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HEALTHY WOMEN OR RISK PATIENTS?

Non-attendance in a cervical cancer screening program

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Låt inte rädslan fatta dina beslut.
Låt hellre glädjen, lättheten och självkärleken fatta besluten.

Barbro Bronsberg

To my friend Karin

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ABBREVIATIONS and DEFINITIONS

ANHC	Antenatal Health Clinic
CCS	Cervical Cancer Screening
CEA	Cost-Effectiveness Analysis
CIN	Cervical Intraepithelial Neoplasia
CIS	Carcionoma In Situ
CSQ	Cervical Screening Questionnaire
HPV	Human Papilloma Virus
NBHW	National Board of Health and Welfare
OR	Odds Ratio
QALY	Quality-Adjusted Life-Years
RCT	Randomized Controlled Trials
SEK	Swedish Crown
TPR	Total Population Register

Attendance rates	The proportion of women who attend cervical cancer screening
Coverage	Proportion of women in the target group with a cervical smear taken during the previous five years
High risk women	Women with few or no cervical smear taken
Intervention	An activity (or group of related activities) intended to promote attendance at cervical cancer screening
Non-attendees	Women with no registered cervical smear during the previous five years
Non-respondents	Women who choose not to participate in this research project
Opportunistic CCS	Cervical smears taken in combination with an ordinary gynaecologic examination performed for other reasons
Organised CCS	National program inviting women every third year to have a cervical smear taken
Promotive efforts	Those activities carried out based on women's requirements
Respondents	Women who choose to participate in this research project
Screening	Investigation of a population for the purpose of detecting a certain disease

PREFACE

The starting point for this thesis is related to my background as a midwife. I worked for many years at an Antenatal Health Clinic (ANHC) where I was involved as a cervical smear taker in the Swedish cervical cancer screening (CCS) program. I was trained within a traditional medical perspective and my opinion was that CCS was beneficial and that every woman ought to have a cervical smear every third year. Each week, we received a list comprising all invited women and some of whom had few or no cervical smears taken. Similar to many others working in health care, we discussed why these women had chosen not to come. We assumed that they had a low socioeconomic status, that they had chosen not to be a part of “normal” society, or that they were afraid of gynaecologic examinations.

These were the assumptions I brought into this project. My view was that a high level of attendance at CCS was an adequate goal. I realized that CCS had seldom been criticized, probably because an association that had been demonstrated between CCS and the number of lives saved when cervical cancer was detected. Therefore even more woman should attend CCS.

Now, five years after this project started, I have gradually adopted another view of the one-sided goal of reaching non-attendees in a CCS program. I will come back to this in the discussion section and at the end of this thesis.

LIST OF ORIGINAL PAPERS

I Oscarsson M., Benzein E., Wijma B. Reasons for non-attendance at cervical screening as described by non-attendees in Sweden. *Journal of Psychosomatic Obstetrics & Gynecology*. In press.

II Oscarsson M., Wijma B., Benzein E. “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. Re-submitted to *Health Expectations*.

III Oscarsson M., Wijma B., Benzein E. Non-attendance in a cervical cancer screening program - What happens if women’s requirements are met? Accepted by *Health Care for Women International*.

IV Oscarsson M., Benzein E., Wijma B., Carlsson P. Promotion of cervical screening among non-attendees - A partial cost-effectiveness analysis. *European Journal of Cancer Prevention*. In press.

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ABSTRACT

Women afflicted with cervical cancer who have the highest morbidity and mortality rates have been the least likely to be screened. The overall aim of this research project was to investigate non-attendance in a cervical cancer screening (CCS) program among women with no registered cervical smear during the previous five years. Both quantitative (I,III) and qualitative methods (II) as well as cost-effectiveness analysis (IV) were used in this research project. In Kalmar County women (aged 23-65 years) are invited to CCS every third year. All cervical smears taken both in opportunistic and organised CCS are coordinated in a register called Sympathy. The coverage is 88.4 %. From Sympathy, a random sample of 400 women served as a study group and another 400 women as a control group (III,IV). From the study group, 133 women participated in study I and 14 women in study II. Data was collected by telephone interviews based on a questionnaire (I), qualitative face-to-face interviews (II), questionnaire, promotive efforts and outcome (III), costs and effectiveness (IV). Quantitative data was analysed by descriptive and analytic statistics (I,III), qualitative data was analysed by content analysis. In study IV, cost-effectiveness analysis was used.

The women believed that CCS was a good idea for all other women, but tended to refer to various circumstances resulting in their own non-attendance. One of the most common reasons for non-attendance was the feeling of being healthy. The women prioritized family and work commitments, and the invitation to attend CCS was sometimes experienced as a stressful disturbance. The feeling of discomfort was related to the gynaecologic examination, or to health care visits in general (I,II). Of 133 women, 120 could consider having a cervical smear taken and their two most common requirements for doing so were to be assured they would be treated in a friendly way (19%) and to find a suitable time (18%) for having the cervical smear. Fifty women wanted to be helped to have a cervical smear taken. Promotive efforts ranged from making a simple telephone call to arranging an appointment time to a combination of promotive efforts including repeated encounters in order to create a trusting relationship with respect to taking the smear. In the study group, 29.5% (n=118) had a registered cervical smear at follow-up compared to 18.5% (n=74) in the control group, ($p<0.001$) (III). In the study group, the cost per cervical smear taken was 66.87 €, and in the control group it was 16.62 €. The incremental cost per additional cervical smear taken was 151.36 € (IV).

In conclusion, women's reasons for not attending CCS are complex and are influenced by both present and earlier circumstances. In settings with high coverage, further contact in order to promote women's attendance at CCS seems to be associated with high costs in relation to the number of additional cervical smears taken.

INTRODUCTION

According to worldwide cancer statistics, cervical cancer is the second most common cancer in women [1]. The highest incidence rates are in Latin America, the Caribbean region, sub-Saharan Africa, Melanesia, southcentral Asia and south East Asia [1]. In developed countries the incidence rates are low and in Sweden approximately 450 new cases occur yearly [2]. There are probably many reasons for the decline in cervical cancer morbidity and mortality, but the most common is the early detection and treatment of pre-cancerous changes, and many countries therefore offer CCS programs. The organisation and the outcome of CCS differ in different countries, but reports from other countries demonstrate that well-organised CCS programs can result in reductions in mortality for cervical cancer [3]. Women with the highest morbidity and mortality rates for cervical cancer have been the least likely to join CCS programs, and one focus has been to increase the attendance of these women [4]. This medical perspective has been predominant in research, with the assumption that CCS attendance is a positive norm. However, this view has been the subject of debate in recent decades, and the issue has been considered from different perspectives including those focusing on ethical issues [5] and gender [6]. CCS programs can be both beneficial and harmful for women and over-diagnosis and over-treatment are well-known negative effects that can cause a great deal of anxiety [7]. CCS programs are planned and organised from a health care perspective, i.e. non-attending women are seen as risk patients rather than healthy women, and women's perspectives, especially those of non-attendees have been lacking. Therefore, women's reasons for choosing not to attend CCS must be identified in order to meet their needs and requirements for having a cervical smear taken, find ways to promote attendance, and calculate the costs for such promotive efforts. These issues are focused on in this research project.

Cervical cancer screening

The aetiology of cervical cancer is not known. However, it has been demonstrated that Human Papilloma Virus (HPV) has a central role and certain types of HPV are linked to 99.7% of all cases of cervical cancer [8]. Compared with the life time estimated risk of 80% for being exposed of a HPV infection, cervical cancer is rare [9]. HPV is one major risk factor, but other factors of importance for development of cervical cancer remain unclear. The discovery by Papanicolaou of a screening method, called the Pap smear, for detecting precursor lesions of cervical cancer changed the diagnosis and treatment regime [10]. Today, cervical cancer is one of the most preventable cancers due to its gradual development from the precursor lesions into invasive cervical cancer, which usually takes ten to twelve years. Since this condition develops over a long period, abnormal changes can be detected and treated in early stages [4]. Because no clinically controlled trials of CCS have been carried out in Sweden or elsewhere [4],

the exact relation between high attendance rates and low mortality rates for cervical cancer is unknown. However, the World Health Organization (WHO) has calculated the level of protection resulting from regular CCS. With a cervical smear every third year (each woman then has a total of 16 cervical smears during her lifetime) it is calculated that the incidence of cervical cancer is reduced by 90.8%, a cervical smear every ten years has a benefit with 64.1% reduction in incidence [11].

More than 90% of cervical cancers develop within a small area of the cervix known as the transformation zone. Early cervical cancer is often asymptomatic and the first sign of disease is usually an abnormal cervical smear which, if left untreated, could lead to cervical cancer. Cervical cancer gradually develops from dysplasia to carcinoma in situ (CIS), to asymptomatic invasive cancer and finally to symptomatic cancer. Cervical intraepithelial neoplasia (CIN) is used to describe dysplasia and is classified into three grades from CINI-CINIII. Most women with CIN do not develop cervical cancer even if they remain untreated [2]. The cervical smear test is not 100% accurate, and over-diagnosis, unnecessary treatments, over-treatment and the creation of anxiety on the part of the women are negative side effects of CCS [7]. Although false positive and false negative results do not occur very often, they may be harmful for those affected. However, regular CCS helps to compensate for false results: if abnormal cells are missed on one occasion, chances are good that the cells will be detected the next time.

Radical improvements have been made in methods for detecting HPV [12], and it has been suggested that HPV tests are more sensitive than cervical smears. HPV testing is one of the evolutionary factors confronting CCS. These would be even greater changes in the management of cervical cancer if an effective vaccination program could be introduced. However, in the future, vaccination and CCS preventive strategies will have to be used in parallel for quite some times [13]. If a prophylactic vaccination program is initiated in 2010 for girls aged 12 years, the vaccination program would not have an impact on the incidence of cervical cancer until 2040 [14].

Cervical cancer screening program

The population-based CCS programs were designed from a medical perspective and were constructed as a national service to detect pre-cancerous changes. In Sweden, the CCS program started during the 1960s, and in 1973 all counties were embraced [15]. The total female population in Sweden is 4.2 million, and 950 000 smears are taken annually in organised and opportunistic CCS, 25 000 cervical smears show signs of dysplasia, approximately 450 new cases are detected, and 150 women die of cervical cancer every year [2]. The counties administer the programs under the supervision of the National Board of Health and Welfare (NBHW). The total population register (TPR) is used for identification of the target population. The TPR receives

information daily from the tax authorities and contains most of the data found in the register, including births, deaths, migration, change of address, and change in civil status. The recommended CCS interval for women aged 23-50 years is every third year, and for women aged 51-60 years it is every fifth year. These age intervals were chosen because invasive cancer is extremely rare in women below the age of 25 years [16]. Lesions that progress will still be screen-detectable at the age of 25 and regressing lesions will no longer be a source of anxiety. A lower age limit of 25 will thus prevent young women from undergoing unnecessary investigations and treatments. New HPV infections are rare in women after 40 years of age, and it has been suggested that sensitiveness for HPV infections is lower among older women than younger women [2].

In the recommendations of the NBHW, it is suggested that the effectiveness of CCS programs should be judged and analysed continuously, such as in terms of coverage instead of attendance rates (the proportion of women attending CCS when invited). Coverage describes the proportion of women who have had a cervical smear taken during a certain period. The population coverage and attendance rates could be very different in regions where a large proportion of women take the cervical smears in opportunistic CCS. The coverage in Sweden, is suggested to be 90% during a CCS time interval (3 years) plus 2 years [2], and attention should be directed toward non-attendees as they are at risk of developing cervical cancer. The NBHW has given the following advice (translated to English by the author):

- increase attendance by professional marketing, such as media campaigns. Material containing appropriate information should be accessible for health care professionals and the women concerned
- address special efforts to subgroups of women with low attendance, such as immigrants
- invite women to CCS in a polite and psychological way
- attempts should be made to inform all parties involved in CCS
- increase the access to CCS, such as possibilities for booking a time and phone contact. The women's financial situation must not be of vital importance (regarding her decision to attend or not; author's note)
- women not attending CCS should receive yearly reminders until a cervical smear is registered or the woman has declined to attend.

Cervical cancer screening program in Kalmar

In Kalmar, in the southeast of Sweden, the organised CCS program was introduced 1968. Today, women aged 23-65 years are invited to CCS every third year. About 20 000 women are invited every year, and 14% choose not to attend. In January 2004, the coverage was 88.4%. The system for sending invitations, registration and follow-up is fully computerized. All cervical smears taken both in organised and opportunistic screening are registered in the same cytology register. All women with no registered cervical smear during the previous three years receive an invitation to attend the organised CCS program. Women are invited to ANHC clinics but they do not have to confirm whether they are coming or not. If they do not attend, they will receive a re-invitation every year until a cervical smear is registered. The invitation-letter contains an appointment time, place and information about the CCS and its purpose. The fee for the cervical smear is 8.87 € (80 SEK), 2004. Those women who are pregnant or newly delivered are recommended not to take part, as are those women who have never had sexual intercourse. The cervical smear is usually taken by a specially trained midwife. Around 65% of all cervical smears are taken as a part of the organised CCS program, and the remaining cervical smears are opportunistic and taken by private gynaecologists, midwives or general practitioners and are combined with an ordinary gynaecologic examination.

The cytology laboratory administers a register called Sympathy, where all cervical smears taken since 1985 are registered. Sympathy is population-based and updated every week against TRP, and includes personal identity number, name, current address, when date invitations were sent and registered cervical smears. Women who have died or have personally/actively asked to be exempted from the CCS program are still registered, but are removed from the call-recall-system. Women who have had a cervical smear outside of the county or have recently moved to the county are registered as having no previous cervical smear.

Non-attendees

A number of studies have examined why women do not attend CCS. International studies have shown that there is low attendance rates in women who are older [17-18], single [17, 19, 20] have low levels of education [19, 21, 22], low socio-economic status [21, 22], and live in rural locations [21, 23]. Studies of CCS attendance and obstacles to attendance have frequently focused on specific racial/ethnic groups because of their observed higher cervical cancer mortality in association with lower CCS attendance rates. It has been suggested that lower attendance rates in screening are primarily associated with low socioeconomic status and interact with race/ethnicity [24]. Comparisons of studies concerning CCS should be considered with caution as sample sizes, selected groups and focuses differs. Large differences exist both between and

within countries in how CCS programs are designed, including factors such as time intervals, target ages and who should perform the examination [25]. Many studies on non-attendance are conducted in settings without an established, organised CCS. Studies of CCS programs also vary; some computerized databases cover organised but not the opportunistic CCS, while others cover both. Therefore, non-attendees are defined in different ways.

Only a few studies [23, 26, 27] have been conducted in Sweden concerning women's CCS attendance and non-attendance. Eaker (2001^a, 2001^b) [23, 26] investigated how attitudes and beliefs [26] about the cervical smear affected women's decisions to attend CCS, and why certain women did not attend [23]. Non-attendees were defined as women aged 30-59 years who had not had a cervical smear within the previous five years and women aged 25-29 years of age who had not had a cervical smear within the previous three years. Non-attendance was more likely among women who had not used oral contraceptives, who used condoms regularly, lived in rural/semi rural areas, had visited different gynaecologists, and/or had visited a physician very often or not at all. The women did not know what the recommended CCS intervals were. Low socioeconomic status was not associated with non-attendance, but non-attendance was more likely among women who did not consider cervical cancer to be as severe as other cancer forms [23]. The women did not perceive the benefits of the test, and obstacles were financial and that it was time consuming. Non-attendees maintained their preferences regarding attendance to a greater extent than attendees, and non-attendees reported that they would not attend CCS unless their preferences were met. Non-attendees were also less likely to attend in the future [26]. Another Swedish study investigated women's (aged 25-60 years) attendance in an organised CCS program. Young age, being single and not part of the labour force were associated with non-attendance. There were no differences in CCS attendance between immigrant women from developing countries and women born in Sweden [27].

We have found only one qualitative study [28] focusing on women's experiences of not attending CCS with a sample similar to that in this research project, i.e. with women invited to organised CCS with no cervical smear taken during the previous five years. In that study [28], some women considered the cervical smear to be inappropriate for them, as they had had a hysterectomy or gynaecologic problems, while others felt embarrassed or expressed feelings of fear or fatalism. Some women were dissatisfied with the location of the CCS.

The relationship between women's non-attendance at CCS and their experiences of discomfort in connection with gynaecologic examinations has been shown in several studies [17, 29]. In one investigation [30], the women believed that the procedure for taking the cervical smear would be embarrassing, painful and humiliating. Others have

studied women's experiences of gynaecologic examinations, and in one investigation [31] it was found that discomfort during the gynaecologic examination was related to young age, negative emotional contact with the examiner, dissatisfaction with present sexual life, a history of sexual abuse, and mental health problems. Wijma [32] showed that the experience of the first and the latest gynaecologic examination influenced women's attitudes toward subsequent gynaecologic examinations. Further knowledge concerning of the relationship between sexual abuse and non-attendance at CCS is limited. Farley [33] showed that women who have been sexually abused in childhood were less likely to have had a cervical smear. This may be explained by the risk these women run to have flash-backs of abusive experiences during a gynaecologic examination, which might be perceived as a new trauma [34].

Promoting cervical cancer screening

During recent decades a substantial amount of research has focused on strategies to improve rates of CCS attendance, including mass media campaigns, invitations, reminders, educational interventions, counselling face to face or by telephone, and economic incentives. A Cochrane review [35] of the literature has provided a broad overview of intervention research as reported in peer reviewed journals. The use of invitations (by letter or telephone) to support CCS was well documented and appeared to be an effective method to increase attendance rates. There was limited evidence to support the use of educational material, and it was unclear whether videos or face to face presentations were most effective. All studies concerned developed countries. Informed consent was not considered by any of the studies. Other researchers have suggested that individual contact might be a solution [28, 36, 37], especially for those who feel anxious about the gynaecologic examination [36] or who are highly resistant for other reasons.

Costs of promoting cervical cancer screening

Economic assessments of health care interventions are of growing importance. Most methods in health care such as screening and new treatments increase costs, and the question for decision-makers is whether or not the intervention is worth these extra costs. The purpose of health economic analysis includes comparing the costs of different methods in health care across a broad array of health programs, and showing how the costs for the efforts and the potential health gains are related to each other [38].

We have found only a few studies dealing with the costs of promotive efforts aimed at having non-attendees attend CCS. In the study by Lynch (2004) [39] the women were randomized into two groups; one group received a tailored motivational outreach (a

letter mailed to each woman and telephone calls), and one group received the usual intervention procedure (invitation letter). The inclusion criteria were women with no cervical smear for at least three years and no mammography screening for at least two years. For effectiveness, the authors calculated the percent of women who had taken part in both programs within 14 months from randomization. The results showed that this outreach intervention could increase participation in CCS and mammography screening in this population for relatively low costs [39]. In another study, Stein (2005) [40] compared the effectiveness and cost-effectiveness of three methods and a control group of inviting women with a long history of non-attendance (15 years) to undergo CCS. Neither a telephone call from a nurse nor a letter from a celebrity to encourage CCS attendance was effective or cost-effective. A letter from the local CCS program director resulted in a small, non-significant increase in attendance rates at a low cost.

THEORETICAL FRAMEWORK

Preventive medicine and health promotion

There are many different ways to improve human health. During recent decades there has been a shift in health enhancing activities from purely treating diseases towards preventing diseases and working with health promotion. The relation between medicine, prevention and health promotion have been confusing and complex [41, 42].

The medical perspective of health and disease has become the norm in Western society. Since the 1400s there has been a duality between the body and the mind. Religious authorities permitted studies in anatomy and physiology only if they focused on the biological processes, the mind and the psychological processes belonged to the sphere of religion. Introduction of the microscope in the 1700th century, enabling discovery of infections in early stages, was of importance regarding final acceptance of the medical definition of health as the absence of disease. Thereafter, disease was seen as a result of biochemical malfunctions. These changes were thought to generate symptoms and deficits which were diagnosed, and advice was given and treatments were prescribed. The patient was viewed as a recipient who must accept treatment and adhere to prescribed regimes [43].

Prevention or preventive activity was designed to protect against diseases and has traditionally been divided into three levels, primary, secondary and tertiary prevention. Primary prevention aims to reduce the incidence of injuries and diseases, for example via vaccination programs, and tertiary preventive activities aim to alleviate the effects of long-term disease and disability, for example rehabilitation. CCS belongs to the secondary preventive level, i.e. an intervention at an early or pre-symptomatic stage aimed at discontinuing further development of disease [42].

The starting point for health promotion was in 1974 when Marc Lalonde introduced the concept. His message was that traditional health care seemed to expend too much energy treating symptoms instead of taking care of their causes. The base for the health promotion perspective was an international conference on health promotion in Ottawa the Canada “Ottawa Charter for Health Promotion”, which took place in 1986, where health promotion was defined as the process of enabling people to increase control over, and to improve, their health [44]. This was done by supporting people in changing their lifestyles and moving towards optimal health, which could be facilitated through a combination of efforts to enhance awareness, including changing behaviour and creating supportive environments that emphasise good health practices. Health has been defined in terms of a sense of coherence, feelings of well-being, the experience of meaning and the ability to reach goals [42]. For example, Nordenfelt

(1998, p.6) [41] define health as “*A person is in a state of complete health if, and only if, this person is in a physical and mental state which is such that he or she is able to realize all his or her vital goals given a set of accepted circumstances*”. The purpose of health promotion is often described as increasing health, well-being and life quality [42]. Since the Ottawa conference, different approaches and definitions of health and health promotion have been developed. Tones (1998) [45] interpreted five core features from the Ottawa document, described here in a shorter version:

- health should be seen from a holistic viewpoint and have a positive meaning
- in health promotion, equity is a most important concern, and an attempt to move towards the achievement of health for all
- health is too essential to be left to medical professionals, so that medical services must be redefined and a wide range of public services must contribute to public health
- health is not an individual responsibility; social, cultural and economic environments contribute to the possibilities a person has to make healthy choices
- it is important for health policy to increase awareness of potential contributions of the general public, and empowerment is an important issue in health promotion work.

Medical services such as primary care and hospital care could contribute to public health by being accessible and meeting the real needs of the population. In doing so, the relations between health professionals and individuals should be based on empowerment, and on co-operation rather than compliance [45]. This is important as there has been strong criticism of the tendency to blame the “victims”, meaning those who do not follow recommended advice [45]. An important task for health promotion is to increase awareness of potential contributions on the part of individuals. Today health promotion is moving towards de-medicalisation and proclaiming the importance of empowering individuals.

The position of medicine in the area of health promotion has been problematic, as much of the literature on health promotion has developed in reaction to a traditional medical perspective on health [46]. Advocates of health promotion [47] have suggested that medicine should have authority over medical knowledge and knowledge aimed at disease prevention but increasing health and well-being should be the province of health promotion. However, the overall intention is for health promotion to cooperate based on a holistic view with traditional medical perspectives [48]. Opinions also differ about the relation between prevention and health promotion. Brubaker (1983) [42] stated in an analysis of the concept of health promotion that

health promotion and prevention were often used as synonyms, but asserted instead that prevention refers to disease, while promotion refers to health and well-being. With this classification, health promotion and prevention have different directions and goals. However, a positive result of health promotive efforts such as improved health could imply an initiative which in its nature is preventive.

Another way of viewing prevention and health promotion is that suggested by Nordenfelt (1998, p.11) [41], who presents a model (Figure 1) in which health enhancement can be divided into two different areas, health care and health promotion. The starting point for health care is a problem, and it is often initiated by the individual. On the other hand, health promotion is directed towards a large group of people, a collective, although it does not exclude cases of individual health promotion. In the model, prevention is one subgroup of health promotion. (For the content of the other subgroups, see Nordenfelt [41]). In addition, three definitions of medicine are proposed in the model that influence the direction of medicine.

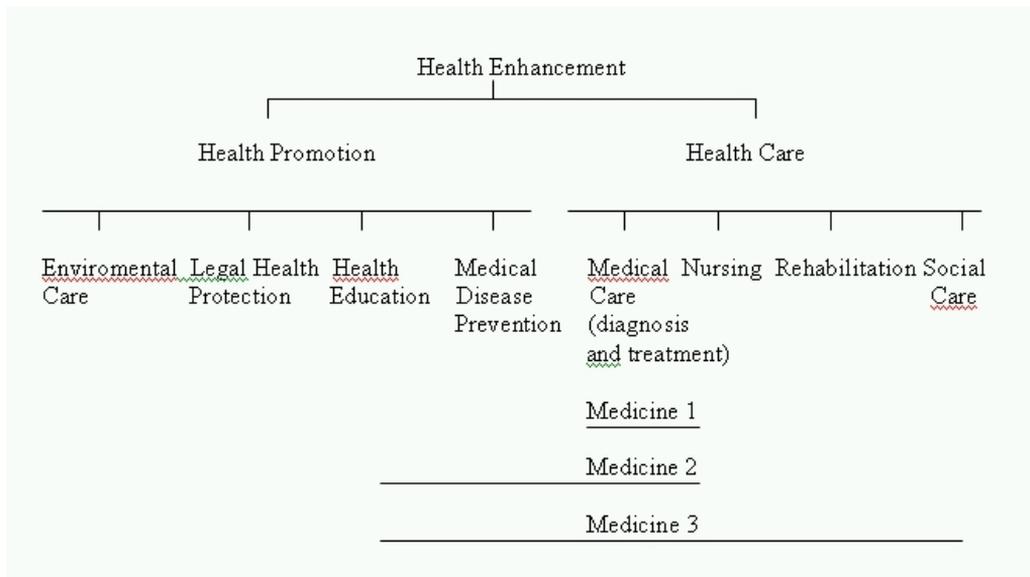


Figure 1. The field of enhancement and an expanded traditional notion of medicine. Modified from Nordenfelt [41]

Three definitions of medicine were proposed by Nordenfelt (1998, p.9-10) [41].

1. *"Medicine is the practice performed or monitored by trained physicians/psychiatrist in their professional activity of enhancing the health of a person by treating his or her diseases, injuries or defects or by reducing the consequences of the diseases, injuries or defects"*
2. *Medicine is the practice performed by trained physician/psychiatrist in their professional activity of enhancing the health of their patients*
3. *Medicine is the practice performed or supervised in the clinic by its physicians/psychiatrists and by its paramedical personnel in their professional activity of enhancing health."*

Using the first definition, medicine will only cover medical care. However, physicians have done much more than treating diseases, including educating and preventing diseases as described in the second definition. In third definition, medicine is not focused so much on the practice of physicians and psychiatrist; instead it is based on the clinic, and all its staff including nurses, physiotherapists, psychologists, laboratory personnel, who are involved in the clinical work aimed at health. Using Nordenfelt's model, preventive medicine has a close relationship to health promotion and empowerment, which is also an underlying assumption in this research project.

Empowerment

There is no general agreement on a definition of the concept of empowerment. Several have been proposed, and empowerment has been seen both as a process used to attain a certain goal and as an outcome [49, 50]. A distinction can be made between individual and community empowerment. Individual empowerment refers to the individual's ability to make decisions and have control over his or her personal life [49, 51]. This is something which is possible, but which might need to be promoted [52]. In this research project the focus is on individual empowerment, but community empowerment will also be described briefly as these concepts are related to each other.

Power is at the core of empowerment as it affects the relationship between people. In an old definition, power is described as "power-over"; one actor will be in a position to carry out his own will despite resistance from another individual [53]. However, in recent definitions of power the concept is described as "power-to", abilities to do or accomplish something by ourselves. Starhawk (1990) [54] further divided "power-to" into two different parts, "power-from-within", i.e. one's individual power as an inner energy, which might include self-knowledge, self-discipline, and self-esteem, and increase control over one's life; and "power-with", i.e. professionals initiate a discussion which will increase individuals' power-from-within rather than dominating

or exploiting them. A professional empowering relationship facilitate for individuals to identify their health requirements, solutions and actions to these solutions [49].

Individual empowerment is sometimes described as a part of community empowerment, but Wallerstein (1992) [55] argues that they are in interaction. Community empowerment is the process by which powerless people work together to increase control over events that determine their lives. Individuals are the start of a collective action, where people come together in order to address their concerns [49]. Rissel (1994) [50] stated that community empowerment also included a political action with some redistribution of resources or decision-making favourable to the community. The concept community has many definitions, but the majority include a place, and common ties such as interests, identities and/or social interaction. People who are motivated come together in small groups (communities) around issues they feel are important to their lives. In an empowered organisation, the members share information control over decisions and are involved in the design implementation and control of efforts towards certain goals defined by the community [49, 56].

Empowerment should strive to encourage people to believe in themselves and to believe that they have the knowledge [57-59] to make informed choices. Knowledge of various kinds is important for the individual's ability to feel good in society. A distinction can be made between "knowing that" (has to do with knowing facts about different matters) and "knowing how" (has to do with having practical skills that can be used). Increased knowledge includes consciousness raising, self-knowledge, etc. which enhance the individual's autonomy and self-esteem [57] and capacity to attain certain goals [57, 60]. This presumes that professionals are willing to understand the individual's world, are tolerant and non-judgemental and act as facilitators; that is they are themselves and are fully participating [51, 57]. Professionals have power, and individuals or groups who want power must work together to create conditions to make empowerment possible [52, 56, 58], as power cannot be given, it must be taken. An important element in empowerment is the relinquishing of professional power [50, 57]. This does not mean that the professionals are not actively helping individuals to achieve changes, but that the individuals are themselves responsible for their problems [49].

One challenge for health care professionals is to introduce the empowerment process in health promotive top-down programs. In a conventional top-down program such as the CCS program, health authorities define the target, develop strategies to reach the target and implement strategies. This is quite the opposite in bottom-up programs with an empowerment approach, where community members identify the problems that are important to them, and professionals support their strategies to resolve these issues [49]. Laverack (2004) [49] presents a framework that might help to change the

thinking from a simple bottom up/top-down dichotomy. He contends that top-down programs can be made more empowering by using participatory planning approaches in the general program design. Professionals should consider how the general program focuses attention on marginalized groups, i.e. those who are most in need but not able to meet their own needs. He suggests the need of building trust, and one way of doing that is through one-to-one counselling relationships. The inclusion of marginalized groups in existing programs is important for a clear understanding of what marginalization is and its relationship to powerlessness [49].

Individual empowerment has been introduced in relation to the gynaecologic examination situation by Wijma and Siwe [61, 62]. There is an increasing awareness among the involved of the imbalance of power during such examinations [62]. Professionals are thought to have a monopoly on medical knowledge concerning patients' bodies [63]. This may create encounters on unequal terms, where the patient is dependent on the examiner [49, 50]. The examiner must be aware of the unequal positions in the encounter and try to shift the balance from power-over to power-from-within; in other words to promote the women's control in the situation [62]. Power-with is used carefully to increase other people's inner strengths and integrity rather than to dominate them [49]. The examiner has a great opportunity to confirm the value of what the women expresses and to increase the woman's sense of mastery [62]. Experiments have shown that when women learn how a gynaecologic examination is performed, they report that the knowledge changes their position in the gynaecologic examination situation [62]. Such implementations of empowerment in the gynaecologic examination increase the power of all involved. This is a win-win kind of power, based on the idea that if any person or group gains, everyone else gains also [49].

Informed consent

Public health goals have focused on maximizing attendance at CCS, and the main aim of the information presented has been to call attention to the benefits, rather than also to mention the risks. This creates problems for professionals, as the goal of high attendance rates might undermine women's autonomy and result in obstacles in relation to their giving their informed consent [5]. In the International Code of Ethics for Midwives [64], it is stated that midwives should respect the woman's informed right of choice and promote the woman's acceptance of responsibility for the outcomes of her choices. In medical ethics, autonomy is one of the four corner stones, in addition to non-maleficence, beneficence and justice [65]. Respect for autonomy requires professionals to determine and ensure understanding of the information and to foster adequate, voluntary decision-making. Women's right to give informed consent about their attendance at CCS has recently become an important issue. A

condition for the achieving informed consent is that professionals give relevant information about risks and benefits. However, the kind of information required to attain informed consent is problematic. It is suggested that women must be informed about the following four things prior to the cervical smear [5]:

- an individual risk estimation; women need to know the particular risk of developing cervical cancer, whether the risk is near zero or relatively high [5, 66]
- what the test is like; women need to know what the procedure is for taking the cervical smear, but less attention should be given to technical aspects. Instead, professionals can spend more time responding to women's individual questions [5]
- accuracy of the test; appropriate information should be given about the precision of the test to avoid misunderstandings, for example false reassurance, i.e. the belief that CCS gives full protection [5, 67]
- what happens if the test is positive; from the women's point of view, information about the possibility of dysplasia is necessary [5].

There are advantages and disadvantages to more information about CCS both for professionals and the women. In some cases the women might have difficulties in processing the amount of medical information that is given. The "information-discussion" raises training needs for professionals so that appropriate information is given prior to the cervical smear procedure, and the costs must be taken into account regarding the time needed to explain CCS more fully to women. The most discussed disadvantages from the medical perspective is the risk of decreased uptakes [67]. However, such misgivings are not justified, as studies including women's informed consent in CCS are thus far limited.

The rationale of the study

The literature on non-attendance at CCS has been dominated by studies identifying demographic characteristics and attitudes. These studies have been undertaken from a medical perspective, i.e. on the basis that CCS is beneficial and high attendance rates should be achieved, as a relation between cervical cancer and non-attendance has been found. I argue that the understanding of why women chose not to attend CCS is not fully understood as long as the women's perspective is not included. Very few studies in the area have a qualitative approach and most of them have interviewed attendees and explored their view of CCS. Moreover, a lot of intervention studies have tested different methods in order to increase women's attendance in CCS. These studies are often designed from the perspective of health care providers and women's perspectives are often disregarded. As far as I know, no previous intervention study has implemented promotive efforts required by the women. Only a few studies have described the costs of motivating women who are highly resistant to CCS. An increased knowledge about the costs of promoting women to have a cervical smear and the potential health gains have to be related to one another in order to constitute a solid basis for future decisions. Therefore, the included studies in this thesis investigate non-attendance from women's perspective, investigate an implementation of an individualized intensive intervention from a health promotion perspective and cost-effectiveness from a health care perspective.

AIMS OF THE RESEARCH PROJECT

The overall aim was to investigate non-attendance in a cervical cancer screening program and the specific aims were to:

- describe reasons for non-attendance at cervical screening as described by non-attendees in Sweden (I)
- describe and interpret why women with no cervical smear taken during the previous five years choose not to attend a cervical cancer screening program (II)
- explore non-attending women's requirements for having a cervical smear taken and describe which promotive efforts were carried out in relation to these requests (III)
- assess whether providing women with personal promotive efforts increased their attendance in cervical cancer screening, compared to attendance reached by routines in an ordinary screening program (III)
- describe the cost-effectiveness of a resource-intensive intervention to promote attendance at cervical screening among women with no registered cervical smear during the previous five years (IV)
- discuss the results in study I-IV from a medical and health promotive perspective.

METHODS

This research project has used quantitative (I,III) and qualitative methods (II) and a cost-effectiveness analysis (IV). The triangulation of methods resulted in a complementary and enriched understanding of the aims of the research project. Investigator triangulations [68] were used to analyse and interpret data (II) and to bring divergent perspectives into the interpretation. An overview of methods and analyses is summarized in Table 1.

Table 1. Overview of participants, methods and analyses in paper I-IV.

	Participants	Methods	Analysis
Paper I	133 women	Structured questionnaire (by telephone interview)	Student's <i>t</i> -test Chi-square test Mann-Whitney <i>U</i> -test Logistic regression
Paper II	14 women	Face-to face interviews	Content analysis
Paper III	400 women in study group 400 women in control group	Structured questionnaire (by telephone interviews) Promotive efforts and outcome	Student's <i>t</i> -test Chi-square test
Paper IV	400 women in study group 400 women in control group	Cost and effectiveness	Cost-effectiveness analysis (CEA) Student's <i>t</i> -test Chi-square test Fisher's exact test

Pilot study

A pilot study was performed to find a suitable design for the research project that would achieve as high a participation rate as possible. The plan was to contact a number of women who had had no registered cervical smear taken during the previous four years and investigate how they believed that women in their same situation wished to be contacted. This was done for the purpose of answering questions about their non-attendance. Twenty-five women were selected at random from Sympathy. A letter including the aim of the pilot study and an inquiry as to whether the researcher was allowed to contact them by phone was sent to the women. If they agreed to be contacted, they were asked to return the enclosed pre-stamped yes-response note.

Only four women responded. When contacted by phone the four women stated their reasons for non-attendance, pregnancy (n=2), having had a cervical smear in another county (n=1), and one with language problems said she had never received an invitation to the CCS program (n=1). As a consequence of the low response rate, the researchers decided that a suitable design for the research project would include telephone interviews, extending the time interval for non-attendance to five years in order to exclude women who do not attend for “natural reasons” such as pregnancy and enclosing a no-response note instead of the yes-response note (a suggestion proposed by the Regional Ethics Committee for Human Research).

Sample

The inclusion criteria for the sample comprised women:

- living in Kalmar county, aged 28-65 years, with no registered cervical smear during the previous five years, January 2004 (I-IV)
- representing as great a variety as possible of reported reasons for non-attendance, and who were Swedish-speaking and willing to participate in a face-to-face interview with the researcher (II).

The exclusion criteria (I,II) comprised women who reported:

- having had a cervical smear taken outside the county during the previous five years
- having undergone total hysterectomy for reasons other than gynaecologic cancer
- non-attendance due to pregnancy or being newly delivered
- never having had sexual intercourse
- being unable to understand and answer the questionnaire.

Since women to whom the exclusion criteria applied could not be excluded before randomization, the women’s answers on the response notes and in the telephone interviews were used to determine if they met the inclusion or exclusion criteria.

Among all 56 644 women (aged 28-65 years) in Kalmar county in January 2004, a total of 6565 (11.6%) had no cervical smear registered in Sympathy during the previous five years. From this population, two random samples were selected: 400 women to serve as a study group (III,IV) and another 400 women to serve as a control group (III,IV). The study group and the control group were compared regarding two available variables: age and cervical smear history. The comparison showed no differences in age ($p=0.111$) and both groups had exactly the same cervical smear history. Background characteristic of the two groups are shown in Table 2.

Table 2. Background characteristics of the two random samples (III,IV).

	Study group (n=400)	Control group (n=400)	P value
<i>Age, m (SD)</i>	46.9 (11.3)	45.5 (11.4)	NS ^a
<i>Age groups</i>	n (%)	n (%)	NS ^b
28-49	231 (58)	245 (61)	
50-65	169 (42)	155 (39)	
<i>Cervical smear history</i>			NS ^b
No cervical smear during the previous ten years	257 (64)	257 (64)	
At least one cervical smear during the previous ten years	143 (36)	143 (36)	

^aStudent's *t*-test

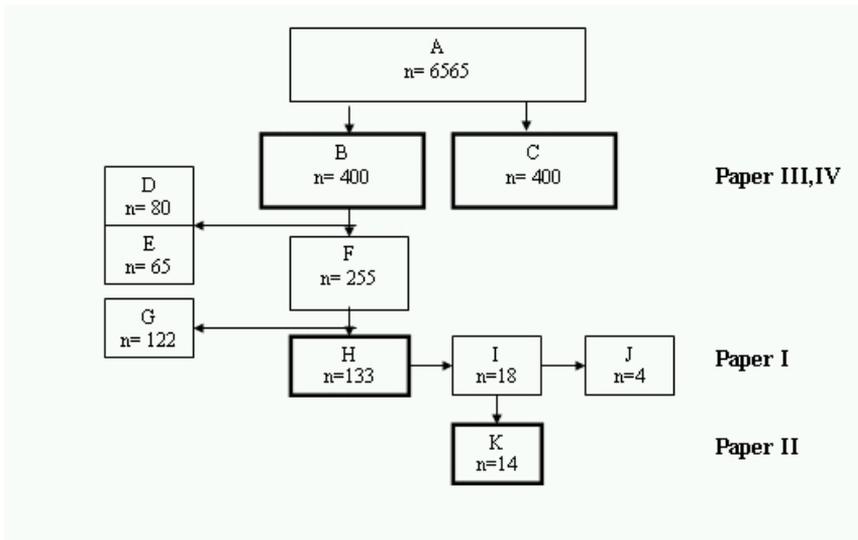
^bChi-square test

From the study group, women were recruited to participate in a telephone interview (I): 255 women were eligible, 122 declined participation and thus, 133 women participated. The final response-rate was 52%. The background characteristics of these women (n=133) are described in Table 3. Respondents and non-respondents were compared regarding two available variables: age and cervical smear history. The comparison showed no differences in age ($p=0.55$), but there were differences in cervical smear history ($p=0.002$). Twenty non-respondents gave reasons for non-attendance by letter or phone that were similar to those of the respondents. Of the participating women in study I, 14 women were purposefully chosen to participate in study II. The total sampling procedure is shown in detail in Figure 2.

Table 3. Background characteristics of women in study I.

	Women (n=133) n (%)
<i>Age</i>	
28-49	75 (56)
50-65	58 (44)
<i>Education</i>	
Primary school	35 (26)
Secondary school	58 (44)
College/university	40 (30)
<i>Civil status</i>	
Living with partner	77 (58)
Single	56 (42)
<i>Parity</i>	
Nulliparous	27 (20)
Parous	106 (80)
<i>Smoker</i>	
Yes	51 (38)
No	82 (62)
<i>Cervical smear history</i>	
	n=121*
No cervical smear during the previous 10 years	59 (49)
At least one cervical smear during the previous 10 years	62 (51)

*Women aged 28-32 years were excluded.



- A Women with no registered cervical smear during the previous five years
- B Study group
- C Control group
- D Excluded based on exclusion criteria
- E Not reachable, missing phone number and/or address, never answered the researcher's calls
- F Eligible women
- G Declined participation in letter or during phone contact
- H Respondents
- I Interested in participating in a face-to-face interview
- J Declined participation or did not keep appointment with researcher for face-to-face interview
- K Informants

Figure 2. The sampling procedure of the four samples in the research project.

Data collections and procedures

Questionnaire (I,III)

The Cervical Screening Questionnaire (CSQ) was constructed by the research team, as no existing questionnaire was adequate for the aims of this research project. The CQS was developed over time based on personal clinical knowledge, literature reviews and by scrutinising existing instruments and questionnaires in similar studies [17, 29, 32, 36, 69]. A group of staff members involved in the CCS program (midwives, obstetricians, enrolled nurses) affirmed the content validity. The first completed version of the questionnaire was tested for its user-friendliness in two groups: one group was a convenient sample of women (n=15) of various ages and the other was a pilot group of 20 randomly selected non-attendees. The tests resulted in minor adjustments.

The CSQ includes 36 questions. Part I includes seven background questions, part II includes five questions aimed at excluding women based on the exclusion criteria. Part III contains twelve questions related to the women's reasons for choosing not to attend CCS and three questions related to the women's experiences of a gynaecologic examination (I). Part IV contains four questions about the possibility of future attendance at CCS (III). Part V contains three questions about sexual abuse (I). Finally, two questions explore the women's experiences of answering the questionnaire and if they have anything to add. The response alternatives are "Yes" or "No", except for four questions which are open-ended. If a woman had experienced sexual abuse, she was asked to estimate how much she currently suffered from the abusive experience on a 7-point scale [70]. The same technique was used to estimate how the women had experienced their latest gynaecologic examination. The questionnaire is described in more detail in papers I and III and is shown in the appendix.

The women received a letter with written information about the aims of the study and the procedure and saying that the researcher would phone them within 14 days. They were informed that participation was voluntary and that they were fully entitled to withdraw without giving any explanation [71]. A no-response-note and a pre-stamped and addressed envelope were enclosed, which were to be returned within five days if the woman did not wish the researcher to phone her. The response note also included the possibility of requesting an interpreter if a non-Swedish speaking woman decided to participate, as well as space for comments. Women with no available phone numbers had the possibility of including a number where they could be reached. The researcher contacted the women by telephone 10-14 days after information was sent, and asked if they were interested in participating in the telephone interview. If they were, the researcher gave additional verbal information. After agreeing to participate appointments were scheduled for a telephone interviews at times convenient for each

woman. The first author performed the telephone interviews, and consecutively asked the questions in the CSQ. The time required to answer the CSQ was 5-15 minutes, although the telephone conversations sometimes lasted up to 45 minutes.

Interviews (II)

At the telephone-interview, a purposively selected group of women were asked a final question “Do you want to participate in a face-to-face interview at a later date?” (II). An information letter was then sent to those who were interested. Later, the researcher phoned the women and gave further information, and appointments were scheduled for interviews at a place convenient to the women. The interviews were carried out as dialogues [72]. The researcher encouraged the interviewees to talk as freely as possible about the reasons for non-attendance. Interviewees were also asked to relate their experiences of CCS and gynaecologic examinations. By repeating and clarifying the women’s stories, potential misunderstandings could be avoided. When clarification was necessary, the interviewer asked questions such as “Can you tell me more about that?” or “What did you feel then?” [73]. The interviews lasted between 20 and 90 minutes and were performed at the researcher’s workplace (n=2), at the women’s primary health care unit (n=6), at the women’s home (n=5), or workplace (n=1). All interviews were tape-recorded and transcribed verbatim.

Requirements/Promotive efforts/Outcome (III)

Women who would consider having a cervical smear taken told different kinds of requirements and an extended dialogue between the researcher and the women often took place at the end of the telephone interviews. The dialogue focused the women’s thoughts and preferences to make a CCS possible. During the conversation, the researcher supported the women to make her own decisions bringing forth the importance of informed consent. Both the women and the researcher contributed suggestions and agreed how to proceed, i.e. how the required efforts should be arranged, either at this telephone conversation or at later telephone calls or physical meetings. When these requirements were met, they were considered as promotive efforts. Each promotive effort was carried out by the researcher, only in relation to the women’s requirements. The outcomes, i.e. registered cervical smears at follow-up were manually obtained from Sympathy. The follow-up was done one year after the latest contact with the researcher (study group) or after randomization (control group).

Costs and effectiveness (IV)

Data included all costs for the intervention. The intervention was defined as every contact/effort (or group of efforts) intended to promote attendance at CCS. In the study group, the measurements of costs included time to identify the women, time to create a system to manage the flow of women through the process, invitations, and promotive efforts, i.e. arrangements in health care, and arrangements by the researcher

for taking a cervical smear. In the control group, costs for taking a cervical smear in an ordinary CCS program were measured. Costs were calculated in Euro, (January 2004, 9.02 SEK=1 €). The effectiveness, i.e. the difference between the study group and the control group due to women with registered cervical smears at follow-up was calculated in study III.

The total data collection period lasted from January 2004 to December 2005.

Data analyses

The choice of statistical analyses was based on the level of data. For continuous data, parametric tests were used, while ordinal and nominal data were analysed with non-parametric tests (I,III,IV) [74]. Age was treated as continuous data. Age group, civil status, education, smoking and CCS history were treated as nominal data. From Sympathy, the CCS history for each woman was identified, and the women were accordingly divided into two subgroups; having no cervical smear, or having at least one cervical smear taken during the previous ten years (I,III,IV). Experiences of the latest gynaecologic examination were treated as ordinal data. The SPSS package 14.0 and Minitab 13 were used for the data analysis (I,III,IV). P-values <0.05 were considered statistically significant.

Statistical analysis (I,III)

Logistic regression was used to investigate the relationship between age and choosing “non-attendance due to experiences of discomfort associated with the gynaecologic examination” (I). The Mann-Whitney test was used to investigate the differences in self-rated “experiences of the latest gynaecologic examination” between “women who choose non-attendance due to discomfort associated with the gynaecologic examination” and “women with other reasons” (I). The Chi-square test was used to investigate if women with a history of sexual abuse choose “non-attendance due to experiences of discomfort associated with gynaecologic examinations” to a greater extent than women who reported other reasons for their non-attendance (I).

The outcomes in the study group and the control group were compared using the Chi-square test (III). The women in the study group were divided into two subgroups, women who had a registered cervical smear at follow-up and women who did not. These two groups were compared regarding background variables, age and cervical smear history (III). Student’s *t*-test was used to investigate differences in mean age, and the Chi-Square test was used to investigate differences in cervical smear history (III). The CINIII cases were summarized in the study and the control group and compared with the corresponding information about all registered cervical smears in Kalmar

County during 2004, using Fisher's exact test (IV). Fisher's exact test is used for nominal data with small expected frequencies [74].

Content analysis (II)

An inductive content analysis was performed to interpret the interview text (II) [75]. The analysis started with a naive reading i.e. the text was read through several times to get a first understanding. Then the text was divided into meaning units i.e. sentences or paragraphs related by meaning. The meaning units were then condensed and coded. The various codes were reflected on in terms of similarities and differences, and thereafter sorted into sub-themes and themes.

Cost-effectiveness analysis (IV)

Incremental cost-effectiveness was calculated by dividing the differences in costs for the study group and control group by the differences in effectiveness i.e. in the number of women with a registered cervical smear in the two different groups. This calculation yields the cost per additional registered cervical smear [38] (IV).

Ethical considerations

In this research project we asked ourselves if we had arguments for contacting a group of women who had not taken part in the CCS program as there is a fine line between violating women's autonomy and searching for more knowledge in this area.

Necessary steps were therefore taken to design a research project in which women's autonomy was respected. As the intention was to establish telephone contact with the women, an information letter asking for permission to call was sent. The information letter included the aim of the study and that participation was voluntary, but also an opportunity to decline participation [71] through a no-response note. A group of women declined participation using the no-response note (n=89), but some of the women declined participation by phone (n=33), and the majority of them initiated a discussion and had questions about CCS. They were not asked again if they would participate in the study, as they had started the conversation by declining to do so. All of the participating women appreciated the fact that someone cared and that their questions could be answered.

Historically, informed consent has not been sought for women's attendance in CCS but it is currently a major issue in CCS. In this study, women were made aware of both the risks and benefits involved in CCS before agreeing to have a cervical smear taken. This view distinguishes our study from conventional intervention studies. The women had to be active in the decisions, rather than being passive attendees. We took the approach of promoting attendance at CCS and offering help to women who were interested in having a cervical smear taken, rather than with the aim of increasing the

attendance rate at CCS. Arrangements for psychological help were made as some questions were of an intimate nature, and the women were referred to gynaecologists when medical questions arose. The women were assured of confidentiality. Collected data and personal data were kept separately in a safe place. The Regional Ethics Committee for Human Research, Faculty of Health Sciences, Linköping University, Sweden, approved the study (Dnr 03-248).

RESULTS

Reasons for non-attendance

A majority of the women had a positive attitude toward CCS in general. The women believed CCS was a good idea for all other women, but tended to report several circumstances and justifications regarding their own non-attendance (II). The women knew they ought to have a cervical smear taken, but their personal resistance was greater than their wish to attend (III). Some women had made an active decision not to attend (II,III). However, the decision not to attend CCS was not always an active decision. Instead women sometimes considered attending but then pushed the decision aside until after the appointment time had passed (II).

Feeling Healthy

One of the most common reasons for non-attendance was the women's feeling of being healthy (55%) (I). These women stated that they did not need to attend as they had no symptoms and there was no indication of disease in their body. Preventive health check-ups were not a sufficient reason for health care visits. Instead, reasons such as symptoms and gynaecologic check-ups in connection with pregnancy or contraceptives were more natural reasons. In cases where there were physical problems, the women said they would contact a physician. When they were younger they had had several health check-ups and everything had been normal. This had created a sense of security for them (II). Women described attendance at CCS as something that could even threaten health. They expressed that attendance at CCS was not worth it because it could cause anxiety, and anxiety was not healthy (II). Several of the women emphasised the benefits of a holistic view of their body and that treating only a small part of it could disturb the capability of the body as a whole (II). Absence of a history of gynaecologic cancer or other kinds of cancer in previous generations was often referred to as a factor that decreased their risk of cancer (II).

Prioritizing more important things in life

The women prioritized family and work commitments (I,II), and the invitation to attend CCS was sometimes experienced as a stressful disturbance. Time for personal health and check-ups had low priority in their busy schedules (II) and one of the requirements for having a cervical smear taken was to be offered a suitable time (III). However, even if they reported lack of time as their reason for non-attendance (23%) (I), they added that lack of time was a convenient excuse in order to avoid something unpleasant (II). The women who suffered from serious diseases demanding repeated health care visits reported that they could not manage even more visits to health care by taking part in CCS (I). The actual cost of having a cervical smear taken was not a common reason for the women not to attend CCS (8%) (I), but the costs for

transportation and time off from work were sometimes reported as influencing their ability to afford CCS (II).

Feelings of discomfort

Feelings of discomfort could be divided into two categories. One comprised feelings of being treated badly by health care professionals. The other was focused on personal feelings of discomfort. The women reported feelings of discomfort when seeking health care in general (23%) (I). In the qualitative study (II), they presented a more complex picture of their experiences of earlier negative encounters with health care and they described how they had tried to avoid not only gynaecologic examinations, but also health care visits in general. Several of the women related experiences where they had consulted health care but had not received the help they wanted. Instead, they experienced that they had been ignored or not taken seriously, which resulted in sometimes choosing alternative medicine (II).

The women also related feelings of discomfort about their non-attendance in relation to themselves. In their stories the women implicitly or explicitly expressed fear about the outcome of the CCS (II). In one way, they argued, it was better to remain ignorant, without knowledge, and not attend CCS. In this way one stressful situation in life could be avoided. Few (5%) of the women chose the response “dissatisfaction with my body” as a reason for non-attendance (I). Yet in the face-to-face interviews they related how poor body image and low self-esteem influenced their decision not to attend CCS. The low self-esteem was a result of being treated badly, i.e. being physically and psychologically abused by those closest to them during their childhood (II). Some women over the age of 50 had been taught to hide their naked body and had felt discomfort in exposing their most private body parts during gynaecologic examinations. They were confident about their decision not to attend CCS and reported not needing to go for gynaecologic examinations, as they were no longer of reproductive age (II).

“I feel discomfort about being confronted with gynaecologic examination” was chosen by 29% of the women as the reason for non-attendance (I). Earlier negative experiences of gynaecologic examinations in connection with childbirth, contraception or gynaecologic check-ups influenced the women’s decisions not to attend CCS. Most previous gynaecologic examinations were evaluated as positive, but the experience of one single frightful examination made them afraid that this situation could be repeated (II). Women who reported non-attendance due to discomfort associated with the gynaecologic examination, gave higher ratings to feelings of discomfort during their latest gynaecologic examination than those who stated other reasons ($p < 0.001$) (I). No relationship was found between age and “non-attendance due to experiences of

discomfort associated with the gynaecologic examinations” (OR=0.99, 95% CI=0.96-1.03, p=0.521) (I).

Among the 22 women who reported a history of sexual abuse, the most common reason for their non-attendance was “non-attendance due to experiences of discomfort associated with gynaecologic examinations” (n=7). However, women with a history of sexual abuse did not choose this reason to a greater extent than women who reported other reasons for their non-attendance (p=0.785) (I).

Requirements and promotive efforts

Of the 133 women who answered the telephone survey, 120 could consider having a cervical smear taken if their requirements were met. The two most common requirements related by the women were to be assured they would be treated in a friendly way (19%) and to find a suitable time for having the cervical smear (18%) (III). They described friendly treatment as being met with respect by the examiner, being treated as a human being, being able to establish some form of contact with the examiner, having an opportunity to express their fears or concerns about the examination and that the gynaecologic examination should be carried out in a careful way. This kind of treatment was an absolute requirement, as the examination was considered to place the women in a vulnerable situation. Other requirements included a particular examiner (e.g. female, known/unknown examiner) (9%), having a cervical smear taken at a specific locale (e.g. near home or work) (8%), and/or having a cervical smear taken at a lower cost/free of charge (5%). Many women (41%) had difficulties talking about their requirements, i.e. they could not point out anything in particular or they needed more time to think it over (III).

Fifty women wanted help to have a cervical smear taken (III). Promotive efforts ranged from making a simple telephone call to arranging an appointment time, to a more complicated combination of such efforts, such as arranging repeated meetings in order to create a trusting relationship. In addition to 623 attempts and phone calls to reach the women, 272 phone calls were made to arrange CCS for those 50 women who wanted help. The promotive efforts carried out are described in Table 4.

Table 4. Promotive efforts carried out for women who wanted help in making arrangements to have a cervical smear taken (n=50) (III).

Promotive efforts	Number of efforts
Arranging appointment times of 30 minutes or more	50
Contacting female examiner	25
Establishing personal contact with an examiner who was expected to correspond to the women's wish to be assured of friendly treatment/known examiner	25
Arranging appropriate appointment times	23
Creating dialog and practical arrangements during the cervical smear procedure	8
Finding a suitable locale/providing access to a locale in home district	8
Referral to gynaecologist/department of clinical sexology	3
Arranging drop-in times	2
Reducing time gap between invitation, cervical smear procedure and result	2
Helping with transportation	2
Organising appointments free of charge	2

Outcome and cost-effectiveness

In the study group, 29.5% (n=118) had a registered cervical smear at follow-up compared to 18.5% (n=74) in the control group ($p < 0.001$) (III). There was a difference in women's willingness to have a cervical smear taken and their actual attendance. Of the women who could consider having a cervical smear taken (n=120), 42.5% had a registered cervical smear at follow-up. When studying the outcome in different subgroups, the actual attendance was highest in the group of women who asked for help in having a cervical smear taken (70%). In addition, women who declined participation (n=122), were excluded (n=80), or were not reachable (n=65) also had registered cervical smears at follow-up. The outcome in different subgroups is described in Table 5 (III). In the study group, the cost per cervical smear taken was 66.87 € (603 SEK) and in the control group it was 16.63 € (150 SEK). Table 6 shows the summarized costs of the resource intensive interventions. The cost per additional registered cervical smear taken was 151.36 € (1365 SEK) (IV). For details see Table 7. In the study group, there were significant differences in age ($p = 0.004$) and cervical smear history between those who actually had a registered cervical smear at follow-up and those who did not ($p = 0.001$) (Table 8).

An additional finding was the difference regarding the number of women with CINIII between all “non-attending” women (n=800) who had a registered cervical smear at follow-up and “attendees” in Kalmar County (p=0.025) (IV).

Table 5. The outcome of registered cervical smears at follow-up divided in five subgroups (III).

Sub-groups	Could not consider having a cervical smear taken n= 13 (%)	Could consider to have a cervical smear taken n=120 (%)	Excluded n=80 (%)	Not reachable n=65 (%)	Declined participation n=122 (%)
Outcome	1 (7.7)	51 (42.5)	32 (40.0)	12 (18.5)	22 (18.0)

Table 6. Costs for reaching the women and having a cervical smear taken (IV).

Type of cost	Study group € (SEK)	Control group € (SEK)
Identifying women in register, administration	1421.72 (12 824)	
Telephone calls	2745.51 (24 765)	
Cervical smear in ordinary CCS program	1380.29 (12 450)	1230.62 (11 100)
Help with arrangements to have a cervical smear taken	2343.15 (21 135)	
Total costs	7890.67 (71 174)	1230.62 (11 100)

Table 7. Incremental cost per additional women with a registered cervical smear (IV).

	Study group (n=400)	Control group (n=400)	Differences
Number of women with registered cervical smear at follow-up	118	74	44
Total costs (€)	7890.67	1230.62	6660.05
Incremental cost per additional women with a registered cervical smear (€)			151.36

Table 8. Background characteristics of study group divided according to whether or not there was a registered cervical smear at follow-up (III).

	Had a registered cervical smear at follow-up (n=118)	Had no registered cervical smear at follow-up (n=282)	P value
<i>Age, m (SD)</i>	44.4 (11.19)	48.0 (11.26)	0.004 ^a
<i>Cervical smear history</i>	n (%)	n (%)	0.001 ^b
No cervical smear during the previous ten years	62 (52.5)	196 (69.5)	
At least one cervical smear during the previous ten years	56 (47.5)	86 (30.5)	

^a Student's *t*-test

^b Chi-square test

DISCUSSION

The results showed that women's non-attendance at CCS was influenced by present and previous circumstances as well as intra- and inter-personal circumstances. The most common reasons for non-attendance were feeling healthy, lack of time, and feelings of discomfort associated with the gynaecologic examination. When the women's requirements were met, the number of registered cervical smears was higher for the study group than for the control group, and the cost per additional registered cervical smear was calculated at 151.36 €. These results could be considered from different perspectives, but in this discussion I will reflect on two views of the CCS program: the medical view, i.e. the CCS program is a preventive intervention in order to hinder further development of disease at an early, asymptomatic stage [42], and the health promotive view, i.e. the CCS program is based on a holistic view of health and promotes the individual's own capacity and decision-making capabilities. Irrespective of which view is adopted, there will be an impact on the "non-attending" women.

In the 1960s CCS was introduced as a national service with the aim of detecting pre-cancerous changes [15]. The program was designed from a medical perspective at a time when health care dealt mainly with curing of diseases. However, health care has evolved in recent decades and today there are a multitude of health care centres comprising a variety of professions involved not only with curing diseases, but also with rehabilitation and general health promotion. Health promotion activities are also the agenda at a governmental level [41]. These developments give rise to the question as to whether the CCS program should be seen merely as a disease preventive program, or as a health promotive program including disease prevention. From a medical perspective CCS has until recently included goals such as reaching high attendance rates, which have been related to a decreased incidence of cervical cancer. However, when high coverage has been attained, there is a fine line between efforts to further increase the attendance rate in CCS and the risk of violating the autonomy of the women (III).

Women generally agree that they ought to attend CCS [6], and this was confirmed in the present research project, as a majority of the women interviewed by phone seemed to appreciate my contacting them and that they had the possibility to relate their reasons in order to justify their non-attendance (III). The women who chose not to attend CCS had a view of the concept of health and of CCS that differed from the medical perspective (II). Women's statements such as "I do not attend CCS as I feel healthy" (I), and "I do not need to go because I feel healthy" (II) could be interpreted as women's failure to understand the purpose of CCS. From a medical perspective, non-attendees have sometimes been described as irresponsible, irrational and not knowing what is best for them [6, 76, 77]. This argument is contradictory to the results

in this research project. Further, the women had not fully accepted the medical definition of “health” (II). It is interesting to note that the women related “being healthy” to a subjective feeling of well-being, and required health care professionals to have a more holistic view of the body (II). CCS could even threaten the women’s health and cause anxiety (II) and discomfort (I,II). The women had prioritized their family and work in order to attain well-being (II) and not attending CCS therefore seems to be an appropriate decision. This argument also seems rational from a health promotive perspective.

Rapid developments in medical technology have made it possible to detect pre-stages and stages of diseases on a cellular level. This gives rise to the question of how to classify those who are healthy and those who are sick. The fact that CCS searches for abnormalities within a seemingly normal population, may have some disadvantages [7]. The results from the cervical smear can range from normal test results to the discovery of cell abnormalities and precancerous cells [6]. That they are not confirmed as being either healthy or sick could be confusing for the women. Few individuals can be defined as not being at risk when concepts such as abnormality and risk factors are introduced [78]. This means that the individual must enter into a process of endless preventive examinations in order not to be a burden to society [6].

It has been suggested from both a medical perspective [4] and a health promotion perspective [49] that professionals should consider how general programs focus attention on marginalized groups, i.e. those who are most in need, but are unable to meet their own needs, often as a result of limited access to resources or a social network [49]. However, there is a fine line between informing and empowering women to attend a program such as CCS and blaming women for their decision not to attend. Based on the results of this research project, I suggest that future incorporation of health promotion assumptions could improve women’s possibilities to make individual decision about whether or not to have a cervical smear taken. This can be accomplished by active discussions on an equal, collaborative basis between women and health care professionals with respect to the CCS program as well as other health care areas. This is in line with the intentions of the WHO principles concerning health promotion, which state that the relationship between health service and individuals should be based on empowerment and co-operation, rather than on compliance [45].

Up until now there have been two ways to increase women’s attendance at CCS, either emphasising the benefits of the CCS or emphasizing the risks. Certainly, the positive effects of CCS have to be emphasised, but by giving prominence to benefits, women may get unrealistic expectations regarding CCS. For example, they might believe that CCS provides full protection against all kinds of different gynaecologic problems [67]. This was shown in a study from the UK [79], where women overestimated the current

incidence of cervical cancer and the efficacy of CCS. Risk calculation of getting cervical cancer is different if based on non-attendees or based on women with diagnose of cervical cancer. For example, in a study investigating women diagnosed with cervical cancer, an 11-fold increased risk of being diagnosed with invasive cancer among non-attendees compared to attendees was shown. The authors concluded that these findings could be used to motivate women to attend CCS [80]. However, if these results are used in order to motivate women to attend CCS, it could unnecessarily cause women anxiety.

Classifying non-attendees as a homogenous group and as “high risk” patients is not fully congruent with the findings in this research project, and I argue for viewing the woman as a subject and discussing her own particular risk of developing cervical cancer. For example, non-attendees in this research project included women with near zero risk of cervical cancer, such as middle-age women with many earlier normal cervical smears (III). On the other hand, some women seemed to have a higher risk since they had had earlier abnormal cervical smears. In a study from Värmland, a county in Sweden [81] with 90% coverage, the attendance at CCS of all women (n=112) diagnosed with cervical cancer was studied. Of the studied women 68% had a cervical smear less than three years before the invasive cancer, 18% had no cervical smear taken and 46% had had atypical cervical smears which had regressed or had been treated. If efforts are to be made to reach high risk women, my suggestion is that most efforts should be focused on contacting non-attending women with earlier atypical or abnormal cervical smears.

The women had two simple requirements: a suitable time and friendly treatment (III). When women do not attend an organised CCS program, health care professionals sometimes ask, ”How can we make them come at the appointment times we offer?”, instead of asking “How can we change the CCS program in order to suit the women of today?” I suggest a more flexible service with opportunities to choose the locale/examiner, and introduction of drop-in times and evening appointments. Women should have the option of changing appointment times over the Internet and greater possibilities to come in contact with CCS professionals in order to discuss individual problems.

Friendly treatment was one condition many women demanded in order for them to have a cervical smear taken (III). This is in line with Crane (1998) [82] who stated that personal contact between health care professionals and individuals is especially important in populations that underutilize health care resources. Other authors [31, 83] have emphasised the importance of a good relationship between the examiner and the woman when a gynaecologic examination is to be performed. Attendees at CCS have mentioned examiners in terms of my “own” gynaecologist or my “own” midwife

[84], and physicians have described the special relationship between them and their “own” patients [76]. In order to offer all women the possibility of having a cervical smear taken, the CCS program has to be organised in an effective way at low costs. However, an effective organisation does not have to exclude friendly treatment. Nevertheless, some women do not fit into this system, and must be offered extra time and assurance of friendly treatment (III).

The significant differences in outcome between the study group and the control group (III) could be interpreted as a successful outcome of the intervention. However, despite personal contacts and resource-intensive arrangements, a majority of the women who could consider having a cervical smear taken never had a registered cervical smear at follow-up. This indicates the difference between women’s verbally expressed willingness to have a cervical smear taken and their actual attendance (III). On the one hand, this might be due to the complexity of the reasons for non attendance (II), and/or that the promotive efforts carried out were insufficient. On the other hand, it could be due to the fact that the CCS program is designed from a top-down program perspective. Health authorities have defined the problem as “had no cervical smear taken”. When other people define “the problem” for a person and the necessary step to solve the problem, this sidesteps the empowerment process [49], which is a corner stone in health promotion. For some of the women, “having no cervical smear taken” may have been unimportant. When women had a combination of reasons, such as other serious diseases (I), low self-esteem (II) and negative body-image (II), their willingness to have a cervical smear seemed to be overcome by the obstacles. The extra costs involved in reaching, inviting and to meeting women’s requirements for having a cervical smear taken (IV) might be better used when women themselves search for help. If health care comprised more activities that supported holistic health, attendance at CCS might be a positive side-effect. This is in line with Medin [42] who stated that if health were defined as a physical and mental state enabling the individual to realise all his or her vital goals, this could lead to initiatives from the individual to take preventive actions.

There is overwhelming evidence that CCS saves lives [3]. The proportion of women with CINIII was significantly higher among the non-attending than the attending women (IV). Although, the numbers of women with CINIII in the control group and the study group were small, the results were in line with studies [85, 86] showing that non-attendees are at higher risk for developing cervical cancer. It should be emphasised that a large number of women have to be screened in relation to the incidence of cervical cancer [87]. Further, in this research project resource intensive efforts were carried out at high costs, which facilitated having a cervical smear taken for these women (118/400) (III). And yet the most highly resistant women still did not attend. It can be questioned if increasing attendance rates at high costs is justified. It is

probably neither profitable nor practical to introduce such resource intensive efforts in health care. Instead, improved and increased accessibility to CCS might be more cost-effective (III).

METHODOLOGICAL CONSIDERATIONS

Qualitative and quantitative approaches constitute alternative ways of viewing and interpreting science [68]. The use of triangulation is advantageous in that it is an integrated approach that can lead to enhanced theoretical insight into the multidimensional nature of reality that might otherwise be unattainable. The training of most researchers concentrates on quantitative or qualitative research methods, and the researcher's limited skills may be an obstacle to the use of different methods [68]. However, in this research project this weakness is overcome by the varied experiences of different researchers. This kind of collaboration provides opportunities for triangulation regarding methods and analyses [68].

Study I

Previous studies have shown that it is difficult to reach women who choose not to attend CCS using traditional postal questionnaires [30, 88]. Therefore, a pilot study was performed to find a design for the research project with as high a participation rate as possible, and this resulted in the choice of telephone interviews. The response rate of 52% might be considered low, but also as "the best possible", even if not fully satisfactory (I). It is probably neither possible nor ethically correct to try to achieve higher participation rates considering the characteristics of the target group. Consequently, the present findings should be generalised with caution. The dropout analysis showed that non-respondents had had no cervical smear taken the previous ten years, making it probable that women who had given up CCS many years ago are those women who are most difficult to reach. Among the non-respondents (n=122), 20 women reported reasons for non-attendance and their reasons were similar to those of the respondents. It can be assumed that there was a group of women among the non-respondents with reasons for not attending CCS that are comprised in the exclusion criteria of study I. In the study group, women were excluded based on self-reports, as it was impossible to gather such information by other means such as with Sympathy. This must be considered when interpreting the results.

The CSQ is a structured interview formula and except for content validity no further psychometric tests could be performed. The internal dropout was low. Only four questions were unanswered. Two women were unable to assess the experiences of their latest gynaecologic examination. One woman did not want to answer the question about sexual abuse and one woman preferred not to indicate whether she chose not to attend CCS due to dissatisfaction with her body. The low number of dropouts might be a result of the study design using telephone interviews, which have an advantage over postal questionnaire in that individuals who can not fill in questionnaires can get help, and the interviewer can determine whether questions have been misunderstood and provide clarification [68, 89].

Study II

To reach a deeper understanding of the women's reasons for non-attendance, face-to-face interviews were performed with 14 women. The interviews were conversational [72] and a trusting relationship was established, which is a prerequisite for a good interview [73] and for credibility [68, 90, 91]. The interviewer is the main tool in the data collection, and the background, personality and competence of the interviewer affect the results. Therefore it was important to carry out the interviews without imposing any of my own views [72] and to verify the findings in the data in order to reach confirmability [68, 90, 91]. We analysed data to determine common patterns which were then described in themes [75]. Investigator triangulation was used in the analysis in order to reduce the possibility of biased or one-sided interpretation of the data. Similarities within and differences between codes were discussed with co-authors and the analysis process was described and illustrated in a table (see paper II) in order to strengthen the credibility. The findings must be understandable to others and regarded as reasonable and we therefore described the context and the informants to make transferability judgements possible [91]. However, there is no correct or single interpretation of such research findings, only the most probable meaning from a particular perspective [75].

Study III

Selection biases refer to systematic differences in groups [68]. The strength of this study was the random register-based sample of women, making the results possible to generalise, although they are not fully comparable to those of other studies as non-attendees are defined in various ways. The two groups were selected by means of a computer in a sample based on coverage rates and not on attendance rates. In order to reach internal validity, the whole study group sample was compared with the control group. The study group and control group were compared regarding available background factors, age and cervical smear history, without finding any differences. It would have been desirable to have access to more background variables such as civil status and education.

Introduction of combinations of efforts to promote attendance at CCS differs from the approach of regular intervention studies. The method that is sometimes called outcome research [68] does not always fall within the traditional research framework, and the complex and multidisciplinary nature of outcome research offers opportunities for methodological creativity [68]. Outcome research is a type of evaluation, and the purpose is to measure the net impact of a specific new intervention over and above the effects of other factors [68]. However, it is important not to compare outcome research with evaluation research, as evaluation research involves finding out how well an existing program, practice or procedure is working, and outcome research is designed to document the effectiveness of a health care service,

for example. A major obstacle is attribution, i.e. linking the outcome of interest to a specific intervention [68]. In this study the outcome of a larger number of registered cervical smears in the study group compared to the control group is difficult to relate exclusively to the promotive efforts that were carried out.

Another strength is the outcome of registered cervical smears, instead of self-reported data or willingness to attend, which are common in most studies in the field [92]. However, 11 women in the study group and eight women in the control group had moved from the county at follow-up, although these figures are probably false low, since women live in other counties without reporting this to the tax authorities.

Study IV

CEA is the most common type of economic assessment. It is a form of economic evaluation where both the costs and the consequences of health programs or treatments are examined. One of the first decisions in this kind of evaluation is to determine the viewpoint of the analysis; for example, an item may be a cost from one point of view but not from another. Study IV was a partial cost-effectiveness analysis, undertaken from a health care cost perspective and with an outcome of registered cervical smears. Such an approach does not consider cost per extra life-year gained and it is limited, as it does not take into consideration the women's experiences of having a cervical smear taken [38, 93]. An analysis approach where both these aspects of outcome are measured would probably have given a broader understanding. However, as I was involved in the intervention, I found it difficult to reach an objective evaluation of the women's experiences of having a cervical smear taken. Nor was it possible to measure cost per extra life-year gained considering the small size of detected abnormalities and the short-term perspective.

IMPLICATIONS AND CONCLUSIONS

First some general reflections on this research project. The CCS program has been underway for four to five decades, and its quality has been measured in terms of attendance rates, diagnostic procedures and treatments and lives saved. Up until now such quality parameters have been adequate. However, when the recommended coverage goal (90%) [2] has been reached, I contend that other quality parameters have to be taken into account such as ability to reach target groups, accessibility, capacity to offer individualised CCS, coverage rates and women's satisfaction regarding having a cervical smear taken. Another challenge is development and incorporation of other CCS methods, both for taking a cervical smear, for instance a self sampling test, as well as new methods for analysing cervical smears in order to reduce over-diagnosis.

A general discussion is needed, including all groups involved, concerning the directions the CCS program should take and whether CCS is still a disease prevention program or if it is a health promotion program. The latter direction involves women's right to be informed and to be empowered to make an informed decision [64] about whether or not to attend CCS. Until now, the recommendations from NBHW have included informing women about the aim of CCS and preparing women for abnormal cervical smears. However, an informed decision includes more according to Foster, 1998 [5] and Chew Graham, 2006 [66]. In line with these authors I suggest that the recommendations also include women's right to receive an individual risk assessment. Women need to know the particular risk of developing cervical cancer, i.e. whether the risk is near zero or relatively high [5, 66]. Professionals should spend more time responding to women's individual questions [5] and less on one-way information. Finally, the precision of the test should be discussed to avoid misunderstandings and giving false reassurance, i.e. the belief that CCS gives full protection [67].

The concept of the CCS program as a health promotion program could involve new organisational ideas. Perhaps it is time to establish health care centres organised from women's perspective, where different professions co-operate and offer health promotive activities such as mammography and CCS. In such health care centres, midwives with specialist training could meet women with fear or great anxiety for CCS and for example offer health fostering conversations.

The results of this research project have the following clinical implications for professionals in CCS indicating that it is important to:

- pay increased attention to women who have had few or no cervical smears taken when they themselves make contact, and to pave the way for a collaborative discussion about CCS

- respond to women's own queries rather than giving one-way information
- establish personal contact and communication with the women
- ensure informed decisions by encouraging women to make their choices on the basis of unbiased information
- acknowledge women as individuals and not as objects
- identify women with feelings of discomfort concerning the gynaecologic examination before performing the examination; e.g. examiners should ask about prior experiences of gynaecologic examinations and sexual abuse
- work toward the possibility of practicing on gynaecologic simulators and on professional patients with the respect to the interplay between technical and communication skills in gynaecologic examinations
- increase possibilities for women to choose the examiner and the most convenient locale
- work for increased accessibility; e.g. drop-in times, evening appointments, extended telephone hours, and making appointments over the Internet, which could facilitate women's attendance.

In conclusion, it seems reasonable that some women choose not to attend CCS. Women's statements about their non-attendance are complex and are influenced by both current and earlier circumstances. Additional attempts to reach non-attendees are associated with high costs in relation to the increased numbers of cervical smears taken. A majority of the non-attending women can be considered as healthy but some of them as potential risk patients, e.g. women with earlier abnormal smears. It will be a challenge for health care professionals to identify these women. When meeting women with few or no cervical smears the issue should not be to convince the women to attend CCS, but rather to understand the women's decision about whether or not to have a cervical smear taken and include women's right to have individual risk estimation. This can be done through active, collaborative discussions between women and health care professionals. Such relationships would enable the women to make choices that both fit their lives and also take into account the medical view of CCS. I argue that it is time to reconsider the original purpose of CCS as merely a disease prevention program, as well as to incorporate health promotion values.

Future investigations about how to promote women who feel discomfort in association to gynaecologic examination is needed. Also, studies about women's attendance at CCS if informed consent is implemented are called for. Further, in this area we have to consider ongoing changes with screening of HPV virus and vaccination. If and when a vaccination program is introduced in Sweden, it will be interesting to see how it affects women's attendance in the CCS program.

AFTERWORD

At the beginning of this thesis I related the assumptions about CCS and non-attending women that I brought into the project. It is still my opinion that CCS is beneficial and that it provides good protection against cervical cancer. However, I believe that a struggle to reach 100% attendance will include elements of persuasion and compulsion. The question is where the limit should be set for coverage rates that is beneficial for women and does not threaten their well-being.

If I were to work as a midwife again, the following metaphor would illustrate my present view: Our children cycle to school and to other activities on a road with heavy traffic, sometimes late in the evening. As parents we have discussed the extent to which we should warn our children about the heavy traffic as well as about strangers. The risk of meeting a person with bad intentions is small and there is also a risk that the warnings will make them feel insecure and anxious. We have of course told them to exercise caution regarding strangers but most of the time we have encouraged them to cycle and to enjoy the open air and the delightful landscape. I am convinced that some of the non-attending women have chosen to cycle through life and enjoy life without worrying about what might happen, while others are so busy that they have no time to think of risks even if they are aware of them. Henceforth, I do not want to be the person who exclusively informs women about risks. Instead I choose to ask whether they have had problems during their cycle tour and if so, if there is anything I can do for them.

SWEDISH SUMMARY

Bakgrund

Cervixcancer (livmoderhalscancer) är en av de vanligaste cancerformerna bland kvinnor i hela världen. Genom deltagande i gynekologisk cellprovskontroll (gck) kan antalet kvinnor som insjuknar eller dör i cervixcancer minska och därför har screeningprogram införts i många länder. Sedan gck infördes på 60-talet i Sverige har antalet cervixcancerfall minskat med ca 50%. Det har visat sig att de kvinnor som sällan eller aldrig går på gck, är de kvinnor som löper störst risk att få cervixcancer.

I Kalmar län inbjuds kvinnor i åldrarna 23-65 år att delta i gck. Barnmorskorna i de olika kommunerna tar de gynekologiska cellproven, men cellprov tas även i samband med andra gynekologiska undersökningar. Alla tagna gynekologiska cellprov i länet registreras i ett gemensamt cytologprovsregister. De kvinnor som ej tagit prov de tre senaste åren får en kallelse utsänd, och om kvinnan uteblir från den förbokade tiden, får hon en ny kallelse inom ett år, vilket sedan upprepas årligen om kvinnan fortsätter att utebli.

Tidigare studier har fokuserat på att finna karaktäristika för icke-deltagare t.ex. ålder, socio-ekonomisk status eller etnicitet. I Sverige har det visat sig att det inte finns några skillnader mellan deltagare och icke-deltagare beträffande sådana bakgrundsvariabler, förutom att kvinnor som bor i glesbygd mer sällan går på gck. Det finns emellertid få studier som belyser gck från kvinnans perspektiv. Många internationella interventionsstudier är gjorda för att öka kvinnors deltagande. Numera är tendensen att insatser skall fokuseras på högriskgrupper, dvs. de som sällan eller aldrig deltar, istället för att få ett fåtal kvinnor att ta många prov. Idag är kunskaperna begränsade om varför svenska kvinnor avstår från gck, och så vitt vi vet finns inga interventionsstudier som är utformade efter icke-deltagares önskemål. Sådan kunskap skulle kunna ligga till grund för att anpassa interventioner till individuella önskemål, så att fler kvinnor kan delta i gck och insjuknandet i cervixcancer kan minskas. Eftersom hälso- och sjukvårdens ekonomi blir allt mer ansträngd, bör ekonomiska aspekter ingå som underlag för beslut om val av åtgärder.

Det övergripande syftet var att undersöka varför kvinnor väljer att avstå från gynekologisk cellprovskontroll och de specifika syftena var att:

- beskriva vilka skäl kvinnor anger om varför de väljer att avstå från att delta i gynekologisk cellprovskontroll (I)
- beskriva och tolka varför kvinnor väljer att avstå från att delta i gynekologisk cellprovskontroll (II)
- beskriva under vilka förutsättningar kvinnor som avstått från gynekologisk cellprovskontroll de senaste 5 åren, kan tänka sig att ta ett cellprov (III)

- beskriva de individuellt anpassade åtgärder som forskaren genomför för att hjälpa de kvinnor som önskar få ett cellprov taget (III)
- undersöka om det finns en skillnad i antalet registrerade cellprov vid uppföljning mellan en studiegrupp och en kontrollgrupp, som endast fått ordinarie inbjudan (III)
- beskriva kostnadseffektiviteten av en resursintensiv intervention, som syftar till att stödja kvinnors deltagande i gynekologisk cellprovskontroll, bland kvinnor som saknade ett registrerat gynekologiskt cellprov under de senaste fem åren (IV).

Metod

Urvalet var gemensamt för samtliga ingående studier och kvinnornas personuppgifter hämtades från cytologprovsregistret i januari 2004. Inklusionskriterie för studierna var att kvinnorna ej skulle ha ett registrerat cellprov i cytologprovsregistret under de senaste fem åren (I-IV). Inklusionskriterierna i studie II var att kvinnorna skulle uppge varierande orskaker till att de avstått från att delta i gck samt tala svenska och vara villiga att delta i en personlig intervju. Exklusionskriterierna i studie I och II var att kvinnan hade tagit ett gynekologiskt cellprov utanför landstinget under de senaste fem åren, genomgått total hysterektomi, varit gravid, nyligen fött barn, och/eller hade svårigheter att förstå och svara på ett frågeformulär.

Ca tolv procent (n=6565) av kvinnorna i åldern 28-65 år saknade ett registrerat cellprov och av dessa slumpades 400 kvinnor till en studiegrupp och 400 till en kontrollgrupp (III,IV). I studiegruppen var 255 kvinnor kvalificerade att delta i studie I. Det var 122 kvinnor som tackade nej, och 133 kvinnor deltog därmed i studien, vilket gav en svarsfrekvens på 52%. Fjorton kvinnor deltog i en personlig intervju (II).

Ett frågeformulär konstruerades för att användas i telefon-intervjuer. Detta omfattade bl.a. bakgrundsdata, frågor om varför kvinnorna valt att avstå från gck (en öppen fråga samt en med förutbestämda svarsalternativ), samt frågor om upplevelse och erfarenhet av gynekologisk undersökning och sexuella övergrepp (I). Frågeformuläret innehöll också frågor om framtida deltagande, om kvinnorna kunde tänka sig att genomgå gck om de själva fick bestämma villkoren för genomförandet, och om de kunde beskriva dessa villkor, samt om de önskade forskarens hjälp för att få ett prov taget (III).

Ett brev skickades till studiegruppen (n=400) med information om studiens syfte och genomförande samt en fråga om jag fick kontakta kvinnorna per telefon. De som inte ville bli uppringda kunde i ett frankerat brev skicka in en förtryckt blankett där de kunde tacka nej till deltagande. De kvinnor som accepterat att delta besvarade frågeformuläret i telefon (I,III). I slutet av telefonsamtalet fördes en längre diskussion med de kvinnor som önskade hjälp med att få ett prov taget. Vid ett senare tillfälle genomfördes provtagning och de önskemål som kvinnorna uppgivit tillgodosågs så

långt som möjligt (III). Kostnaderna beräknades på de insatser som gjordes f.o.m. det att forskaren identifierat kvinnorna fram till dess att ett prov blev taget. Alla insatser antecknades och kostnadberäknades (IV). Ett år efter sista kontakten med mig hämtades uppgifter i cytologprovsregistret på antalet registrerade prover (III,IV). Beskrivande och analytisk statistik användes för att bearbeta data i studierna I och III. Innehållsanalys användes i studie II och kostnads-effektivitetsanalys användes i studie IV.

Resultat (I)

I den öppna frågan svarade kvinnorna att de vanligaste skälen till att de avstått från gck var att de hade brist på tid (n=30), kände obehag inför den gynekologiska undersökningen (n=26), hade andra sjukdomar (n=24) eller kände sig friska (n=16). Bland de förutbestämda svarsalternativen var de vanligaste skälen till att kvinnorna avstått från gck: att de kände sig friska (n=73), kände obehag inför den gynekologiska undersökningen (n=39) och/eller kände obehag för att uppsöka sjukvård i allmänhet (n=30).

De kvinnor som angav att de avstod därför att de kände obehag inför den gynekologiska undersökningen, skattade att de hade upplevt den senaste gynekologiska undersökningen de varit med om obehagligare än de kvinnor som uppgav att de avstått från gck pga andra orsaker. 16.5% av kvinnorna uppgav att de varit utsatta för sexuella övergrepp. Resultatet visade emellertid att de inte avstått från gck pga den gynekologiska undersökningen i större utsträckning än kvinnor som avstått pga andra orsaker.

Resultat (II)

”Jag behöver inte”...

Kvinnorna upplevde att de kände sig friska, och så länge kroppen inte signalerade några symptom behövde de inte delta i gck. När kvinnorna passerat den reproduktiva delen av sitt liv ansåg de att gck var av mindre intresse. Många kände sig nöjda med att denna tid i livet var över och att de ”slapp” gå på kontroller. Kvinnorna relaterade risken för att de skulle få cervixcancer till ärftlighet. Vissa konstaterade att risken var liten, eftersom ingen i familjen eller i tidigare generationer hade haft någon form av underlivscancer.

”Jag vill inte”...

Kvinnorna berättade om negativa upplevelser i sin uppväxt eller att de som vuxna levit i destruktiva förhållanden där de blivit illa behandlade och kränkta. Detta hade medfört att de fått dålig självkänsla och att de hade en negativ kroppsbild. De kunde inte tänka sig att en främmande person skulle beröra deras kropp. En del av kvinnorna hade varit med om negativa upplevelser i samband med tidigare gynekologiska

undersökningar. Dessa upplevelser präglade dem och de gjorde allt för att undvika att hamna i samma situation igen. Även om de flesta undersökningar de varit med om var positiva så kunde upplevelsen av en enda negativ undersökning göra det omöjligt för dem att delta i gck. Några kvinnor menade att den oro de skulle känna om de deltog i gck kunde leda till ohälsa.

”Jag prioriterar inte”...

Kvinnorna i studien uppgav att de hade svårt att få tiden att räcka till. De prioriterade den tid de hade till familj och arbete, och inbjudan till gck blev ett ytterligare stressmoment i deras liv. Det fanns ett motstånd mot hälso- och sjukvården, alltifrån en obehagskänsla till totalt avståndstagande. En del hade dåliga erfarenheter av sina kontakter med sjukvården, andra trodde inte på den sjukvård som bedrevs inom hälso- och sjukvården. En del kvinnor prioriterade alternativ medicin.

Resultat (III)

En majoritet av kvinnorna kunde tänka sig att ta ett prov om de själva fick bestämma villkoren för genomförandet (n=120). De främsta önskemålen var att bli försäkrade om att få ett vänligt bemötande (19%). Kvinnorna ville bli bemötta med respekt och uppleva att undersökaren hade tid och lyssnade på dem och att undersökningen skulle genomföras försiktigt och mjukt. Det andra vanligaste önskemålet var att få en passande provtagningstid (18%). Kvinnorna önskade kvällstider, drop-in tider, samt möjlighet att lättare kunna ändra bokade tider t.ex. bokning via internet.

Femtio kvinnor önskade hjälp med arrangemang för att få ett cellprov taget. De individuellt stödjande åtgärderna var anpassade efter kvinnornas önskemål och en stor del av tiden ägnades åt att ordna passande tider samt undersökare som kvinnan kunde känna förtroende för. För de kvinnor som var rädda för gynekologisk undersökning eller som av andra skäl kände sig osäkra, gjordes försök att etablera förtrolig kontakt genom upprepade samtal och möten. De praktiska åtgärder som genomfördes var att ordna gratis provtagning, provtagning på hemorten, korta väntetider mellan ”inbjudan”, provtagning och svar, samt hjälp med transporter.

Det var fler kvinnor i studiegruppen än i kontrollgruppen som hade ett prov taget vid uppföljningen, 29.5% kontra 18.5%. Kvinnor med ett registrerat cellprov vid uppföljningen hade oftare ett tidigare cellprov taget under den sista tioårsperioden än de kvinnorna som saknade ett registrerat cellprov under denna period.

Resultat (IV)

I studiegruppen var 118 prov registrerade vid uppföljningen och varje prov kostade 603 SEK (66.87 €). I kontrollgruppen var 74 prov registrerade vid uppföljningen till en kostnad av 150 SEK (16.63 €). Resultatet av kostnadseffektivitetsanalysen visade att varje extra prov kostade 1365 SEK (151.36 €).

Kliniska implikationer och konklusion

Kvalitetsparametrar för gck-programmet har främst berört antalet deltagare, diagnostisering och behandling. När målet med 90% täckningsgrad har uppnåtts bör andra kvalitetsparametrar övervägas t.ex. förmåga att nå rätt målgrupp, mätning av tillgänglighet, möjlighet att erbjuda individualiserad provtagning och mätning av kvinnors tillfredsställelse att få ett prov taget. En diskussion bör föras om vi fortfarande skall betrakta gck-programmet som ett preventionsprogram eller om det också är ett hälsopromotivt program. Det senare inbegriper att ett informerat samtycke bör inhämtas före provtagning.

Baserat på resultaten från detta forskningsprojekt föreslås följande kliniska implikationer för personal som arbetar med gck:

- öka uppmärksamheten på de kvinnor som har tagit få eller inga gynekologiska cellprov, när de själva tar kontakt, och initiera en diskussion om gck
- svara på kvinnornas egna frågor och lägga mindre vikt vid envägs-information
- försöka etablera kontakt och samtal
- försäkra sig om informerat samtycke, genom att uppmuntra kvinnorna till att göra ett val grundat på opartisk information
- betrakta kvinnorna som enskilda individer och inte som objekt
- identifiera kvinnor som känner obehag inför den gynekologiska undersökningen före undersökningen t.ex. genom att fråga om tidigare undersökningar och om de varit utsatta för sexuella övergrepp
- om tillfälle ges, bör undersökare få utökad möjlighet att träna sig i att utföra gynekologisk undersökning i syfte att träna samspelet mellan de tekniska och kommunikativa förmågorna t.ex. genom professionella patienter eller simulatorer
- öka möjligheten för kvinnor att välja undersökare och mottagning
- arbeta för att öka tillgänglighet t.ex. genom drop-in tider, kvällsmottagning, utökade telefontider, möjligheter att reservera tider via internet
- arbeta för att inrätta särskilda hälsocentra, där olika hälsopromotiva aktiviteter erbjuds t.ex. mammografi, gck m.m.

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APPENDIX

Formulär för semistrukturerad telefonintervju

Del Ia

Först kommer några frågor om ålder m.m

1. Hur gammal är du?

.....

2. Vilket är ditt nuvarande civilstånd?

- Gift/ sammanboende
- Ensamstående
- Annat alternativ.....

3. Har Du fött barn?

- Ja, jag har föttbarn
- Nej

Del II

4. Har Du genomgått en operation där livmodern tagits bort?

- Ja

Varför?.....

Gå vidare till fråga 30

- Nej

5. Har du tagit gynekologiskt cellprov utanför länet under de senaste fem åren?

- Ja Gå vidare till fråga 30
- Nej

I brevet med inbjudan till gynekologisk cellprovskontroll (gck) finns information om att vissa kvinnor kan avstå från undersökningen. Nu kommer frågor om du tillhör denna grupp?

6. Har Du haft samlag någon gång med en man?

- Ja
- Nej Gå vidare till fråga 30

7. Har du avstått från gck de senaste åren på grund av att du varit gravid eller nyligen fått barn?

- Ja
- Nej Gå vidare till fråga 9

8. Kommer du att gå på gck när du inte längre behöver avstå på grund av graviditet eller barnafödande?

- Ja Gå vidare till fråga 30
- Nej

Del III

9. Kan Du berätta för mig vad som är den främsta anledningen till att du valt att avstå från att ta ett gynekologiskt cellprov? Ta den tid du behöver för att svara.

.....
.....

Det kan kanske finnas fler orsaker till varför du valt att avstå från gynekologisk cellprovskontroll. Nu kommer några påståenden, där du får svara ja eller nej om det stämmer in på dig. (Jag kommer att använda uttrycket gck istället för gynekologisk cellprovskontroll).

10. Jag avstår från gck därför att jag i princip är emot denna typ av kontroller.

- Ja
- Nej

11. Jag avstår från gck därför att jag tycker det är obehagligt att uppsöka sjukvård i största allmänhet.

- Ja
- Nej

12. Jag avstår från gck därför att jag har svårt att förstå det svenska språket.

- Ja
- Nej

13. Jag avstår från gck därför att det kostar för mycket (80 kr).

- Ja
- Nej

14. Jag avstår från gck därför att jag känner mig frisk och inte behöver gå på gck.

- Ja
- Nej

15. Jag avstår från gck därför att jag har ett handikapp, rörelsehinder eller en funktionsnedsättning som gör det svårt för mig att ta mig till platsen, eller att få provet taget.

- Ja
- Nej

16. Jag avstår från gck därför att jag lider av nedstämdhet/ångest eller psykisk sjukdom.

- Ja
- Nej

17. Jag avstår från gck därför att jag är rädd för att man skall upptäcka något onormalt, t.ex. cancer.

- Ja
- Nej

18. Jag avstår från gck därför att jag är missnöjd med min kropp.

- Ja
- Nej

19. Jag avstår från gck därför att jag är generad över att visa mig naken.

- Ja
- Nej

20. Jag avstår från gck därför att jag känner provtagaren.

- Ja
- Nej

Nu kommer några frågor om gynekologisk undersökning

21. Har du blivit gynekologiskt undersökt någon gång? (Ej i samband med barnafödande)

- Ja
- Nej Gå vidare till fråga 23

Tänk på den senaste gynekologiska undersökningen

22. Hur upplevde du att bli gynekologisk undersökt?

Svara genom att ange den siffra mellan 1 och 7 som bäst motsvarar hur du upplever situationen. 1 motsvarar ”inget obehag alls” och 7 motsvarar ”oerhört mycket obehag”.

_____ valt nummer

23. Avstår du från gck därför att du känner obehag inför gynekologisk undersökning?

- Ja
- Nej

Del IVa

Nu kommer några frågor om hur du ser på ditt deltagande i framtiden

24. Skulle du kunna tänka dig att genomgå gck om du själv fick bestämma villkoren för genomförandet?

- Ja Gå till 25a
- Nej Gå till 25b

25a. Skulle du kunna berätta för mig vilka dessa villkor är? Ta den tid du behöver för att svara.

.....
.....

25b. Vill du berätta för mig varför? Ta den tid du behöver för att svara.

.....
.....

26. Om du skulle ta ett cellprov, skulle du föredra att en kvinna eller en man tar provet?

- Föredrar kvinna
- Föredrar man
- Spelar ingen roll
- Kan inte tänka mig att jag skulle vara med om det

Del V

Många kvinnor har någon gång under sitt liv blivit utsatta för sexuella övergrepp. Exempel: Om någon mot din vilja tagit på eller använt din kropp för att tillfredställa sig. Detta kan ha skett under hot om våld

27. Har du blivit utsatt för sexuellt övergrepp?

- Ja
- Nej.....Gå vidare till fråga 30

28. Hur mycket plågas du nu av följderna efter det/de sexuella övergrepp du upplevt?

Svara genom att ange den siffra mellan 1 och 7 som bäst motsvarar hur du upplevde situationen. 1 motsvarar plågas inte alls och 7 motsvarar plågas oerhört mycket.

_____ valt nummer

29. Avstår du från gck därför att du nu plågas av följderna av det/de sexuella övergrepp du upplevt?

- Ja
- Nej

Del Ib

Till slut kommer några frågor om utbildning m.m

30. Vilken är din (högsta) avslutade utbildning?

- Grundskola, folkskola eller motsvarande
- Gymnasium, yrkesskola eller motsvarande
- Högskola, universitet eller motsvarande

31. I vilket land är Du född?

- Sverige
- Annat land.....
- Ange i så fall hur länge Du har bott i Sverige.....

32. Röker du?

- Ja, jag röker..... cig/dagl
- Nej

33. Har du varit på mammografi under de senaste två åren?

- Ja
- Nej

Del IVb

34. Vill du ha min hjälp med att få ett prov taget?

- Ja
- Nej

35. Innan vi slutar vill jag fråga om du har några ytterligare funderingar kring gck som vi inte tagit upp i intervjun?

.....

.....

36. Hur har du upplevt att svara på dessa frågor?

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