

# A qualitative study of women who experience side effects from human papillomavirus vaccination

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## ABSTRACT

**INTRODUCTION:** In Denmark, vaccination against human papillomavirus (HPV) is offered to girls and women to prevent cervical cancer. Unfortunately, reporting of possible side effects from vaccination has increased in recent years. Therefore, the present study examines women's experiences of side effects from the HPV vaccine.

**METHODS:** In-depth qualitative interviews were conducted with eight HPV-vaccinated Danish women, aged 25-44 years, who experience side effects from the vaccine. The data were analysed using a narrative methodology.

**RESULTS:** The main reasons for being vaccinated against HPV are fear of cancer and trust in general practitioners (GPs). The women reported feeling stigmatised by GPs and doctors and they feel that these professionals did not acknowledge their symptoms, often assuming that they were due to psychological distress. The lack of acceptance from family and friends has led the women to distance themselves from others and lead a more socially isolated life. The women believe that a diagnosis may validate their symptoms and help others accept their condition.

**CONCLUSIONS:** The women feel exceedingly physically and mentally confined in their everyday life, which led them to live a more restricted and solitary life. Since other people tend not to acknowledge their symptoms, the women's illness behaviour is poorly accepted. The women generally distrust Danish healthcare as they have experienced stigmatisation from physicians and do not trust the evidence for the safety of the vaccine.

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Infections with human papillomavirus (HPV) are commonly acquired and persistent infection can cause cervical cancer. In Denmark, the incidence of cervical cancer is approximately 375 annual cases of whom approximately 100 die from the disease [1].

In 2006, HPV vaccination was introduced in Denmark to prevent cervical cancer in the population. Since 2009 it has been included in the childhood vaccination programme in which 12-year-old girls are the main target group. Moreover, young women born between 1985 and 1995 have been offered the vaccine free of charge within a given period whilst others need to cover the vaccination cost themselves. So far, more

than 500,000 Danish girls and women have been vaccinated, indicating great acceptance of the vaccine [2, 3].

In recent years, we have seen that some Danish girls and women have reported presumed side effects from the HPV vaccine. The side effects include symptoms as fatigue, fainting, neuropathic diseases and diffuse symptoms such as headache and abdominal pain, which do not readily fit into an existing diagnostic entity [2]. Since 2013, this development has triggered considerable attention in the media, which seems to have affected the vaccination rate which has decreased significantly. Thus, Danish healthcare has established a centre in each national region that is responsible for counselling girls and women with presumed side effects to ensure that they receive the best possible treatment [4].

The decreasing vaccination rate may have a negative influence on public health as the incidence of cervical cancer will most likely remain the same or even increase. Hence, it may be beneficial to investigate what challenges Danish healthcare is facing in order to increase the vaccination rate. This study focuses on the perspectives of women who experience side effects from the HPV vaccine and asks what can be learned from their stories.

## METHODS

A literature review was conducted to identify relevant keywords for a semi-structured interview guide aimed at obtaining in-depth knowledge about women's narratives of their experiences with side effects caused by the HPV-vaccine. Qualitative interviews were conducted with eight women, aged 25-44 years, who experience side effects from vaccination against HPV. The women were identified using social media. They were included in the study if aged 18 years or above and if they had received their HPV vaccination within the past three years. The latter criterion was applied to reduce the risk of recall bias. Adult women were chosen as a target group as they are believed to be more contemplative and reflective than young girls and thus capable of providing more detailed insights into their experiences with side effects. Despite this, a potential risk of selection bias was present as the women were enrolled by self-admittance rather than random identification. Hence, the women included in this study may not fully represent the whole

## ORIGINAL ARTICLE

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population [5]. In **Table 1**, the women's characteristics are listed. Their names are fictitious and all have signed a consent form ensures them that they will remain anonymous.

The interviews were audiotaped, transcribed and later analysed in retrospect using a narrative approach focusing on the way the participants frame their disease experiences. As a part of the analysis, the results of this study were interpreted using relevant theory and compared with similar studies to ensure the quality of the present study. The health belief model [6] was used as a framework to explain the women's decision-making process. Theory about illness perception [7-9], stigma [7, 10] and trust [11] has been used to explain how the women perceive their life situation and their experiences with Danish healthcare.

A systematic literature search in the three databases Pubmed MEDLINE, PsycInfo and Web of Science revealed that there is limited literature on the subject of HPV vaccination, especially studies investigating women who experience side effects from the HPV vaccine. Hence, this is, to our knowledge, the first study on the subject and thus a solid foundation for further research.

*Trial registration:* not relevant.

## RESULTS

### The human papilloma vaccine

The main reasons why the women received HPV vaccination were fear of cancer and trust in general practitioners (GPs) and in Danish healthcare. Confidence in their GP prior to vaccination was the reason why the

women took the GPs recommendation to become vaccinated. In the following, Maja tells how trust in her GP made the decision to be vaccinated an easy one.

*"(...) and I guess, I was not really in doubt since both my family and my GP told me that it was a great idea to get vaccinated because then I would not worry about getting cancer anymore". (Maja)*

The women described the vaccine as one that can prevent cancer, which accommodates their fear of developing cancer later in life. The fear of cancer was based on the women's own risk perception, which could be influenced by their family history of cancer. When the women talked about cancer, they discussed cancer in general and not the specific type of cancer that the HPV vaccine is assumed to prevent.

### A changed life situation and illness perception

All the women link their symptoms to the HPV vaccine because they occurred soon after vaccination. Generally, the women tend not to perceive themselves as ill, but rather as more physically and mentally constrained than they were before having their vaccination.

Since the symptoms strike at random times, it is difficult for the women to make arrangements in advance. They therefore often choose not to participate in social events. Furthermore, the symptoms are neither consistent nor visible, why the women perceive that others find it difficult to relate to and accept their situation. Consequently, as the women do not feel that their symptoms receive acknowledgement, many choose not



TABLE 1

Characteristic of the included subjects.

Name	Age, yrs	Marital status	Children, n	Occupation	Vaccination status	Time of side effects	Health status before vaccination
Birgitte	44	In a relationship	3	Student, sick leave	3 injections, latest in 2013	After 1st injection and aggravated after the next injections	Healthy
Signe	44	Single	0	Student, part time	2 injections <sup>a</sup> , latest in 2012	After 1st injection and aggravated after the next injection	Healthy, stress symptoms 1 yr before vaccination
Trine	29	Single	0	Student, full time	2 injections <sup>a</sup> , latest in 2012	After 1st injection and aggravated after the next injection	Healthy, antidepressant medicine 1 yr before vaccination
Maja	41	Married	4	Teacher in primary school, sick leave	2 injections <sup>a</sup> , latest in 2013	After 1st injection and aggravated after the next injection	Healthy
Sanne	25	Single	0	Shop assistant, sick leave	3 injections, latest in 2013	After 2nd injection aggravated after the next injection	Healthy
Line	25	In a relationship	0	Student, full time	3 injections, latest in 2012	After 1st injection aggravated after the next injection	Healthy
Kathrine	28	Single	1	Early retirement	3 injections, latest in 2013	After 1st injection and aggravated after the next injection	Healthy, signs of depression in childhood
Helle	40	Married	2	Graphical designer, full time	3 injections, latest in 2013	After 1st injection and aggravated after the next injection	Healthy

a) The woman chose not to get the last injection, due to the side effects she experienced.

to socialise with people who show no recognition of their symptoms. As their symptoms and discomfort worsen, they need to adjust to a changed life situation.

Half of the women have had part of their illness diagnosed, a fact which they feel ambiguous about as demonstrated by the below statement. On one hand, they find it difficult to perceive themselves as ill, but on the other hand, they wish to be diagnosed as they believe that a diagnosis may earn them acknowledgement and acceptance of their symptoms among other people.

*"(...) until then I have had the feeling that no one really listened to me or believed me because I did not have a diagnosis. Then, when I got the diagnosis it was like everyone better understood what I was going through". (Trine)*

#### **Attitudes towards Danish healthcare after vaccination**

In general, the women were dissatisfied with the many consultations they had had with physicians. The dissatisfaction was primarily due to the physicians' lack of recognition; they felt that the physicians tended not to take the women seriously, not to listen to them or acknowledge their symptoms. Instead, the physicians often dismissed the symptoms or considered that they were due to stress or depression, even if most of the women had not previously had any symptoms of this kind. In the following, Maja and Kathrine tell how they feel that their GP and family neglect their symptoms and discomfort.

*"(...) Well, one gets labelled as a hypochondriac... mainly by my GP, but also by my family, right? And that is like, that is because they cannot understand, they cannot understand a disease they cannot see". (Maja)*

*"(...) she [GP] does not listen to me; she does not believe what I tell her; she did not take it seriously. She made me feel as if it [physical symptoms] was something I imagined. I felt more frustrated when I left than when I came". (Kathrine)*

The women feel that physicians lack knowledge about the HPV vaccine and its possible side effects. As a result, physicians are not capable of offering the women sufficient help. Consequently, they singlehandedly seek information about their illness and become "experts" on their own symptoms, which has resulted in self-diagnosing.

Finally, the women's negative experience with physicians after their vaccination has made them feel frustrated, angry and powerless, which has led to a basic distrust in Danish healthcare. Due to their side effects, they would like HPV vaccination stopped until more evidence is available on its safety.

## **DISCUSSION**

### **The decision to have the vaccination**

According to the health belief model, the women's fear of cancer rests on their perception of cancer as a dangerous disease, and the likelihood that they themselves will develop cancer later in life due to their specific family history and the risk of getting cancer in general. Hence, vaccination is perceived as one's own effective attempt at preventing cancer [6]. In line herewith, a Swedish study found fear of cancer to be the main factor that motivates young women to become HPV vaccinated [12].

The health belief model points out that trust in GPs is a cue to action since the GPs recommend the HPV vaccine and thereby influence the women's decision to have the vaccination [6]. A literature review among high-income countries, e.g. USA and Great Britain, reported similar results. Thus, acceptance of the HPV vaccine depends on trust in national vaccination programmes and vaccine manufacturers [13].

### **Illness perception**

Initially, the women tend not to perceive themselves as ill, probably because they are able to handle the symptoms and adjust to them in their everyday lives [8]. As their symptoms and discomfort aggravate, they recognise their physical and mental limitations and need to adjust to these limitations. Since other people find it difficult to relate to their symptoms, they do not accept the women's illness behaviour, which may make it harder for the women to perceive themselves as ill [8]. Thus, they may feel obliged to keep up appearances and try to meet others' expectations, e.g. go to work and meet with friends on a regular basis.

One explanation for the lack of acknowledgement from other people may be that others perceive the women's symptoms as normal nuisances and so do not take them too seriously [8]. Additionally, worries about when their symptoms will strike make the women involuntarily isolate themselves more from social events. Consequently, their constant worries might make them restrict themselves more than necessary, leaving them feeling lonely [7]. Studies of people with migraine or chronic fatigue have reported behaviours similar to the tendency towards social isolation described above [14, 15].

### **Ambiguous attitude towards diagnosis**

The present study has identified an ambiguous attitude towards diagnostics. On one hand, the women do not want to perceive themselves as ill, but on the other, they express a wish to become diagnosed as they believe that a diagnosis will serve to legitimise their symptoms and allow them to become accepted by others.



Vaccination against human papillomavirus is offered to girls and women in Denmark in order to prevent cervical cancer cases. Unfortunately, little is known about the possible side effects the vaccine or how these may affect the life of those affected.

A Swedish study among women with chronic fatigue also emphasised the need for a diagnosis as it was seen as important in trying to gain acceptance from others [16].

When visible physical symptoms are lacking, physicians tend to either reject the symptoms or think they are caused by psychological distress [7, 10]. This may be the reason why most of the women had been told that their symptoms were possibly caused by stress or depression. It is worth considering if the women to some degree are being stigmatised when physicians do not acknowledge their symptoms. Such stigma can cause the women to abstain from seeking help from physicians in time at other occasions, resulting in a lack of proper treatment and possibly greater social costs, e.g. sick leave and reduced work ability.

#### Distrust in Danish healthcare

Generally, the women expressed distrust in the Danish healthcare system due to their negative experience with physicians after their vaccination. As trust is the basic prerequisite for the healthcare system and the welfare state, distrust may possibly lead to a lack of legitimacy which may in turn risk degrading the political welfare model of universalism [11]. It can also be discussed whether social trust is put at risk and what consequences that might have. Based on this study, it seems plausible that self-diagnosing will become more common, and that GPs will be used more as an instrument for referral to a specialist or to specific treatment. This may result in unnecessary expenses due to medical appointments and treatments, which might have otherwise been avoided provided a trustful relationship with the GP had existed. Trust may be gained if GPs actively listen to the women and demon-

strate empathy towards their concerns as this can encourage patients to communicate more openly [17].

#### Adult women compared with young girls

It seems probable that there may be differences in reasoning and perception between young girls and adult women. Even so, the results of the present study have similarities to studies among young girls in relation to the decision-making process before HPV vaccination [13]. Previous research has focussed mainly on acceptance of the HPV vaccine and possible side effects [18]. To date, this is the first study to provide information concerning personal experiences with side effects. Although there is a high degree of consistency between the statements made by the various women included in the present study, they do represent a small sample and a target group that is older than the primary one for HPV vaccination. This may complicate generalisation of the results to other women, including young girls.

#### CONCLUSIONS

The aim of this study was to investigate HPV vaccinated women's experiences with side effects caused by the HPV vaccine. The side effects make the women feel more physically and mentally confined in their everyday life, which led them to live a more restricted and lonely life. Other people tend not to acknowledge their symptoms, and the women's illness behaviour is therefore poorly accepted. In general, the women distrust Danish healthcare system and current evidence on the safety of the vaccine. This distrust is further fuelled by their experiences of being stigmatised during their encounters with physicians. Collectively, these experiences weaken the perceived legitimacy of the healthcare system and physicians alike.

This study emphasises the need for more evidence in the field. For further research, it would be interesting to conduct the same study among young girls and to include physicians' experiences to achieve a more nuanced picture [19]. Also, it would be interesting to investigate further the views of the public or family and friends about side effects caused by HPV vaccination.

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