



Young Danish HPV vaccinated women's knowledge, barriers and facilitators towards cervical cancer screening: A qualitative study

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ABSTRACT

Cervical cancer occurs more often in under-screened women, and participation rates in cervical cancer screening among young women are worryingly low worldwide. In Denmark only about half the women in their twenties participate in cervical cancer screening. 64–80% of women between 20 and 29 have been HPV vaccinated with a vaccine protecting against 70% of all cervical cancers. Thus screening is still an important supplement to HPV vaccination for the next decades.

The aim of this study was to investigate knowledge, facilitators and barriers towards cervical cancer screening among young HPV vaccinated women in Denmark. This qualitative study used an anthropological approach, and data was collected using semi structured focus group interviews as this is an effective method for promoting self-disclosure among participants. Eight focus groups were conducted with participation of 49 HPV vaccinated women aged 20–29 years.

We identified five main themes providing an understanding of the women's barriers and facilitators towards cervical cancer screening: Lack of knowledge about HPV and cervical cancer, the screening invitation, the GP as gatekeeper, the gynaecological examination and perceived relevance of cervical cancer screening. Former vaccination did not impact the women's reflection about screening attendance. We argue that systematic information and the attitude and tone of the GP are the primary facilitators for filling the knowledge gap we found among young HPV vaccinated women. As an important gatekeeper, the GP can explain, motivate and remind young women about the importance of a regular Pap smear.

1. Introduction

Worldwide, cervical cancer is the fourth most common cancer among women. Each year approximately 600,000 women are diagnosed with cervical cancer and about 300,000 die from the disease. Pap smear testing combined with HPV vaccination are effective measures towards eradicating cervical cancer as a global public health problem, as stated by WHO in 2018 (WHO, 2021).

The incidence of cervical cancer in Denmark has decreased since the introduction of cervical cancer screening (CCS), from 40/100,000 to 10/100,000, i.e. from around 900 to 375 cases per year (Engholm et al., 2010). The Danish CCS program was introduced in a few counties in the 1960s. By 1996, Denmark was administering a national organized screening program (Pedersen et al., 2018; Lynge et al., 2018) which today targets women aged 23–64. All women in this group receive an invitation letter to screening with follow-up reminder letters sent to non-responders at three and six months after the first invitation. Women

aged 23–49 are offered a Pap smear test every third year, and then every fifth year for women aged 50–64. Cervical cancer occurs more often in under-screened women (Harder et al., 2018) and at least half of the women diagnosed with cervical cancer in Denmark have not been screened regularly (Dugué et al., 2012; Kirschner et al., 2011; Bchtawi et al., 2019). Thus, a high participation rate is essential in order to ensure an effective screening program. The overall participation rate in Denmark (proportion of women screened out of all invited women) is 62 pct. but only 55 pct. among women in their twenties (Livmoderhal-skræftscreening] DQDFCCSDKf, 2019).

The HPV vaccine was introduced to girls in the Danish Childhood Vaccination Program in 2009. The combination of routine vaccination and catch-up programs means that all girls and women born in 1985 and later have been offered HPV vaccination free of charge against HPV types 16 and 18 causing about 70% of all cases of cervical cancer. Among Danish women aged 20–29, the vaccination uptake is between 64 and 80 pct.

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Earlier qualitative studies by the Danish Cancer Society uncovered several interrelated barriers towards screening participation. In 2005, focus groups with women aged 23 to 39 revealed a range of barriers for participation. The most crucial factor was lack of knowledge about the purpose of CCS and about HPV being a common sexually transmitted virus causing dysplasia and cervical cancer (Espersen and Holten, 2005). A few women were opposed to screening on principle. A 2015 study among women aged 30 to 50 found similar interrelated barriers, with lack of knowledge being the most important factor (Kvernød and Hansen, 2016). Despite their lack of knowledge, most of the women interviewed in 2015 intended to attend CCS, but a busy everyday life led them to forget to make an appointment with their GP. We expected that young HPV vaccinated women would not be characterized by the same knowledge gap as women over age 30.

A recent Danish study has shown an 86 pct. reduction in the incidence of cervical cancer among women who were vaccinated before age 20 (Kjaer et al., 2021), thus screening is an important supplement for the first generation of HPV vaccinated women.

2. Objective

The aim of our study was to investigate young, HPV vaccinated women's knowledge about HPV and cervical cancer and to elucidate those factors that would either motivate or discourage them from participating in CCS. Understanding the facilitators and barriers towards screening participation is essential for planning future initiatives to increase the uptake among non-participants and first-time attenders.

3. Methods

3.1. Design

This is a qualitative study using an anthropological approach (Spradley, 1979; Hastrup, 2004) and interpretive description (Thorne and O'Flynn-Magee, 2004) in order to elucidate how the women thought and felt about cervical cancer screening and ultimately, to uncover facilitators that would increase their participation in screening. Data was collected using semi-structured focus group interviews (FGIs), as this is an effective method for promoting self-disclosure among participants and creating an environment where participants feel comfortable about sharing their thoughts about a certain subject (Krueger and Casey, 2000). All interviews were conducted by the first and last author, (MScPH and anthropologist), both of whom working at the Danish Cancer Society, where the focus groups were held. We made sure to encourage both negative and positive comments from the women regarding CCS explaining that we aimed to hear their point of view without hiding the fact that the Danish Cancer Society supports cancer screening programs. The interviews were recorded and transcribed. The data collection took place between June 2017 and June 2019. At the beginning of each interview we asked the participants to write down their immediate thoughts about 'cervical dysplasia' and 'the cause of cervical dysplasia' in order to gain insight into each woman's knowledge prior to the discussions. Afterwards, they discussed their written responses. The interview guide consisted of questions regarding screening status e.g. Have you ever had a Pap smear? and open-ended questions regarding preventive health behaviour and the participants' relationship to their GP in order to encourage in-depth responses and to obtain a deeper understanding of factors that would encourage or impede their screening participation e.g. What do you do to stay healthy? What does a good GP mean for you?

3.2. Participants and recruitment

In total, 49 women aged 20–29 participated in eight FGIs. Data saturation was reached with the two final FGIs. An external agency undertook the recruitment of participants using the following selection

criteria: HPV vaccinated, aged 20–29, with no higher education, had received one or more screening invitations (for those above 23 years) and had not been screened regularly. Most of the 49 women were employed, with occupations such as lorry driver, gardener and cook. Thirteen were in some kind of training or education, some at university level. Thirty of the women reported that they had attended screening and nineteen had never been screened as shown in Table 1. All data including screening status were self-reported with no external validation.

For one group, we specifically recruited participants who had been screened at least once in order to achieve an indication of whether and how they differed from the attenders and non-attenders in the other groups.

Each woman received a voucher for two movie tickets worth 200 DKK (approximately 27 EUR). A challenging recruitment process necessitated an increase in the incentive payment, such that the women in the last two groups received a 400 DKK voucher (approximately 53 EUR). All the participants in the last two groups attended except for one woman. In the first groups, however, we received many last minute cancellations and no-shows.

3.3. Analysis

Each transcription was read several times by the first and last author. We used open coding and made notes and headings in the transcripts in order to obtain a comprehensive view of data. We looked for traces and patterns in the data, which we then organized within five overall themes examined with an inductive approach (Hastrup, 2004; Thorne and O'Flynn-Magee, 2004). The authors cooperated in performing the analysis and made an ongoing comparison of different views on data. After preliminary analysis of the focus group interviews, we derived five overall themes: 1) knowledge about HPV and cervical cancer, 2) the screening invitation, 3) the GP as gatekeeper, 4) the gynaecological examination and 5) perceived relevance of cervical cancer screening. In describing the women's attitudes, we use a series of quotations.

4. Results

To shed light on the women's preventive health behaviour, we included questions about health and how to stay healthy. Their answers mainly related 'health' to exercise and diet, largely reflecting the conventional recommendations from the health authorities, e.g. to eat more fruit and vegetables and exercise more. The women translated and used the recommendations in a way that made sense to them, trying to achieve a balance between what they ought to do and what they felt they needed to 'feel good'. Neither dental visits nor cervical cancer screening was mentioned as part of their discussion of their health prevention behaviour.

4.1. Knowledge about HPV and cervical cancer

During the interviews, it became clear that the women had no or very limited knowledge about HPV as the cause of cervical cancer and about CCS. Only one woman mentioned HPV as the cause of cervical dysplasia and only a few could explain the purpose of CCS.

I know that HPV has something to do with cervical cancer and that's why I'll eventually have a Pap smear. But I don't know anything about HPV. I don't even know what it means. If people knew more about it, they would take it more seriously. – 21 years old, never screened

The participants showed a tendency to mix the information they had received over time from their GP, their mothers, friends and social media. Most of the women had been HPV vaccinated as children, so their parents had decided about vaccination and apparently described it to be just another routine childhood vaccination.

Table 1
Characteristics of informants in the FGIs

FGI	Place and date	Age				Self-reported screening status		Parity		
		20–22	23–25	26–28	29	Screened	Never screened	0	1	2
1 n = 6	Copenhagen 16th of June 2017	3	1	2	–	2	4	6	–	–
2 n = 6	Copenhagen 26th of September 2017	2	2	2	–	3	3	6	–	–
3 n = 5	Odense 16th of October 2017	–	5	–	–	5	–	5	–	–
4 n = 4	Odense 16th of October 2017	–	–	4	–	1	3	2	–	2
5 n = 4	Vejle 17th of October 2017	–	2	2	–	3	1	3	1	–
6 n = 5	Copenhagen 30th of November 2017	–	1	4	–	1	4	5	–	–
7 n = 10	Copenhagen 28th of May 2019	–	5	4	1	6	4	10	–	–
8 n = 9	Copenhagen 3rd of June 2019	–	5	2	2	9	–	8	1	–
Total n = 49		5	21	20	3	30	19	45	2	2

Was HPV vaccinated as a kid /.../ I did it because my mum said I had to. So we just went to our GP's and since then I haven't thought much about it – 20 years old, never screened

None of the women could remember being told about cervical cancer and HPV at the time of their vaccination and some made incorrect connections between the vaccination they received and the screening program.

I got my last Pap smear about a month and a half ago. My vaccination is about three years old, so I guess that's right if you're invited every third year, right? – 26 years old, screened

All but two of the 49 women, had undergone gynaecological examinations, and they could therefore relate the procedure to other check-ups. However, they lacked knowledge about the CCS procedure. They described birth control, pregnancy and sexually transmitted diseases such as chlamydia as being obvious reasons to undergo a gynaecological examination. But they did not associate it with the need to have a Pap smear test.

The women in the focus group consisting only of women who had attended screening knew more about both HPV as the cause of cervical cancer and about the screening procedure than the women in the other groups who were either unscreened or not screened regularly. All five women mentioned cancer or precursors to cancer when asked about their immediate thoughts on 'cervical dysplasia'. Some women in the other groups initially thought they had not been screened, but during the discussions they realised that they had actually had a Pap smear.

4.2. The screening invitation

Most of the women received the screening invitation by letter, a few received it digitally. Since 2020, all invitations are digital. The first invitation includes a pamphlet explaining CCS, but only a few remembered having seen or read this, describing the pamphlet text as informative, but too long. The invitation was crucial as a material reminder, typically hung on the door of the refrigerator along with other important messages or laying in a pile with other papers on the dining-room table. Only one woman immediately discarded the invitation, certain that she did not want a Pap smear. All the others kept the invitation for months with the intention to book an appointment. They explained that they did not have the time right now, thinking they could always do it later. Somehow, however, the invitation disappeared, and they forgot about it.

I open it [the invitation letter] and think: I have to remember this. So I put it somewhere where it won't disappear and then I'm all busy and don't make the phone call during the [GP's] opening hours. Then all of a

sudden, I've forgotten it again. I usually place it on the dining table, and then I move it around and then all of a sudden it's not on the dining table anymore. – 24 years old, never screened

The women discussed the wording of the invitation and questioned why it did not expressly emphasize CCS as an important supplement to HPV vaccination. Some of the women suggested that the invitation would have felt more personally relevant if it had been signed by their own GP instead of, as now, by the hospital in charge of the CCS.

The invitation presents CCS as an optional service offering which for some women made it seem less important. Others mentioned that the invitation itself stated the significance of participation, because they regarded letters from the health authorities to be important per se.

When they send the invitation it must be because it is something, you should do. Then I just booked a time at the GP /.../ there is no reason not to do it. – 26 years old, screened

The women had many questions regarding CCS and the Pap smear procedure, but they apparently did not endeavour to seek out information themselves, nor did they thoroughly read the invitation or reminder letters.

4.3. The GP as gatekeeper

The women preferred that their GP explain the procedure and why it was important for them. Whether or not they wanted their own GP to perform a Pap smear depended on the GP being a 'good doctor'. A good GP was described as 'competent, knowledgeable and professional' as 'someone who makes you feel safe and comfortable', 'takes you seriously' and will 'take their time'. Most of the women preferred that their own GP perform the Pap smear. Some preferred a female GP. Others preferred a male, but not if he was too old or too young. Some had experienced female GPs performing gynaecological examinations as being more 'rough' than male GPs.

Most of the women found it inconvenient to make an appointment for a Pap smear within the GP's opening hours and wanted a more accessible booking procedure. However, they did not fail to book appointments when they deemed the purpose to be essential for their health e.g. during pregnancy or when renewing their prescription for oral contraceptives.

If you know more about 'What's in it for me' I think I would give it priority. Because it's not really any trouble to book a time with your GP, well it is – but if it's really urgent and you need your annual check-up for the pill, then you book an appointment, because you don't want to miss the pill. So it's all about how essential it is to you. If you understand the

seriousness of the examination, you start taking it more seriously and book an appointment. – 27 years old, screened

Some participants suggested that pre-booked appointments would be more difficult to postpone or cancel. The women wanted their GP to send them a reminder of the Pap smear, just as they received routine reminders about renewing prescriptions. However, the GP seldom did that. They agreed that it would be helpful if their GP mentioned the Pap smear when they consulted for other reasons. Some women preferred a text message reminder from their GP, similar to what they receive from their dentist prompting them to remember their dental visits.

4.4. The gynaecological examination

None of the women looked forward to having a gynaecological examination. They wanted it over and done with as quickly as possible. They described it as being ‘awkward’ because it was an intimate situation where they ‘lose control’. An explanation from their GP about how and why the examination was being conducted was considered to be essential in order for them to ‘feel secure’ and ‘relaxed’.

If someone has to put a needle in me, I want to see it. And the person in question has to tell me what they are doing. In a way, you're not in control. You just lie there looking up at the ceiling, and it's really close and at the same time far away. That's really a bummer. – 28 years old, never screened

The women emphasized that a first bad experience e.g. a ‘rough GP’ with ‘little empathy’ clearly affected their anticipation about having future examinations. However, the gynaecological examination was viewed less negatively when the purpose was seen as justified, e.g. the young mothers attended their examination several times during pregnancy and after having given birth.

4.5. Perceived relevance of cervical cancer screening

As shown, screening was not an integrated part of the women’s preventive health behaviour. However, only two women deemed screening as unimportant, as they had received the HPV vaccine. The others made no connection between the HPV vaccination and the screening program, probably due to their low level of awareness about HPV as the cause of cervical cancer. During the interviews, the women received new information about CCS and its relevance, and by the end of the interviews, both the unscreened women and those who had postponed screening now expressed a willingness to book an appointment for a Pap smear test as soon as possible.

I'm just thinking: how hard can it be to just get it over with? I don't get it. What's the worst thing that can happen? It's just about getting it done. I don't understand why I haven't done it. – 27 years old, never screened

Both the screened and unscreened women stated that they wanted to ‘stay ahead of things’ and that screening was ‘the responsible thing to do’. Thus, obtaining additional knowledge (in the right setting) may be a step towards having a Pap smear. However, a nudge from the GP, family or friends seemed to be equally effective. Some women were encouraged by their mothers or friends, who themselves had had cervical dysplasia. One was encouraged by her boyfriend, who made sure she made an appointment with the GP. Others were motivated by a family history of cancer.

5. Discussion

In this study we have uncovered a range of barriers and facilitators. The primary impeding factor was the young women’s lack of knowledge about HPV and CCS, including lack of knowledge of their own screening status.

The women did not necessarily remember receiving their last

invitation or their last Pap smear. Some thought they had never been screened, because they apparently confused the Pap smear with other gynaecological procedures. The same confusion was found in a US study following the introduction of the HPV vaccine: no improvement in women’s knowledge about CCS resulted after introduction of the HPV vaccine (Head et al., 2009). Studies have found that younger women were more likely to be unaware of the screening program than were older women and less willing to make a screening appointment (Lancucki et al., 2010; Marlow et al., 1990). Contrary to the findings in the US study, we found the same low levels of knowledge about HPV and CCS among young Danish HPV vaccinated women in their twenties and unvaccinated women between 30 and 50. CCS participation rates among young women have long been worryingly low in both high-income and low-income countries (Kirubarajan et al., 2021), but very few studies have investigated barriers towards CCS among young HPV vaccinated women (Marlow et al., 1990).

It is important to fill the knowledge gap in order for young women to be able to make an informed decision about whether or not they should attend CCS. Providing clear and relevant information is thus an important facilitator that would increase the perceived relevance of CCS. The question, however, is the extent to which additional knowledge dissemination will eventually increase screening participation and what kind of information is important for the women so that they feel well-informed about CCS and HPV. Increased knowledge clearly motivated the women in this and other studies (Blomberg et al., 2011), but while knowledge may increase their perceived relevance of CCS, this may not necessarily lead to behavioural change. The women in our study appreciated the information, they received during the FGIs. They even expressed a desire for more information, but evidently, they did not seek out this information for themselves.

The women received the invitation and the pamphlet in their letterbox or in a few cases digitally. The pamphlet provides answers to the women’s basic questions, such as ‘What is a Pap smear?’ Only a few women remembered receiving the pamphlet. As a result, essential information might have been overlooked. Blomberg et al. (2011) asked whether systematic information on HPV may provide a missing link in motivating young women to attend CCS. Our study has shown that providing information is an indispensable element in stimulating a willingness to attend screening. Nevertheless, the question remains as to how to provide the information so that it leads them to make informed choices. Clearly, the information about CCS needs to be made more relevant and accessible in the women’s everyday lives. It must be informative, precise and readable. The women appreciated the reminder letters and by receiving them, they felt reassured that the health authorities were concerned about their welfare, an attitude also found in other studies (Aasbø et al., 2019). However, the invitation needs to emphasise screening as being important even when a woman has been HPV vaccinated, and a ‘kind regards from your GP’ could seemingly increase the perceived relevance of being screened.

The women kept the invitation as a physical reminder, so in this respect the paper invitation could be an effective information channel. Whether the ‘hard copy’ letter being replaced by a digital invitation would affect screening uptake has not been investigated.

This study confirmed findings of others in singling out the GP as an essential gatekeeper regarding the uptake of CCS, as the GP can play a key role in informing, reminding and encouraging women to get their regular Pap smear tests (Gyulai et al., 2018). A woman’s first gynaecological examination is important for her future participation in CCS (Grundström et al., 2011; Oscarsson et al., 2007) as is a familiar GP who acts empathic, gentle and is a good listener. The GP’s attitude and tone can thus help reduce the barriers related to having a Pap smear. A nudge from the GP e.g. reminding the woman during other consultations was shown to be highly appreciated by the women. A Norwegian intervention study that tested pre-booked appointment systems for CCS showed increased screening participation consistently across all target ages (Lönnberg et al., 2016). It is unknown whether a similar intervention

study would have the same effect in Denmark, although pre-booking might help elevate the importance of CCS among the women (Ryan et al., 2019; Waller et al., 2012). Nevertheless, the women in our study stated that they had no difficulties in booking an appointment with their GP when the purpose was essential to them. Non-attendance in screening therefore seems to be a matter of attitude and priority rather than a technical access problem.

Two Scandinavian studies showed that HPV vaccinated women were more likely to attend or intend to attend CCS than were unvaccinated women (Kreusch et al., 2018; Hestbech et al., 2016). In this study we have interviewed only HPV vaccinated women and our comparison was between HPV vaccinated young women and unvaccinated women over age 30. The women in our study clearly did not take their vaccination status into consideration when deciding whether to attend or postpone their screening. An Australian study found a generally low uptake of screening and poor knowledge of screening guidelines amongst both vaccinated and unvaccinated women (Mather et al., 2012).

The gynaecological examination is often mentioned as a major negative factor, discouraging women from attending screening. In recent years HPV self-sampling has been tested in Denmark as a method to increase screening attendance. A study of unscreened women aged 27–65 found that 31,7% of all those invited requested a home test. 20% returned the home test to the laboratory, and 10% had a Pap smear at their GP's after receiving the invitation (Lam et al., 2017). Our study shows that a negative attitude toward the gynaecological examination can be overcome when the purpose of the examination is viewed as vital and relevant to women's health.

The women in our study kept the invitation to remind them to have a Pap smear. Ideally, they should make an appointment for a Pap smear as soon as they received their first invitation. Women who undergo screening at a young age are more likely to continue this as a lifelong habit and to recommend screening to their peers and children (Kirubarajan et al., 2021; Jepson et al., 2000).

5.1. Strengths and limitations

To our knowledge this is the first Danish qualitative study investigating the reasons behind the low uptake of cervical cancer screening among HPV vaccinated women in their twenties with no higher education.

The recruiting was difficult despite the low participation-rate in this age group, and furthermore the women were not quite sure about their screening status, so we had more non-regular attendants, than non-attendants in the focus groups than we aimed at initially.

5.2. Clinical implications

The HPV vaccines do not completely protect women from cervical cancer. Young women postpone or miss CCS because they do not know about the importance of CCS for HPV vaccinated women. Thereby they miss the opportunity to have the best possible protection against cervical cancer.

6. Conclusion

This study has shown a range of barriers and facilitators affecting young women's screening attendance: the primary obstacle has been shown to be their lack of knowledge about CCS and HPV. We argue that systematic information and the attitude and tone of the GP are the primary facilitators for filling the knowledge gap we found among young HPV vaccinated women. As an important gatekeeper, the GP can explain, motivate and remind young women about the importance of a regular Pap smear. Information that will enhance the personal perceived relevance can help reduce structural barriers posed by the unpleasantness of the gynaecological examination or complicated booking procedures at the GP's.

We need to carefully target information to reach young women at their own level. Based on our findings, we suggest that it is time for a national awareness-raising campaign that can supplement existing information.

If we can make screening participation the same kind of natural part of young women's health prevention behaviour as exercise and healthy diet, it will be a major step toward eliminating cervical cancer.

7. Contribution to authorship

The authors designed the analysis together. All interviews were conducted by Julie Hedegaard Mortensen and Ann-Britt Kvernørød who also carried out the analysis and wrote the original drafted paper. Co-author Janne Bigaard contributed with critical reading and feedback.

8. Ethics

This study did not require ethical approval in accordance with Danish legislation.

9. Data availability statement

The data supporting the findings of this study are available from the corresponding author upon reasonable request. The data consists of anonymous interview transcriptions in Danish.

10. Patient consent statement

All informants gave oral consent to the recording of the interviews and the publication of the findings. The recordings were deleted after anonymous transcriptions were made. Written consent is not required for this type of study in Denmark.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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