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'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

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Abstract

Objective To describe and interpret why women with no cervical smear taken during the previous 5 years choose not to attend a cervical cancer screening (CCS) programme.

Background CCS programme is a service for early detection of cervical cancer. Today, some women choose not to attend the programme.

Design Data were collected by tape-recorded interviews and analysed by qualitative inductive content analysis.

Setting and participants Purposive sample of 14 women in south-east Sweden, who had chosen not to attend CCS during the previous 5 years.

Findings The following themes were revealed: *I do not need to…, I do not want to…* and *I do not give it priority….* The women had a positive attitude to CCS but as long as they felt healthy, they chose not to attend. A negative body image, low self-esteem, feelings of discomfort when confronted with the gynaecological examination and fear of the results also influenced their non-attendance. The women prioritized more important things in life and reported various degrees of lack of trust in health-care.

Conclusion Women's choice not to attend CCS were complex and influenced by present and earlier intra- and inter-personal circumstances. They had a positive attitude to CCS, but other things in life were more important. Health-care professionals have to facilitate a co-operative discussion with the women in order to contribute to a mutual understanding for the perspectives of the women and the professionals.

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Background

Cervical cancer screening (CCS) is a service for the early detection of cervical cancer, which in some countries, such as Sweden, is organized as a national screening programme. This study is carried out in a Swedish county with high coverage (88%), and thus 12% choose not to have a cervical smear taken. The research on non-attendance at CCS has been dominated by studies identifying background characteristics such as, e.g. age,[1] socioeconomic status[2] and ethnicity.[3] Standardized instruments and questionnaires tend to reflect this issue from a medical perspective, i.e. that all women should have a cervical smear taken. Instead of blaming them for their non-attendance,[4,5] we argue that attention should be paid to the individual woman to understand her decision not to attend CCS. This study was undertaken by researchers working at the university and the first author has previously worked as a midwife in the CCS programme.

A small number of studies address non-attendance from the perspective of the women by using a qualitative approach. Two studies[6,7] include interviews with non-attendees in a setting with no organized CCS programme. Inadequate public health education, lack of patient-friendly health services, socio-cultural health beliefs and personal difficulties were the most prominent barriers to CCS among Serbian women.[7] In the Canadian study,[6] women aged 45–70 were interviewed in focus groups. They estimated the CCS procedure from being mildly unpleasant to intensely traumatic, and the physicians seldom encouraged them to have a cervical smear taken. To our knowledge, there is only one qualitative study[8] with a sample similar to ours, i.e. women invited to organized CCS and with no registered cervical smear during the previous 5 years. In that study,[8] the interviewed women believed that the cervical smears were inappropriate for them, e.g. due to having had a hysterectomy or gynaecological problems, while others felt embarrassed, or expressed feelings of fear or fatalism. Although that study was performed approximately 20 years ago, knowledge about non-attendance from the non-attending women's point of view is still limited. The aim was therefore to describe and interpret why women with no cervical smear taken during the previous 5 years choose not to attend a CCS programme.

Method

Setting

In the CCS programme in a rural county in southeast of Sweden, all women between the ages of 23 and 65 (n = 62 000) are invited to have a cervical smear taken every third year. An invitation letter is sent to the women with information about the purpose of the CCS and an appointment at their local Antenatal Health Clinic. The system for calling, registration and follow-up is computerized in a register which is population-based, updated every week and contains all cervical smears taken in the county. Midwives or gynaecologists take the cervical smears, which cost 80 SEK = 11.95 USD (2007).

Subjects and procedure

The participants in this interview study were recruited from a random sample of 400 women with no cervical smear taken during the previous 5 years. Of these, 133 women answered a telephone survey with the aim to describe reasons for non-attendance at CCS.[9] Eighteen of the women, who completed the telephone survey, were informed of and asked to participate in an interview about why they choose not to attend CCS. We tried to attain a sample of women with as great a variety as possible, related to their answers concerning their reasons for not attending CCS and to age. All 18 women were interested to participate and were sent written information about the study. When the first author phoned them after a couple of days, appointments was scheduled for interviews with 17 women as one of them could not be reached. Two women never showed up at the appointed time and one said she could not get off work. Thus, 14 women participated in the study. Their age varied between 33

and 64 years, and the median age was 50 years. Eight women were living with a partner and six were single, 11 had children and three had not. Four women had never had a cervical smear, three had no cervical smear during the previous 10 years, but seven had.

Interviews

The interviews were performed at the women's local health-care centre ($n = 6$), in the women's homes ($n = 5$), at the researchers workplace at the university ($n = 2$) and at one women's workplace ($n = 1$). The women were asked to narrate as freely as possible[10] why they chose not to attend CCS, and they were sometimes asked to repeat and clarify to avoid potential misunderstandings. The interviews were conducted between January and July 2004, lasted between 20 and 90 min, were audio-taped and transcribed verbatim.

Analysis

An inductive content analysis inspired by Graneheim and Lundman[11] was used to interpret the text. The text was read through several times to get a sense of the whole. Then, the text was divided into meaning units, which could be a paragraph, a sentence or several sentences, depending on shifts in the content. The meaning units were condensed, abstracted and coded. The codes were then reflected on and interpreted into sub-themes and themes (Table 1). The main analysis was done by the first author and the last author read the interviews and co-interpreted the codes into sub-themes and themes. The second author validated the analysis.

The study was approved by the Regional Ethics Committee for Human Research, Faculty of Health Sciences, Linköping University, Sweden (Dnr 03-248).

Findings

The women's decision not to attend CCS was complex and none of them stated a single reason for their non-attendance. They also told that

Table 1 Examples of the procedure in the content analysis

Meaning unit	Condensed meaning unit	Code	Sub-theme	Theme
I think it's because I feel healthy and strong and I probably haven't got anything and so it's not as important for me	Feels healthy and therefore a gynaecological check-up is not so important	Feeling healthy	… because I feel healthy	I do not need to …
I haven't really had any discharges or any trouble from down there	Has no gynaecological trouble	No symptoms		
There's no one in my family that has ever had any problems there. Not one, neither my mother nor grandmother nor great-grandmother or anyone. Not my sisters and not my mother's sister, nothing like that. So there's no worries	No one in the family has had any gynaecological disease, which is reassuring	No heredity for cancer	… because this will not happen to me	
Nobody among my closest relatives, among my sisters or among my mother's sisters and father's sisters has had any problems with the uterus or anything, so I feel that I ought not to have any problem	No one in the family has had any diseases in the uterus or elsewhere and therefore she should not get any	No heredity for cancer		

earlier experiences in life influenced their decision not to attend. A majority of them stated that they had a positive attitude to the CCS in general, but tended to relate to several circumstances causing their own non-attendance. They argued they had individual responsibility for their own health, and they could only blame themselves if they got ill.

The following themes emerged from the analysis: *I do not need to…*, *I do not want to…* and *I do not give it priority…* Figures within brackets refer to the particular participating women.

'I do not need to'…because I feel healthy

The women were aware of the benefits of CCS but argued that as long as the body did not give signs of any disease, they felt healthy. They told that the absence of symptoms could spare them visits to health-care. There was a strong belief that only the presence of symptoms justified health-care visits. One of the women expressed it like this:

> I think it's because I feel healthy and strong and I probably haven't got anything and so it's not as important for me[11]

The post-menopausal women described that the gynaecological health check-ups had been more essential for them in younger days. They felt confident with their decision not to attend, and as they had not had any post-menopausal problems, the CCS was not relevant for them. Visits to midwives and gynaecologists belonged to their reproductive ages, to pregnancy and birth control. Several previous gynaecological examinations and cervical smears with normal results had lulled them into a sense of security.

…because this will not happen to me

Some women included their family history of gynaecological cancer or other kinds of cancer when judging their personal risk of getting gynaecological cancer. This judgement was sometimes related to the fact that nobody in the family had ever got gynaecological cancer. They expressed a tendency of 'this will not happen to me'.

> Well, it's quite stupid really because it is important to check. But then I think that there's no one in my family that has ever had any problems there. Not one, neither my mother nor grandmother nor great-grandmother or my sister. So there's no worries[14]

'I do not want to'…because I do no like my body

Some women felt they had such a disfigured body and such low self-esteem that their attendance in organized CCS was impossible. This negative body image was grounded in their childhood and was influenced by earlier bad relationships. They expressed feelings of not being loved and of occasions of physical or psychological abuse. The women described events when their self-esteem had been extremely threatened, had been ignored or insulted by their family or partners. This is what one woman told:

> I was beaten and abused by my father all the time I was growing up. Mum just stood and looked on … that I was never good for anything and everything I did was wrong[7]

Such events made women experienced their body as disgusting, and by choosing not to attend CCS they could avoid a situation in which they felt vulnerable. The women described the body as a private sphere, and it was out of the question to let a stranger see and touch their body. One of the younger women who had had a personal history of having anorexia said:

> when I feel ill it has to do with my body. The idea of a doctor touching my body like that makes me feel ill, a sense of discomfort, quite simply[9]

Especially middle age women (50–65 years) had been taught that being naked was nasty and they had been told not to expose their bodies.

> I have always been what they call a bit shy at times, you know. I've never really wanted to show myself. And it's probably got something to do with my upbringing.[5]

This unwillingness to show their naked body made them avoid CCS. Some of them told they considered their body different from young days and the resistance to exposing the body had increased during the years. They had huge difficulties to overcome these feelings.

…because I feel discomfort about gynaecological examinations

Discomfort associated with the gynaecological examination procedure was a theme brought up by all women. Negative experiences of anxiety and pain during earlier examinations or childbirth contributed to the feelings of discomfort. They found it almost impossible to stand the thought of being exposed like a helpless object in a vulnerable situation like CCS. Even if the women mostly had undergone examinations which they considered positive, one single fearful examination could ruin their willingness to attend. One woman described the situation when she had an intra-uterine contraceptive device:

> It hurt so much that they held me down, that he didn't stop it then. Forced up in some way that I wanted to get up higher. I moved and they held on to me, I was pinned down. They used force on me, that's how I felt. I can picture myself as a victim who had to suffer torture[13]

This experience greatly influenced her decision not to attend CCS and she feared that this could happen again.

…because I do not want to know the result

Some women explicitly expressed fear of knowing the results of the CCS. They argued they were aware of the necessity to go and knew their behaviour was considered irrational. Other women more implicitly mentioned that by avoiding CCS, one source of distress was diminished in situations when they had private trouble. Women above 50 described some kind of fatalism, i.e. 'what is to be will be'. CCS was not worth while as it could cause anxiety, and some women added that anxiety was unhealthy.

> I stopped because I didn't believe in it because I thought to myself, I don't know how I'll react if I find out that I have something. And then go around thinking about it, then perhaps I put something on instead, and the body will surely take care of that. And if it doesn't, then I'll have to take it when it comes, so to speak[6]

'I do not give it priority'…
…because I have other things to do in life

The women said that their lives were full of commitments and as long as they felt healthy they did not prioritize gynaecological check-ups for themselves. They had been occupied by personal matters, such as busy jobs or child rearing, and the CCS was a small marginal note in their lives. The invitation was an additional burden in their stressful lives. Some women told the specific cost of the CCS was acceptable but the summarized cost, e.g. the costs of transportation and a day-off work was troublesome. The decision not to attend CCS was not always a conscious choice. Instead, they contemplated attending, but put off the decision until the appointment time had passed. However, some women stated that lack of time was a handy excuse for unpleasant things, such as CCS, and said that they felt stupid or guilty about being non-attendees.

> Yes, I have got the invitation, yes I have, but as it happened I was really busy, more than I ought to be, recently, so it's very easy to blame it on not being able to find the time[14]

…because I do not trust the health service

There was a lack of faith in the health service, ranging from a slightly negative view to total distrust. Earlier negative experiences in encounters with health-care providers had decreased the women's trust, and therefore they did not prioritize CCS. This was sometimes related to their experiences of uncaring treatments in connection with gynaecological examination, but also to health-care visits in general. They stated, e.g. that they had been treated like an object and not like a human being. They felt that they or their

relatives had been ignored when they had pain or other problems related to illness. Others had tried to explain their situation but had experienced that the professionals were not interested. Several of them had shown interest in alternative medicine. One woman who had prioritized alternative medicine told about a visit to her general practitioner:

> And I asked them if the symptoms that I show now can have something to do with getting cancer of the bowel. Somehow he looked at me as if I was some kind of hypochondriac, you know, imagining things, and that everything about me was some kind of imagination[2]

Some women did not trust the ability of the health-care to prevent them from diseases, and two women had made an active decision not to attend CCS for that reason. They expressed that the women's body should be considered from a holistic point of view and criticized the biomedical view, i.e. examining and preventing disease in a small part of the body, ignoring the rest of the person. This, they argued, could disturb the system or the capacity of the body. Thus, the CCS did not fit into their beliefs about the functioning and healing processes of their body.

Discussion

The women's decision not to attend CCS revealed a complex picture of integrated reasons and they intentionally or unintentionally carefully weighed advantages and disadvantages.

The results showed that the theme 'I do not need to…' were based on the experience of feeling healthy, i.e. having no symptoms. This should be considered when reflecting on the purpose of CCS, i.e. to identify individuals who are at risk of developing disease in a population of healthy women. The introduction of CCS has questioned the definition of what is normal,[12] and how to define 'healthy'. Cervical smears can show results on a spectrum from normal to pathological, which might be confusing for women when neither health nor disease can be excluded or confirmed.[13] In our study, the women interpreted absence of symptoms as feeling healthy while in an interview study[14] with attending women they reported they attended CCS to gain confirmation of being healthy. The ambiguous meaning of 'feeling healthy' is also described by the women in our study, who claimed they did not want to know whether they had an abnormal cervical smear or not. They described the paradox of participating in preventive health-care, which creates increased anxiety and stress, which they considered antagonists to good health. Such conflicting experiences have also been described by attending women.[15]

In our study, especially women above 50 years considered gynaecological check-ups to belong to reproductive ages, which also justified their non-attendance and thus, they 'do not need to go'. International studies[1,16,17] have shown an association between old age and non-attendance in CCS. One might assume that physical changes through ageing and menopause challenge established social norms, such as attending CCS. In a study[18] interviewing middle age women, when they had consulted health-care for menopause changes and asked for medical advice, they have been told they are healthy. This calls for further research on post-menopausal women's health-related issues and feelings of being ignored by health-care.

Our study shows that the women experienced a low risk of contracting cervical cancer, as nobody in their family had such disease. Thus, they believed that 'this could not happen to me'. Also in a study by Forss *et al.*[14] interviewing attendees, reasons for attendance were referred to family members' or friends' cancer diseases. Nevertheless, heredity has not been considered as a risk factor for cervical cancer in epidemiological studies.[19]

In our study, the theme 'I do not want to…' included the women's low self-esteem and negative body image as parts of their choice not to attend CCS. Their reasoning included an incorporation of negative images of themselves, which had been developed in relations with people closest to them. According to Price,[20] body image is the picture of our body which we form in the mind, the way in which the body

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appears to ourselves, and not only the visible but also the invisible body. Studies have shown the relationship between low self-esteem and being frequently teased, receiving cruel comments and adopting a negative body image.[21] In an initial stage, attendance in CCS might be of subordinate importance for these women, and if health-care professionals try to persuade them to attend, this might be considered insulting. For individuals with a strong sense of powerlessness, the starting point for change might indeed be to take personal actions that build a sense of power-from-within.[22] Therefore, we argue if further contact should be taken with non-attending women, the purpose should be to enable them to express their reasons for not attending CCS, and to support the women's own solutions to their problems. This which might lead to higher self-esteem and to initiative to take preventive actions but could also decrease their feelings of guilt. However, it can not be taken for granted that empowered women will obey social norms, as for example attendance in CCS. It has been shown that people who have a good self-esteem are more likely to take care of themselves and to have the courage to resist normative pressures.[23] This is shown in our study by the women who told that health check-ups belonged to their reproductive lives and the women who did not trust the ability of the health-care to prevent them from diseases. They were confident with their decision not to attend CCS. It might be a challenge for health-care providers to accept and even promote women's active choice not to attend CCS.

The theme 'I do not want to…' included the women's experiences of discomfort with gynaecological examinations. Both in this and in an earlier study[24] describing women's experiences when undergoing gynaecological examinations, the women could describe in detail how they lost control and felt vulnerable during the examination. The woman is influenced by personal experiences, e.g. fears, worries and ideas[25] when exposing her genitals from a position of submission.[26] It is reasonable to assume that women with negative experiences of gynaecological examinations do not attend CCS, as the examination might be associated with the danger an unfamiliar environment and by an unknown examiner. It has been suggested that training of examiners in the delicate interplay between technical and communication skills required in gynaecological examination could create a more positive experience of the examination for the women[26,27] and thereby increase attendance in CCS.[27]

The theme 'I do not give it priority…' included women's thoughts of choosing family and work commitments before CCS. Today, women are busy and for most women it is a puzzle to fit all the pieces together. The women in our study had received several invitations during the previous 5 years or even longer, but they had taken the decision not to take time off for CCS. One might assume, as several women stated, that lack of time is a handy excuse, when the real reasons for non-attendance are complex. It is noteworthy that the women in our study often did not prioritize attending CCS due to negative experiences in their earlier contacts with health-care in general. Others called for a more holistic view when meeting health-care providers. Several studies report the importance of professional caring and its contribution to health and well-being, e.g. being open to and perceptive of others, having a genuine interest in patients, and being truly present for patients.[28–31]

Strengths ands limitations

The trustworthiness of the study was enhanced by allowing the women to reflect and tell their stories during the interviews without being interrupted. The interviews were carried out as dialogues, giving space to the women's own 'voices'. They claimed no one had actually asked for their stories before. This is one way of empowering the women.[10] Trustworthiness was also strengthened during the interview as the dialogue facilitated clarification of potential misunderstandings. Although the women provided rich data, a greater variation in the interview data could have been achieved if the sample also had involved women with other background characteristics, for example women with

other ethnicity or women from urban settings. This is a potential limitation of this study. The fact that more than one researcher was involved in the analysis process strengthens the dependability of the study.[32,33] We do not argue that our sample represent all non-attending women, but it has been our intention to be as transparent as possible when describing our method, and it is now up to the reader to decide the extent of transferability of the results to similar contexts.[11,34]

Conclusion

Women's non-attendance in CCS is influenced by present and previous circumstances as well as intra- and inter-personal circumstances. Their choice not to attend CCS is not based on a single reason but on several integrated reasons. The women had a positive attitude of CCS but other things in their lives were more important. On basis of these findings, health-care providers have to facilitate a co-operative discussion with the women in order to contribute to a mutual understanding for the perspectives of the women and the professionals.

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