CD, exploratory factor analyses are recommended. The results of this study contribute with evidence concerning linguistic validity, internal consistence reliability and homogeneity of the Swedish FACIT-CD.

**Conclusion**

This thesis indicated that the women did not understand their abnormal Pap smear result and misinterpreted it as cancer. This misinterpretation does not seem to impact on women’s HRQoL but evokes anxiety. In turn, this anxiety could lead to lower attendance at further investigation, treatment and follow-up, as women adapt a passive approach. Information might help the women to become prepared and to understand their test result, as well as the importance of investigation and treatment; moreover, it serves as a coping strategy. Oral notification of an abnormal Pap smear result might help reduce the level of anxiety. Moreover, the findings also indicated that Swedish women had low awareness of HPV infection and its sexually transmitted nature, as well as of HPV’s relation to abnormal Pap smear results and cervical cancer. However, awareness of HPV as a sexually transmitted infection does not seem to lead to higher level of anxiety or more depression symptoms or worse HRQoL than not being aware. It is essential that women become aware of HPV, partly since it plays an important role in the upcoming CCSP. Finally, the Swedish FACIT-CD is equivalent to the English version and linguistically valid and exhibited good internal consistency reliability.

**Contribution of this thesis**

The findings could be helpful when the HPV-based screening programme is introduced, as well as to improve the CCSP for women with an abnormal Pap
smear result – both in developing the manner in which test results are delivered to the women, as well as in developing the care for these women to meet individual needs and to enhance health and well-being. From a long-term perspective, the findings of this thesis can contribute to increasing women’s motivation to participate in the CCSP, as well as in investigation, treatment and follow-up. In addition, the findings could also serve as a reference in the debate when other screening programmes are under consideration of being introduced. The vision is that this thesis will be useful, both on an individual and societal level. Finally, this thesis has also contributed with a Swedish disease-specific instrument for assessing women’s HRQoL associated with cervical dysplasia. This provides a possibility for other researchers to use a disease-specific instrument when conducting research in this field among Swedish women.

Clinical implications

The findings in this thesis may be useful for HCP’s who work in the CCSP and for decision-makers in healthcare.

- The CCSP would benefit from being developed in a manner that offers women oral notification of their abnormal Pap smear result. Oral notification could provide an opportunity for the women to ask questions and to get information from the HCPs. However, all Swedes are going to have access to their medical records sooner or later, which, has to be taken into account, if the test results are communicated orally.

- When an abnormal Pap smear result is communicated to the women, it should also include clear (e.g. not using medical terminology) and consistent information, based on the individual women’s test result, covering key areas such as: the link to HPV, how common it is, emotional reactions, what cellular changes mean, the follow-up process, how fertility is affected, possible risk for recurrence, and the fact that it is not the same as cancer. However, HCP’s need to enter into a dialogue with the women to evaluate the individual women’s need for information.

- When the women are notified of their abnormal Pap smear result, the HCPs should also inform and explain the aim and importance of attending further investigation, treatment and follow-up.
The HCPs should encourage women to use the Internet as a source of information, and support how to find reliable information and medical links, as well as how to filter and analyse that information. This requires HCPs to have competence and knowledge within the field.

The HCPs in the CCSP should be offered education about the new CCSP, abnormal Pap smear results, HPV in general and the HPV vaccination, as well as about women’s possible emotional reactions to their test result and how to handle these reactions.

The healthcare needs to provide information about HPV infection, and the HPV-based screening programme, for example, at websites, on helpline, and on the Pap smear test invitation.

Further research
Currently, the Swedish CCSP is undergoing the greatest changes since the introduction in the 1960s. Thus, more research is needed, such as the following.

Further studies are required in order to develop the manner in which women are notified of their abnormal Pap smear result. Interventions with a larger sample of women, comparing those who become notified of their abnormal Pap smear result orally with those notified in writing. This should be done in order to evaluate the manner in which women become notified. Potential outcomes to assess might include satisfaction with the manner of notification, levels of anxiety, depression symptoms and HRQoL.

Recently, women have started to have access to their medical record via their computer at home. Studies, both qualitative as well as quantitative, should be conducted to evaluate women’s experience of becoming notified of their abnormal Pap smear result as stated by the physician in their medical record.

Studies among women with an immigrant background are important to undertake since many of these women migrate from countries with another culture, and varying views on STIs as well as limited access to CCSP. In addition, interventions should also be conducted among this group of women in order to increase attendance at CCSP, since they have lower attendance rates than Swedish born.
• Studies among men are important since they be source of emotional support for the women with abnormal Pap smear result. Also, they have a part in HVP infections, since they become infected or infect. Individual interviews as well as focus groups with men to investigate their experiences of abnormal Pap smear results as well as awareness of HVP infections is necessary, in order to identify need for information.

• Further studies are needed with a larger sample to conclude that the Swedish FACIT-CD is valid and reliable. In addition, an exploratory factor analyses can be conducted in order to conform the original factor structure of the Swedish FACIT-CD.
SVENSK SAMMANFATTNING

Bakgrund

I Sverige introducerades ett nationellt screeningprogram för livmoderhalscancer på 1960-talet. Screeningprogrammet har medfört att både incidens och mortalitet i livmoderhalscancer har minskat markant (1). Huvudorsaken till livmoderhalscancer är humant papillomavirus (HPV), där högrisktyper av HPV (HR-HPV) återfinns i nästan alla cancerfält (2). Livmoderhalscancer utvecklas från precancerösa cellförändringar, vilket vanligtvis tar 10–12 år (38). Cellförändringarna kan upptäckas via ett gynekologiskt cellprov, innan de utvecklats till cancer (3). Ärligen tas cirka 490 000 cellprover i screeningprogrammet, varpå cirka 10 % visar på cellförändringar (4). De vanligaste cellförändringarna är atypiska skivepitelceller av obestämd betydelse (ASC-US) och skivepiteldysplasi (CIN), vilken klassificeras CIN1 (lätt), CIN 2 (måttlig) samt CIN3 (grav). Klassificeringen har numera ersatts av en två-stegs-nomenklatur; låggradig skvamös intraepitelial lesion (LSIL) vilken motsvarar CIN1 och höggradig skvamös intraepitelial lesion (HSIL) vilken motsvarar CIN2/3 (84-86).

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Syfte

Det övergripande syftet var att utforska erfarenheter av att erhålla ett avvikande gynekologiskt cellprovsvar och dess inverkan på kvinnors hälsorelaterade livskvalitet samt utforska kvinnors medvetenhet om humant papillomvirus.

Metod och material


I den explorativa (I) och beskrivande studien (II) deltog 20 hälso- och sjukvårdspersonal (I) och 10 kvinnor (II) i individuella intervjuer. En intervjuguide konstruerades för vardera studien och genomfördes antingen i ett avskilt rum på kvinnoklinikerna (tjugo) (I), eller i kvinnans hem (åtta), eller via Skype (två) (II). Intervjuerna varade mellan 10–30 minuter (I), eller 20–70
minuter (II), inspelades med mp3, transkriberades och analyserades med innehållsanalys enligt Burnard (183).

Den metodologiska studien (III) bestod av två delar; 1) översätta och tvärkulturellt anpassa det Engelska instrumentet FACIT-CD, inkluderat en pilot test av den Svenska FACIT-CD testversionen med kognitiva intvjuer; 2) utvärdera det Svenska FACIT-CD-instrumentets reliabilitet (Figur 1).

FACIT-CD utvärderar hälsorelaterad livskvalitet associerat med livmoderhals dysplasi. Instrumentet består av 36 items fördelat på fem domäner: Fysiskt välbefinnande, Tillfredsställelse med behandling, Allmänna uppfattningar, Känslomässigt välbefinnande, och Relationer. FACIT-CD poängsätts på en Likert-typ skala (0–4), förutom två items (Ja/Nej). Summan av subskalanas poäng bildar den totala poängen, max 136: högre poäng indikerar bättre hälsorelaterad livskvalitet (147).

I översättningens och tvärkulturella anpassnings processen deltog sju personer. Processen genomfördes i enlighet med Functional Assessment of Chronic Illness Therapy (FACIT) översättnings metodik (178, 179). I de kognitiva intervjuerna deltog 10 kvinnor och i utvärderingen av instrumentets reliabilitet deltog 34 kvinnor. De kognitiva intervjuerna genomfördes med hjälp av ett testpaket innehållande den svenska testversionen av FACIT-CD och ett semistrukturerat frågeformulär bestående av frågor gällande FACIT-CD. Intervjuerna genomfördes antingen i kvinnans hem (nio) eller på ett universitet (en), varade mellan 43 and 90 minuter, dokumenterades i frågeformuläret och analyserades av en projektledare vid FACIT organisationen. Utvärderingen av reliabiliteten genomfördes med ett frågeformulär bestående av socio-

Figur 1. Ett flödesschema över hur de olika delarna i studie III är relaterade till varandra.
demografiska frågor och den svenska versionen av FACIT-CD. Intern konsistens reliabilitet beräknades med Chronbach’s alpha, varpå värden ≥0.70 ansågs acceptabla; ≥0.80 ansågs goda och ≥0.90 utmärkta (185). Homogenitet beräknades med item-total korrelation, varpå ett acceptabelt värde var ≥0.20 (178).


Resultat

Studiernas olika karaktär medför att resultaten presenteras i två delar, vari första delen består av resultat från studie I, II och IV, medan följande del består av resultat från studie III.

Erhålla ett avvikande gynekologiskt cellprovsvar (I, II, IV)

Både kvinnorna (II) och hälso- och sjukvådspersonalen (I) rapporterade att ett normalt provsvar förväntades, och av olika anledningar var kvinnor inte förberedda att provsvaret visade cellförändringar. Kvinnorna blev chockade och känslor som nedstämdhet och ångest kunde uppstå (I, II). Ångest rapporterades hos 48.4 % av kvinnorna, varpå HADS-A visade en medianpoäng på 7.0 (q1–q3 = 4.0–10.0), medan depression rapporterades hos 13.1 % av kvinnorna, varpå HADS-D visade en medianpoäng på 3.0 (q1–q3 = 1.9–5.3) (IV). Kvinnornas hälsorelaterade livskvalitet var i övrigt god, utifrån
FACIT-CD (md = 97.6; q1–q3 = 81.8–107.0) (IV). Kvinnorna (II) och hälso- och sjukvårdspersonalen (I) uttryckte att en av anledningarna till att kvinnorna upplevde ångest var att provsvaret associerades med cancer, detta på grund av ordvalet cellförändringar. Andra anledningar till att kvinnorna upplevde ångest var tron att fertiliteten påverkats negativt (I, II) och/eller att partnern skulle smittas med HPV (II). Alla kvinnor (II) var inte medvetna om HPV, av kvinnorna (IV) var 50 % medvetna om HPV, 40.2 % var medvetna om HPV infektionens sexuella överförbarhet, och 45.9 % var medvetna om att HPV kunde orsaka livmoderhalscancer. Oavsett om kvinnorna (IV) var medvetna om HPV infektionens sexuella överförbarhet eller inte rapporterade de likvärdiga nivåer av ångest (HADS-A; md = 7.0, q1–q3 = 4.0–10.0 kontra 7.0, 3.0–10.0), depressiva symtom (HADS-D; md = 3.0, q1–q3 = 1.0–5.5, för båda grupperna) och hälsorelaterad livskvalitet (FACIT-CD; md = 98.0, q1–q3 = 83.5–106.7 kontra 96.6, 78.4–107.0). Både kvinnorna (II) och hälso- och sjukvårdspersonalen (I) ansåg att istället för att meddela provsvaret via brev kunde ett munligt besked eventuellt lindra eller minska kvinnors ångest. Ett munligt provsvaret kunde erbjuda kvinnorna en möjlighet att ställa frågor och få information från hälso- och sjukvårdspersonalen.

Hur kvinnorna hanterade sitt provsvar fanns det delade meningar om. Kvinnorna (II) angav att deras främsta copingstrategi var att söka emotionellt stöd, framför allt från sin mamma och partner (97 %) (IV), men även från andra släktingar, vänner och bekanta (II) (61.5 %) (IV). Medan hälso- och sjukvårdspersonalen (I) angav att kvinnorna främst sökte information, varpå Internet var den primära källan. Även kvinnorna (II, IV) angav att de sökte information, dels från Internet (59.2 %) (IV), men också från hälso- och sjukvårdspersonalen på kvinnokliniken (I, II, IV) (18 %) (IV). Att informera och besvara kvinnornas frågor angavs av hälso- och sjukvårdspersonalen (I) som deras främsta copingstrategi för att hjälpa kvinnorna att hantera sin ångest. Dock framkom delade meningar mellan kvinnorna (II) och hälso- och sjukvårdspersonalen (I) gällande ifall informationen kvinnorna erhöll var lugnande. Hälso- och sjukvårdspersonalen menade att information hade en lugnande inverkan på kvinnorna, medan kvinnorna angav att de inte erhöll den information de efterfrågade från hälso- och sjukvården, vilket bidrog till att ångesten kvarstod. Vid utredning och behandling hade kvinnorna en annan åsikt och angav att informationen då var lugnande. En copingstrategi hälso- och sjukvårdspersonalen (I) använde för att hjälpa kvinnorna hantera sin ångest var att erbjuda en tidigare läkartid än planerad.

Erfarenheter kring kvinnornas deltagande i utredning, behandling och uppföljning skiljde sig åt mellan kvinnoklinikerna (I). Ena kliniken uppfattade att kvinnor generellt deltar, medan den andra kliniken uppfattade det som ett problem att kvinnor inte deltar. Cancerrådsla angavs som främsta anledningen till att kvinnor deltar likväl inte deltar i utredning, behandling och uppföljning.
Läkarens åtgärder skilde sig åt ifall kvinnor inte deltog i utredning och behandling jämfört med deltagande i uppföljning efter behandling. Till kvinnor som inte deltog i utredning och behandling sände läkaren ett brev vari det framkom allvaret med att inte delta, i vilket oftast resulterade ett deltagande. Genom läkaren vid utebliven uppföljning efter behandling lät det vara kvinnans eget ansvar att delta.

**Översättning och tvärkulturell anpassning av FACIT-CD samt utvärdering av lingvistisk validitet och reliabilitet (III)**

**Översättning och tvärkulturell anpassning samt pilot test**

Översättning och tvärkulturell anpassning framskred i stort utan problem. Tre item innehållande termen ”pelvic area” (CD1, CD2 och CD3), stod i fokus gällande valet av svensk term, ”bäckenområde” kontra ”underliv”. Den svenska testversionen innehöll termen ”bäckenområde” då det var en mer bokstavlig översättning. Dock utvärderades de båda termerna i den kognitiva intervjun. Resultatet var en svensk version med termen ”underliv”. Andra förändringar i den svenska FACIT-CD gentemot den engelska versionen var att fyra item förändrades strukturellt och en item fick ordet information tillagt. Resultatet av översättningen och den kulturella anpassningen förordade en svensk FACIT-CD, lätt att fylla in, bestående av relevanta item, heltäckande och entydiga svarsalternativ, samt lingvistisk valid.

**Utvärdering av instrumentets reliabilitet**

Den totala skalan av FACIT-CD uppvisade god intern konsistens, med en Chronbach’s alpha på 0.84. Av fem subskalor uppvisade fyra en acceptabel till god intern konsistens, α = 0.71–0.81. Däremot uppvisade subskalan Relationer en Cronbach’s alpha på 0.67, vilket var under acceptabelt värden på ≥0.70. Majoriteten av items uppvisade acceptabel item-total korrelation, ≥0.20, förutom fyra items.

**Slutsats och kliniska implikationer**

Resultaten i avhandlingen visar att kvinnor inte förstår vad deras avvikande gynekologiska cellprosvsar innebär och misstolkar det som cancer. Kvinnors hälsorelaterade livskvalitet verkar inte påverkas av erhållandet av provsvaret men ångest kan framkallas. Ångest i sin tur kan leda till lägre deltagande i utredning, behandling och uppföljning av provsvaret. Information kan minska ångest genom att bidra till att kvinnor bli förberedda och förstå sitt avvikande provsvar. Informationen bör vara tydlig och konsekvent, baserad på den individuella kvinnans provresultat och inom nyckelområden så som: provsvarets samband med HPV, hur vanligt det är, emotionella reaktioner, vad
ACKNOWLEDGEMENTS

In 2011, I was accepted into the PhD-programme at Linnaeus University, and I am very grateful that I got that opportunity. It has been a journey that has developed me both within my profession as well as on a personal level. I would like to express my warmest thanks to all of you, who, in one way or another, have supported me during these years, not only in academia but also in my private life.

I would like to begin by expressing my sincere appreciation to all the women and healthcare professionals who took part in the studies and shared your thoughts and experiences with me. Without you, these studies could not have been conducted.

To my excellent supervisors, who have walked by my side and provided wisdom as well as support and laughter. To you, I would like to cite some words from a song by Josh Groban.

"You raise me up, so I can stand on mountains"

My main supervisor, Associate Professor Marie Oscarsson, thanks for your warm and never-ending support, and for you sharing your knowledge both in the field of this thesis as well as in academic work. Thank you for always believing in me, which in turn made me grow and start to believe in myself, again. You are my role model in the academic world, as well as within private life. To have had you as my main supervisor "I am a lucky girl"

My co-supervisor, Professor Katarina Swahnberg, thank you for sharing your knowledge in the academic world, as well as all the support through these years. Your support is invaluable, and I will never forget what you have done for me.

Vidare indikerar resultaten i avhandlingen att svenska kvinnor har en låg medvetenhet om HPV och dess samband med avvikande gynekologiska cellprovssvar och livmoderhalscancer. Dock verkar inte en medvetenhet om HPV som sexuellt överförbar infektion leda till högre nivå av ångest, mera depressiva sytoment eller sämre hälso relaterad livskvalitet än vid en omedvetenhet. Det är av vikt att kvinnor blir medvetna om HPV, bland annat för att HPV har en stor roll i det kommande livmoderhalscancer screeningprogrammet. Slutligen, den svenska versionen av FACIT-CD är likvärdig den engelska versionen och lingvistisk valid samt uppvisar god intern konsistens.
ACKNOWLEDGEMENTS

In 2011, I was accepted into the PhD-programme at Linnaeus University, and I am very grateful that I got that opportunity. It has been a journey that has developed me both within my profession as well as on a personal level. I would like to express my warmest thanks to all of you, who, in one way or another, have supported me during these years, not only in academia but also in my private life.

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Thanks also to the *Institutions of Health and Caring Sciences* at the *Linnaeus University* for accepting me into the PhD-programme.

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REFERENCES


13. Oscarsson MG, Wijma BE, Benzein EG. 'I do not need to... I do not want to... I do not give it priority...'-why women choose not to attend cervical cancer screening. Health expectations: an international journal of public participation in health care and health policy. 2008;11(1):26-34.


103. Idestrom M, Milsom I, Andersson-Ellstrom A. Women's experience of coping with a positive Pap smear: A register-based study of women
with two consecutive Pap smears reported as CIN 1. Acta obstetricia et
107. McRae J, Martin C, O'Leary J, Sharp L. "If you can't treat HPV, why test for it?" Women's attitudes to the changing face of cervical cancer prevention: a focus group study. BMC women's health. 2014;14:64.
115. O'Connor M, Costello L, Murphy J, Prendiville W, Martin CM, O'Leary JJ, et al. 'I don't care whether it's HPV or ABC, I just want to know if I have cancer.' Factors influencing women's emotional responses to undergoing human papillomavirus testing in routine management in cervical screening: a


Appendix 1  FACIT-CD (Version 4)

Below is a list of statements that other people with your illness have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

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*Are you sexually active or would you like to be sexually active? If yes, answer the following three questions. If no, skip these questions and move on to the next section.*

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| CD4                 |            |              |          |             |           |
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Appendix 1  
FACIT-CD (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

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Appendix 1

FACIT-CD (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

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<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q9 I have told my partner/spouse about my infection:</td>
<td>No</td>
<td>Yes</td>
<td>If yes:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD2 I get emotional support from my partner/spouse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Q10 I have told family members about my infection:</td>
<td>No</td>
<td>Yes</td>
<td>If yes:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CD2 2 I get emotional support from family members</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>GS1 I feel close to my friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HB I have people to help me if I need it</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2

FACIT-CD (Version 4)

Nedan finner du en lista med uttalanden som andra människor med din sjukdom tycker är viktiga. Ringa in eller markera en siffra per rad för att ange ditt svar som ska gälla de senaste 7 dagarna.

**FYSISKT VÄLBEFINNANDE**

<table>
<thead>
<tr>
<th>CD</th>
<th>Fråga</th>
<th>Inte alls</th>
<th>En aning</th>
<th>Något</th>
<th>Ganska mycket</th>
<th>Väldigt mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD1</td>
<td>Jag känner obehag i mitt underliv</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD2</td>
<td>Jag känner smärta i mitt underliv</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD3</td>
<td>Jag har kramper i mitt underliv</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD4</td>
<td>Jag besvärar av flytningar eller blödningar från slidan</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD5</td>
<td>Jag besvärar av biverkningar av behandlingen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**TILLFREDSTÄLLELSE MED BEHANDLING**

<table>
<thead>
<tr>
<th>CD</th>
<th>Fråga</th>
<th>Inte alls</th>
<th>En aning</th>
<th>Något</th>
<th>Ganska mycket</th>
<th>Väldigt mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD1</td>
<td>Jag har förtroende för min(a) läkare</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD2</td>
<td>Jag känner att jag har fått den behandling som var rätt för mig</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD3</td>
<td>Min läkare gav mig förklaringar (information) som jag kunde förstå</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>CD4</td>
<td>Min läkare förklarade de eventuella fördelarna med min behandling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix 2   FACIT-CD (Version 4)

Ringa in eller markera en siffra per rad för att ange ditt svar som ska gälla de senaste 7 dagarna.

### ALLMÄNNA UPPFATTNINGAR

<table>
<thead>
<tr>
<th></th>
<th>Inte alls</th>
<th>En aning</th>
<th>Något</th>
<th>Ganska mycket</th>
<th>Väldigt mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GF1</strong></td>
<td>Jag kan arbeta (innehåller även arbete i hemmet)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>GF3</strong></td>
<td>Jag kan njuta av livet</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>HB1</strong></td>
<td>Jag är hoppfull inför framtiden</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>Sp9</strong></td>
<td>Jag finner tröst i min tro eller inre övertygelse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>GF7</strong></td>
<td>Jag är nöjd med min livskvalitet just nu</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD9</strong></td>
<td>Jag känner att jag kan hantera saker som dyker upp runt den här infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD10</strong></td>
<td>Jag har accepterat att jag har den här infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### KÄNSLOMÄSSIGT VÄLBEFINNANDE

<table>
<thead>
<tr>
<th></th>
<th>Inte alls</th>
<th>En aning</th>
<th>Något</th>
<th>Ganska mycket</th>
<th>Väldigt mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CD11</strong></td>
<td>Jag oroar mig för att infektionen kommer bli värre</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD12</strong></td>
<td>Jag har dolt detta problem så att andra inte kommer att märka det</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD13</strong></td>
<td>Jag är bekymrad över min förmåga att bli gravid</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD14</strong></td>
<td>Kostnaden för min behandling är en börda för mig eller min familj</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD15</strong></td>
<td>Jag oroar mig för andra människors attityder till mig</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD16</strong></td>
<td>Jag känner mig generad över infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD17</strong></td>
<td>Jag har en tendens att klandra mig själv för infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD18</strong></td>
<td>Jag var försiktig med för vem jag berättade om infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD19</strong></td>
<td>Jag har haft svårt att berätta för min partner/make om infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD20</strong></td>
<td>Jag är frustrerad över infektionen</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td><strong>CD21</strong></td>
<td>Jag är nöjd med min livskvalitet just nu</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### Appendix 2 FACIT-CD (Version 4)

Ringa in eller markera en siffra per rad för att ange ditt svar som ska gälla de senaste 7 dagarna.

<table>
<thead>
<tr>
<th>RELATIONER</th>
<th>Inte alls</th>
<th>En aning</th>
<th>Något</th>
<th>Ganska mycket</th>
<th>Väldigt mycket</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q9</strong> Jag har berättat för min partner/make om min infektion:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Nej ____ Ja ____</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CD21</strong> Om ja: Jag får känslomässigt stöd från min partner/make ......................................................................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Q10</strong> Jag har berättat för familjemedlemmar om min infektion:</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Nej ____ Ja ____</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CD22</strong> Om ja: Jag får känslomässigt stöd från familjemedlemmar ......................................................................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>GSI</strong> Jag känner närhet till mina vänner ......................................................................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>H3</strong> Det finns personer som hjälper mig om jag behöver det ......................................................................................</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>