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Abstract: Aim: Each year almost 15,000 Danish women are diagnosed with cervical dysplasia, a precursor to cervical cancer. The period of medical follow-up, or 'watchful waiting', to monitor for regression or progression of the lesion before deciding if treatment by conisation is necessary can be long. The aim of this study was to examine the experiences of women with different stages of cervical dysplasia and to examine whether their knowledge of human papillomavirus (HPV) as the cause of cervical dysplasia influenced their perception of their disease.

Subject and Methods: We used focus-group and individual interviews with 12 women diagnosed with different stages of cervical dysplasia - women who had and had not been conised. Interview guides were prepared on the basis of a literature review that identified important issues and questions for the participants.

Results: The participants considered cervical dysplasia to be a highly distressing condition and experienced monitoring as a worrying delay before regression of the lesions or treatment could be initiated. Women expressed a fear of cancer that was not proportional to the stage of their dysplasia, but was determined by their degree of knowledge about their condition. Unlike other sexually transmitted diseases, information about HPV did not result in stigmatisation as the perception of this disease was dominated by cancer.

Conclusion: This study showed that it is extremely important to address women's fears, their need for information and to ensure better communication with medical practitioners about cervical dysplasia immediately after diagnosis, irrespective of the disease stage.

Response to Reviewers: Responses to reviewers comments summarised in a separate file.

Qualitative study of women's anxiety and information needs after cervical dysplasia diagnosis

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The results of this study have been published previously in *Ugeskrift for læger*, a Danish medical journal (Mortensen and Adeler 2009).

1 **Qualitative study of women’s anxiety and information needs after cervical dysplasia diagnosis**
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1 **Abstract**

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5 period of medical follow-up, or 'watchful waiting', to monitor for regression or progression of the lesion before deciding
6 if treatment by conisation is necessary can be long. The aim of this study was to examine the experiences of women
7 with different stages of cervical dysplasia and to examine whether their knowledge of human papillomavirus (HPV) as
8 the cause of cervical dysplasia influenced their perception of their disease.
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25 condition. Unlike other sexually transmitted diseases, information about HPV did not result in stigmatisation as the
26 perception of this disease was dominated by cancer.
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34 to ensure better communication with medical practitioners about cervical dysplasia immediately after diagnosis,
35 irrespective of the disease stage.
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40 [247 words]

41
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43 **Keywords:** cervical dysplasia, human papillomavirus, disease perception
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1 **Introduction**

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4 Cervical dysplasia, the abnormal growth of cells of the uterine cervix (also known as cervical intraepithelial neoplasia
5 or CIN), is a precancerous lesion. It is estimated that 90% of these lesions regress spontaneously while the others
6 progress into a more severe lesion and possibly cancer. Persistent infection with human papillomavirus (HPV) is a
7 necessary cause of cervical dysplasia (Bosch and Lorincz 2002; Trottier and Franc 2006; Smith et al. 2007). Cervical
8 dysplasia can be detected at an early stage by the Papanicolaou (Pap) cytological smear test. It can then be monitored
9 regularly for regression of the lesion, or progression, before deciding if treatment by conisation is necessary
10 (Bjerregaard 2007; National Board of Health 2007a). The introduction of cervical screening programmes based on the
11 Pap smear has resulted in significant reductions in the incidence of cervical cancer, although some 37,000 women in
12 Europe still die from this disease each year (Engholm et al. 2008).

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18 Cervical cancer is the second most common cancer in women worldwide. In Europe the incidence was estimated to be
19 33,441 in 2002 (Ferlay et al. 2004). In Denmark, which has a population of about 5 million, the lifetime risk of
20 developing cervical cancer is 1%, and every year approximately 400 new cases of cervical cancer are diagnosed and
21 about 175 women die from the disease (Clemmensen et al. 2006; National Board of Health 2007b). Since the
22 introduction of organized cervical screening for women aged 23–60 years in Denmark in the 1960s, there has been a
23 50% decrease in the prevalence of cervical cancer, but the incidence of cervical cancer remains one of the highest in the
24 European Union (Engholm et al. 2008; Clemmensen et al. 2006).

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38 Each year, approximately 14,800 Danish women receive a Pap-smear result that indicates a cervical lesion or
39 abnormality of varying degrees of severity (Figure 1) (Clemmensen et al. 2006). The follow-up and clinical
40 management of these women depends on the specific cytological changes identified, which are classified according to
41 the Bethesda system (National Board of Health 2007a) and explained to the patient as “mild”, “moderate” or “severe”
42 cell changes (Figures 1). In the case of mild changes, including atypical squamous cells of undetermined significance
43 (ASCUS) atypical glandular cells (AGC), or low-grade squamous intraepithelial lesions (LSIL), the patient is monitored
44 by Pap test every 6 months to 1 year to determine whether the dysplasia regresses or progresses. Women with moderate
45 changes, such as atypical squamous cells – cannot exclude HSIL (ASC-H) or high-grade squamous intraepithelial lesion
46 (HSIL), or severe changes, including adenocarcinoma in situ (AIS), are referred to a private or hospital-based
47 gynaecologist who examines the cervix by colposcopy and performs a biopsy. Some women with moderate changes
48 (HSIL) may be managed by 'watchful waiting', which involves monitoring by colposcopy every three months, and they
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1 will be treated only if the lesion is seen to progress. Cases of severe dysplasia and cancer in situ are managed by
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3 conisation (conical section or cone biopsy), which is the surgical removal (under sedation or general anaesthetic) of a
4
5 cone-shaped sample of cervical tissue. This is used as a diagnostics tool and as well as treatment, if the histological
6
7 analysis of the sample shows that all the abnormal tissue has been successfully removed. In Denmark, approximately 1
8
9 in 3 women (5000) with an abnormal Pap result undergo conisation each year (National Board of Health 2007a; Danish
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11 Gyenecological Cancer 2007; Bro et al. 2008). Currently, HPV testing in the setting of cervical cancer screening is not
12
13 routinely performed in Denmark.
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16 The period of 'watchful waiting' between diagnosis of a lesion and confirmation of regression or need for treatment may
17
18 last for several years and can be associated with a considerable psychological burden, as suggested by a number of
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20 studies in the literature (Lauver et al. 1999; French et al. 2004; French et al. 2006; Lerman et al. 1991; Idestrom et al.
21
22 2003; Neale et al. 2003; Campion et al. 1988; McCafferty et al. 2004; Fleurence et al. 2007; Hounsgaard et al. 2004;
23
24 Waller et al. 2005; McCafferty et al. 2006). Overall, the results of these mainly quantitative studies show that women
25
26 diagnosed with cervical dysplasia worried about the development of cancer. They often fear death and suffer from
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28 anxiety, stress and depression associated with worries about their sex life, fertility, medical supervision and potential
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30 interventions. The results show that women's lack of knowledge and poor doctor-patient communication can contribute
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32 the their anxiety (Lauver et al. 1999; French et al. 2004; French et al. 2006; Lerman et al. 1991; Idestrom et al. 2003;
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34 Neale et al. 2003; Campion et al. 1988; McCafferty et al. 2004; Fleurence et al. 2007; Hounsgaard et al. 2004).
35
36 Women's knowledge about HPV is generally poor (Waller et al. 2005; McCafferty et al. 2006), but providing women
37
38 with information about HPV and its role in cervical dysplasia has been shown to have both positive and negative
39
40 effects. On one hand, a better understanding has been reported to have a negative influence on women's perception of
41
42 their condition, causing them to perceive it as a stigmatising sexually transmitted disease and producing feelings of
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44 shame, guilt and low self-esteem (Goffman 1968). Information about the high prevalence of HPV has, on the other
45
46 hand, been reported to improve health-related behaviour (e.g. attendance of organised screening, use of condoms)
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48 (Waller et al. 2005; McCafferty et al. 2006; Kahn et al. 2007; Maissi et al. 2004; Waller et al. 2007; Clarke et al. 1996;
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50 McCree et al. 2005; Kahn et al. 2005).
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53 The aim of this qualitative study, the first of its kind in a Danish context, was to examine the experiences of young
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55 women aged 25-35 years diagnosed with cervical dysplasia. In particular we looked at the ways in which they had been
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57 affected by the diagnosis and subsequent follow-up and treatment. We focused on the women's own understanding of
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1 the stage of their disease and its course, distinguishing between women who had undergone conisation and those who
2 had not. We also sought to determine whether knowledge about HPV affected the women's perceptions of their disease.
3 Patients' perceptions of a disease are known to be related to their socio-cultural context and these perceptions can
4 influence the way in which they cope with the disease (Bishop 1991; Kleinman 1988; Hahn 1984).
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13 **Methods**

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16 Qualitative research methods can provide insights into the qualities of a phenomenon and the meanings that patients
17 ascribe to it. The results can be generalised analytically, though not statistically (Malterud 2004), and can give a
18 detailed understanding of the patients' perceptions of their illness. We used focus groups and individual interviews to
19 obtain as broad a range of perspectives on cervical dysplasia as possible. Focus groups were chosen to create a
20 confidential environment in which women could openly discuss their experiences with cervical dysplasia, allowing us
21 to gain insights into the social construction of meaning and the perception of this disease among women who had or had
22 not undergone conisation, while individual interviews provided additional in-depth narratives about personal
23 experiences with cervical dysplasia (Berger and Luckmann 1987; Halkier 2003; Bech et al. 2005; Kvale 1996; Spradley
24 1979).
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38 ***Recruitment of study participants***

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41 The participants were recruited from the practices of three private general practitioners (GPs) and two gynaecologists in
42 the cities of Aarhus and Aalborg, Denmark, and from the gynaecology and obstetrics outpatient ward at Skejby hospital,
43 Aarhus, Denmark. Women aged between 25 and 35 years, who did not have any serious co-morbidity and who had
44 either been diagnosed with cervical dysplasia within the past three months or had had a conical section within the past
45 six months were eligible for inclusion. This age range was selected because of the high prevalence of cervical dysplasia.
46 We did not seek the official diagnosis for the specific stage of cervical dysplasia for the woman from their medical
47 records since what was important was the women's own understanding of their stage (mild, moderate or severe
48 dysplasia) and whether they had or had not been conised. We selected more women who had undergone conisation
49 because they would have a longer experience of living with their condition and would be able to talk about how they
50 felt before and after the conisation. Women were invited to participate in either an individual interview or in a focus
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1 group. We had individual interviews with one woman who had not undergone conisation, and one who had (table 1).
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3 Focus groups were organised with people of similar age to improve comparability of results and to facilitate honest and
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5 open group discussions. Also, since the topic was considered to be personal and potentially sensitive, we decided it was
6
7 important that the focus groups included only a few participants. If the groups are too big one or two participants could
8
9 dominate the discussion or the participants can feel less comfortable talking about sensitive issues (Halkier 2003).
10

11 Women who fulfilled the inclusion criteria were informed orally about the study by the consulting physician who also
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13 gave them a study information sheet. We gave the physicians an instruction sheet describing how to present the study to
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15 their patients, underlining that the purpose of the study was to gain in-depth knowledge about the women's disease
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17 experiences and that no preparation or prior knowledge about cervical dysplasia were required in order to participate.
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19 Patients wishing to participate then contacted GLM, who was an independent researcher. Anonymity and confidentiality
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21 were ensured throughout the study. All women gave their informed consent to participate and the study did not require
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23 ethics committee approval.
24

25 26 27 *Focus-group and individual interviews*

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29 Semi- and funnel-structured interview guides were used to moderate the focus-groups and structure the individual
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31 interviews. The topics and questions in the interview guides were selected on the basis of a literature review carried out
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33 before the start of the study. The questions were open-ended to capture as much information as possible, including any
34
35 that had not been envisaged by pre-interview hypotheses (Halkier 2003; Kvale 1996). Individual interview guides were
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37 designed to produce an in-depth personal narrative of disease experience, while the focus-group guides were designed
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39 to facilitate discussion. The guide used for focus-group interviews with women who had undergone conisation is given
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41 in Table 2 as an example.
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45 The first focus group was held after working hours in a staff meeting room at Skejby hospital. Although this location
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47 was chosen as a neutral but familiar environment, the participants appeared to be uncomfortable in this setting and
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49 subsequent focus groups and interviews were held in small meeting rooms in hotels in Aalborg and Aarhus.
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52 The focus-group interviews were moderated by GLM with assistance from a colleague. The individual interviews were
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54 conducted by GLM only. The purpose and design of the study was explained at the beginning of each interview. It was
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56 emphasized that there were no wrong or right answers to the questions posed and that the aim was to obtain a realistic
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58 picture of all the participants' experiences and thoughts on having cervical dysplasia.
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1 The interviews were transcribed verbatim and analysed using a discourse theoretical approach to the relationship
2 between language and the social construction of meaning (Winther Jørgensen and Phillips 1999). The women's
3 statements were seen as an expression as well as an ongoing construction of the meaning and personal impact of having
4 cervical dysplasia. This approach is used to analyse a diversity of statements such that clusters of meaning are generated
5 and involves an analysis of the terminology used to speak about the subject and the ways in which it is related to other
6 issues. Firstly, the data were coded into the topics that were raised during the discussions. Secondly, the most important
7 themes within each topic were identified. Finally, the frequency of and connections between topics and themes were
8 analysed. This generated a pattern of the relative meaning that the different topics and themes had for the participants,
9 i.e. the women's most significant experiences associated with having cervical dysplasia. All methodological and
10 analytical steps were discussed and alternative interpretations sought with the authors and with an additional
11 anthropologist. Disagreements were solved using Spradley's analytical process of resolution of qualitative data
12 (Spradley 1979).

26 **Results**

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29 In qualitative research, the validity of the results relies more on data collection until no significant new knowledge can
30 be generated from it than the number of participants (Malterud 2004; Kvale 1996; Spradley 1979). In the present study,
31 this point appeared to be reached after interviews had been conducted with a total of 12 women.
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36 The characteristics of the women who participated are summarised in Table 1. Of the four participants who had not
37 undergone conisation, three women had received their first abnormal smear-test result in the three months before the
38 interview. At the time of the study, one of these women had been referred for conisation and two were still waiting for
39 the cytology results. One other woman had recently been declared free from cervical dysplasia after three years of
40 monitoring. Eight participants had undergone conisation in the six months before the interview. Most of these women
41 had received the results of the three-month post-conisation check-up, but none had yet received the results of the six-
42 month check-up. Three of these women had been referred directly for colposcopy and conisation after receiving the
43 initial abnormal smear-test result. The remaining five women had been monitored for one to five years before being
44 referred for conisation.
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48 Two focus-groups were held with women who had undergone conisation, one group with three participants and one
49 with four participants. An individual interview was conducted with the remaining woman who had undergone
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1 conisation. One focus-group was held with three women who had not undergone conisation; one individual interview
2
3 was held with a woman who had not undergone conisation.
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6 The quotes cited below were selected as they illustrate some of the participants' most important experiences associated
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8 with being diagnosed with cervical dysplasia.
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10 ***Initial reaction to diagnosis of cervical dysplasia***

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13 Most of the participants had reacted with shock, panic or tears when they received the first abnormal smear-test result;
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15 they said it was like receiving a diagnosis of cancer. Although most of the women knew that this was not the case, fear
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17 and shock made it difficult for them to understand the explanations provided by the doctor. Many women were quite
18
19 unprepared for an abnormal result because they had considered the test simply as a routine check-up.
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23 *He [the doctor] sat there with my medical record and said: "Well, I see that you have moderate or severe*
24
25 *cervical dysplasia". What?! My jaw dropped, my eyes and ears stop working. I could hardly listen because of the*
26
27 *pounding in my head: "Does this mean I will have cervical cancer soon? Can I have children? Can I do this?*
28
29 *Can I do that? Am I really that sick? Although I see nothing on the outside, it's all wrong on the inside. I can't*
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31 *believe I hadn't noticed anything." It was really disturbing. It means you can actually walk around and develop*
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33 *cancer without knowing it, right?* [Woman who had undergone conisation describing her reaction to receiving the
34
35 results of her first colposcopy]
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38 Even when the initial panic faded, concerns about the evolution of the cervical dysplasia typically persisted. The women
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40 continued to fear for their lives and their fertility and worried about how much treatment they would have to have and
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42 for how long they would need medical supervision.
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Discrepancy between severity of dysplasia and level of anxiety experienced

Our findings suggest that the severity of cervical dysplasia diagnosed did not correspond to the level of anxiety experienced; in fact since some women with low-grade lesions (mild dysplasia) who had not been conised appeared to be more anxious than women who had had higher-grade lesions (moderate or severe dysplasia) and had been conised. The difference in anxiety level between these women seemed to correspond to the level of their knowledge about cervical dysplasia and how long they had been under medical supervision.

When diagnosed with a low-grade lesion (mild dysplasia), the women said that they had not received much information about their condition. At this stage, the women said the follow up period was extremely wearing and full of uncertainty; the longer the period of monitoring, the worse they felt. The unknown duration of follow up and the possibility that the dysplasia would become more severe were worrying. Most of the women currently on this stage felt that their lives were 'on stand-by' and they described themselves as being sad, irritable and anxious. The concerns were particularly acute before new tests and when they were waiting for test results, since these events were important milestones. Many feared that their condition was constantly progressing and this considerably increased their need for explanations and action. At the stage of mild dysplasia, most of the women did not understand the meaning of the test results or the justification for the intervals between check-ups. Some thought that the intervals between check-ups were due to the problem of waiting-lists in the health-care system. Three women had asked for conisation simply to put an end to the waiting because they thought the longer they waited the higher the risk of the condition 'spreading'.

Several times, I experienced a kind of spontaneous fear of death. All of a sudden, it was like getting a bucket of cold water in the face. I'd cry and be sure that it would never turn out well. At the same time, I felt ashamed or guilty of making such a fuss about it because I wasn't really sick. I found that really, really difficult [...]. It was a great relief [when I was referred for conisation] because at that point, I'd been going to the hospital for nearly 1½ years. At that stage, my life was being measured by: 'When am I going to the hospital again?' Those 2½ to 3 months in-between check-ups... A few days before, I'd be really, really upset and be thinking that it was just terrible. Then I'd go, and afterwards I walked around feeling pain and bleeding for a few days and then I had to wait two weeks to get the test result. I'd be nervous about what I'd be told. [...] then it was only 1½–2 months until I had to go back again. All the time, I felt that I was counting down to when it was time to go back. When more than a year had passed, I became so upset when I was at the hospital that the doctor said that when I called the next time to get the result, I could ask the chief consultant about undergoing conisation before the

1 *development of severe dysplasia. And so I did, and he just laughed at me and said that it was the most stupid*
2
3 *thing he had ever heard. That I shouldn't make a big deal of it, because it wasn't like I was sick ... Obviously, I*
4
5 *became extremely upset and I thought: "Well, it's probably just me that's being stupid". Then three months*
6
7 *passed, I went back and it had progressed into severe dysplasia. At that point, I was like, if it can develop one*
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9 *stage in three months, I'll be damned if I want to wait very long for the operation! I was lucky to get a date for*
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11 *the surgery within two weeks. But I was like 'phew' [sighing] because they thought I was being ridiculous*
12
13 *because I wanted the operation before it got to that stage, because I just couldn't take it anymore. It was too*
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15 *hard ... It really had a negative impact on my quality of life. [Woman who had undergone conisation]*
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17 18 ***Reassuring effect of treatment and more information***

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21 Five of the women who had undergone conisation had been through a long period of follow-up before the decision to
22
23 operate was taken, and they were therefore able to provide insights into their experiences with earlier/milder stages of
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25 dysplasia. Where mild cervical dysplasia progressed to a higher-grade lesion, the necessity for conisation was upsetting
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27 but, at the same time, many women felt relief that something was finally being done. The three women who had been
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29 referred for colposcopy and conisation shortly after the initial smear-test result had also been upset, but they were glad
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31 that they underwent the operation promptly (typically within two weeks) and that the time of uncertainty was short. The
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33 women who needed conisation were given more information about cervical dysplasia and the proposed treatment. This
34
35 had a reassuring effect and most of these women thought of conisation as curative and the subsequent medical follow-
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37 up as a precautionary measure.
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40 At the time of the interviews, most of the participants who had undergone conisation had received a negative test result
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42 after the three-month post-conisation check-up. Many considered the next check-up at six-months would be a milestone
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44 after which they hoped to be able to move on with their lives. For most, the diagnosis of their disease made them think
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46 about what was important in their lives. Some felt unsafe after having had a diagnosis of a potentially fatal disease that
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48 was not physically visible.
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50 51 ***Effect of information on the mode of transmission of HPV and its role as the cause of cervical dysplasia***

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54 Women who did not know about HPV feared that they were now pre-disposed to developing cancer. For many women,
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56 the information provided before conisation included the role of HPV as the cause of cervical dysplasia. Learning about
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58 the sexual mode of transmission of HPV resulted in cervical cancer being seen as an unusual form of cancer. It brought
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1 about reflections about infection and re-infection but it did not have adverse psychological effects or cause these women
2 to see cervical dysplasia as stigmatising, unlike some other sexually transmitted diseases (McCafferty 2004; Waller
3 2005; McCafferty et al. 2006; Goffman 1968; Kahn et al. 2007; Maissi et al. 2004; Waller et al. 2007; Clarke et al.
4 1996; McCree et al. 2005; Kahn et al. 2005; Mortensen and Larsen 2008). This was demonstrated by the fact that most
5 of the participants had spoken openly about the disease not only with their closest friends and relatives, but also with
6 colleagues and fellow students. These women viewed sex as a natural part of life and their perception of their disease
7 was dominated by the issue of cancer, not that it was a sexually transmitted disease.
8

16 *The role of communication with medical practitioners*

18 The results from this study indicated that the women's concerns were dependant on the quality of communication with
19 medical practitioners and the amount of information provided. The less the women knew about their condition, the more
20 insecure and worried they felt.
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26 *My really sweet gynaecologist said to me: "It's not like you're dying, you know?" No, but it really takes up a lot*
27 *of space in my life. I'm not sure that it would have made such a big difference if I had cancer. All the time, I felt*
28 *there was so much uncertainty, uncertainty, uncertainty. I was headed toward something, but what was it?*
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30 [Woman who had undergone conisation describing the period of waiting before the operation]
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35 Many of the women felt there was a discrepancy between their own reaction of shock and fear and their GP's relatively
36 carefree attitude when they learnt (sometimes over the telephone or from a secretary) about the first abnormal smear-
37 test result. The women felt the need for clear explanations about the difference between different stages of dysplasia and
38 actual cancer. Vague expressions such as a 'precursor to cancer' or a 'precancerous lesion', for instance, was not
39 perceived as being essentially different from cancer itself and tended to increase the women's anxiety.
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45 *The nurse put her hand on my stomach and said: "... it looks exactly as it should". All the muscles of my body*
46 *relaxed and then she said: "...but I don't think we're all the way up there yet". Then the doctor inserts it a bit*
47 *more and I could easily see [following the images on the monitor] that this tissue didn't look like the tissue we*
48 *had just seen. And then the doctor went all quiet and I thought: "Well, say something, for God's sake!" It's at*
49 *that point that she said: "Well, no, that does not look good at all". I just felt like crying, because I could see for*
50 *myself that it did look really bad. Then they took the biopsies ... And then she said: "If it's as bad as it seems, I'll*
51 *call you within ten days." After that, you just go around in a panic, looking at your phone to see if someone has*
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1 *called, and if it rings you think: "Is it her?" Because that means it's bad, right?* [Woman who had not yet
2
3 received results from a colposcopy]
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5
6 The participants said they would have liked more compassion and better verbal and printed information about cervical
7 dysplasia at the time of diagnosis. Regardless of the stage of dysplasia, they wanted to know about the medical rationale
8
9 for the intervals between check-ups, the meaning of the test results, the possible consequences for fertility and about
10 HPV as the causal factor. Retrospectively, the women who had undergone conisation felt that their anxiety during the
11
12 course of disease had been significantly worsened by poor communication with the various doctors and nurses. Some
13
14 participants suggested that young women in general should be better informed about cervical dysplasia and that more
15
16 women would participate in screening programmes if they knew about the prevalence of HPV and the association of
17
18 HPV with cervical cancer. They also felt that GPs should encourage Pap smear testing when performing other
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20 gynaecological examinations, for instance.
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23 24 25 **Discussion**

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28 The present study is, to our knowledge, the first of its kind to assess and compare the experiences of young Danish
29
30 women diagnosed, via routine cytological screening, with cervical dysplasia of varying grades of severity. The use of
31
32 qualitative research methods has produced an in-depth account of how these young women react to and deal with the
33
34 diagnosis and management of this disease. The results suggest that patients' perceptions of cervical dysplasia
35
36 significantly differ from those of medical professionals and that women's concerns are not aggravated in proportion to
37
38 the severity of the cervical dysplasia.
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41 Our results show that the detection of cervical abnormalities, whatever their severity, leads to significant distress and
42
43 anxiety. As other studies have also shown, many women are quite unprepared for the first abnormal result because they
44
45 had considered the test as a routine check-up (French 2006; Hounsgaard 2004). The participants in our study were
46
47 grouped according to whether they had or had not undergone conisation. The results revealed, contrary to what might be
48
49 expected, that women diagnosed with lower-grade lesions and who had not been conised were more likely to experience
50
51 anxiety and stress due to their disease, since they lacked information about their condition and the period of follow-up
52
53 with regular check-ups, before treatment is initiated or before regression of the lesion is confirmed, can be long. From a
54
55 medical viewpoint, 'watchful waiting' is a means of avoiding unnecessary invasive treatment. From the women's
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57 viewpoint, their lives during this period of 'watchful waiting' are full of apprehension, waiting for check-ups and the
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1 subsequent results and the fear that the lesion will probably 'spread' or develop into cancer. The women diagnosed with
2 lower-grade lesions, in particular, had poor understanding of their condition, its cause and the medical rationale for the
3 follow-up and treatment provided. Their anxiety was linked to inadequate communication with medical professionals
4 (Bunge et al 2009). This is in line with other studies showing that women often have poor understanding of the meaning
5 of cervical smear test results (Lauver et al. 1999; French et al. 2004; French et al. 2006; Lerman et al. 1991; Idestrom et
6 al. 2003; Neale et al. 2003; Campion et al. 1988; McCafferty et al. 2004; Fleurence et al. 2007; Hounsgaard et al. 2004;
7 Maissi et al. 2004).

8
9 In this study, women with higher-grade lesions reported less disease-related anxiety after conisation. To some, the
10 period of uncertainty had been shorter as prompt treatment (conisation) was given, but most importantly, before
11 conisation they had received more information about the causes and clinical management of cervical dysplasia, which
12 reassured them. Results from other studies have also suggested that anxiety related to cervical dysplasia is closely
13 related to lack of knowledge (Lauver et al. 1999; French et al. 2004; French et al. 2006; Lerman et al. 1991; Idestrom et
14 al. 2003; Neale et al. 2003; Campion et al. 1988; McCafferty et al. 2004; Fleurence et al. 2007; Hounsgaard et al. 2004).

15
16 Although we cannot exclude negative selection bias i.e. an over-representation of women with negative experiences
17 who are more likely to accept to participate, the results from this study do not suggest that there was any. We know that
18 focus-group methodology has the risk that unusual experiences are under-reported and negative experiences are over-
19 reported (Halkier 2003). In this study, the focus group participants did not restrain themselves from expressing singular
20 perceptions, Moreover, participants were given the opportunity to express themselves freely, without peer-group
21 pressure, in the individual interviews (Bech Risør et al. 2005; Kvale 1996; Spradley 1979).

22
23 This study was based on qualitative methodology and thus included a relatively small number of participants. Many of
24 our results agree with those of previous studies and we do not consider that more interviews would have produced more
25 qualitative knowledge from women targeted by this study. However, it would be interesting to examine the experiences
26 of women who have been monitored for a longer post-operative period. The women in this study who had undergone
27 conisation said they imagined that a negative test result for the six-month check-up after conisation would indicate cure
28 and thus they could 'start again'. We did not include women who had had the results from this check-up, so we cannot
29 say if they would really have felt that way. Results from other studies do not provide clear-cut answers to whether the
30 psychological effects of having cervical dysplasia are short-term or of longer duration (Lerman et al. 1991; Idestrom et
31 al. 2003; Hounsgaard 2004). Further studies should also investigate the experiences of older women and those of
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1 women from ethnic minorities and explore the effect of factors such as knowledge of the sexual transmission of HPV on
2 their perception of disease.
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6 Knowing that HPV is the cause of cervical dysplasia did not seem to increase the worries of these young Danish
7 women, or lead to feelings of stigma. Some previous studies have suggested that knowing about the sexual transmission
8 of HPV can lead to feelings of empowerment and improve health-related behaviour, for example, by encouraging
9 condom use and participation in screening programmes for cervical cancer (Kahn et al. 2005). On the other hand, others
10 have suggested that this knowledge can lead to women seeing cervical dysplasia as stigmatising (Waller et al. 2005;
11 McCafferty et al. 2006; Kahn et al. 2007; Maissi et al. 2004; Waller et al. 2007; Clarke et al. 1996; McCree et al. 2005;
12 Kahn et al. 2005) and this may act as a barrier to improved health-related behaviour (Waller et al. 2007). We cannot
13 exclude that some women may have not accepted to participate in the present study because of this negative perception.
14 Perception of disease is highly dependent on socio-cultural context (Kleinman 1988; Hahn 1984; Berger and Luckmann
15 1987) and the young Danish women in our study seemed to have associated cervical dysplasia with cancer rather than
16 with a sexually transmitted disease.
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29 In Denmark, HPV vaccination has been included in the childhood immunisation programme and is, therefore, free-of-
30 charge since January 2009 for girls aged 12 and for 13-15 year old girls in an initial catch-up programme. Provided that
31 women's participation in the cervical screening programme remains unchanged, vaccination is expected to prevent
32 approximately 70% of cervical cancer cases, i.e. those caused by HPV 16 or HPV 18 (Bosch and Lorincz 2002; Trottier
33 and Franco 2006; Smith et al. 2007). Our study suggests that the heavy psychological burden experienced by women
34 who are diagnosed with cervical dysplasia during cervical screening could also be greatly reduced by vaccination.
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42 Our study has shown that it is important to address women's fear of cancer and need for information about cervical
43 dysplasia from the moment of diagnosis, regardless of the stage of the lesion. Improved communication may reduce the
44 divergence between patients' and practitioners' perceptions of cervical dysplasia so that women may understand the
45 medical viewpoint of 'watchful waiting' as a reassuring means of monitoring the disease and avoiding unnecessary
46 treatment, rather than as a distressing delay. Vaccinated women also need to understand that the vaccine cannot prevent
47 all cervical cancers and that it will still be necessary to attend screening. With the proper communication about HPV
48 being an extremely prevalent virus that will infect almost everybody during their lifetime (National Board of Health
49 2007b), there is a possibility of promoting health care behaviour regarding the uptake of HPV vaccination as well as
50 participation in screening programmes for cervical cancer.
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Competing interests

GLM received an unrestricted research grant from Sanofi Pasteur MSD for this study. ALA has no competing interests.

Authors' contributions

GLM conceived the study and its design, carried out data collection, analysed and interpreted the data and drafted and translated the manuscript. ALA participated in the inclusion of patients, drafted the medical parts of the manuscript and revised the manuscript critically for important intellectual content. Both authors read and approved the final manuscript.

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1 **Figure legends**

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Fig. 1 The distribution of abnormal results of cervical-smear tests classified according to Bethesda 2006, from Danish pathology departments (Source: Recommendations of Cervical Cancer Screening. Copenhagen. National Health Board 2007b)

Fig. 1 Distribution of abnormal Pap-smear results in Danish pathology departments in 2006. Classified according to the Bethesda classification 2006 (Source: Recommendations of Cervical Cancer Screening. Copenhagen. National Board of Health 2007). ASC atypical squamous cells; AGC atypical glandular cells; LSIL low-grade squamous intraepithelial lesions; HSIL high-grade squamous intraepithelial lesion; AIS adenocarcinoma in situ

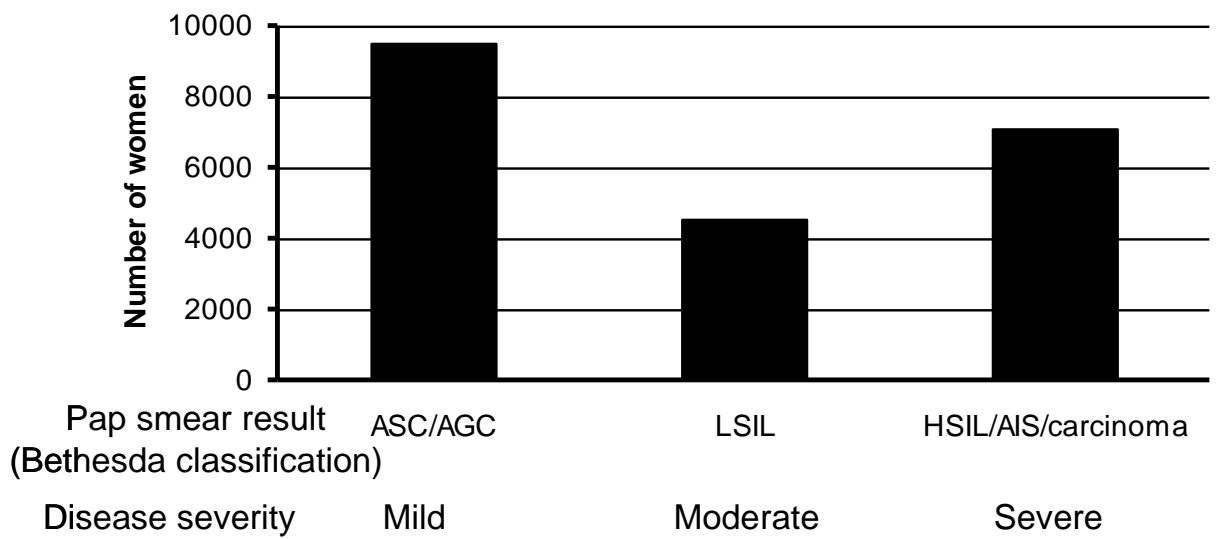


Table 1: Brief description of women included in focus groups or individual interviews

Woman number	Brief description
Individual interview	
1	Woman who had not undergone conisation: Abnormal smear test result 3 years before the interview, declared free of cervical dysplasia 2 weeks before the interview
5	Woman who had undergone conisation: Monitored for 8 months before conisation and, 3-month follow-up results after conisation not received.
Focus Group 1: women who had not undergone conisation	
2	Abnormal smear test result 8 weeks before the interview, referred for colposcopy
3	Abnormal smear test result 14 weeks before the interview, waiting for cytology result
4	Abnormal smear test result 4 weeks before the interview, referred directly for conisation
Focus Group 2: women who had undergone conisation	
6	Referred directly for colposcopy and conisation after initial abnormal smear test result. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.
7	Referred directly for colposcopy and conisation after initial abnormal smear test result. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.
8	Monitored for 24 months before conisation. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.
Focus Group 3: women who had undergone conisation	
9	Monitored for 18 months before conisation. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.
10	Monitored for 12 months before conisation. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.
11	Monitored for 60 months before conisation. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.
12	Monitored for 3 months before conisation. 3-month follow-up results after conisation showed no dysplasia. 6-month follow-up results not received.

Table 2: Example of interview guide used for focus groups: women who had undergone a cone biopsy. The other interview guides were similar and are available from GLM

Interview stage	Aim	Questions
Opening	Presentation of participants	First name, age, how long suffering from cervical dysplasia and when they had undergone cone biopsy
Introductory questions	The participants' perception of cervical dysplasia	<p>1. Before going on to your personal experiences with cervical dysplasia, please describe your views on this disease?</p> <p>Cues: precursor or disease in itself, prevalence, consequences, cause, treatment options, time to cure</p> <p>If woman knows about human papillomavirus:</p> <p>2. When did you get the information?</p> <p>3. Did it influence your views on cervical dysplasia?</p> <p>4. Overall, do you feel you have been well informed about cervical dysplasia?</p>
Transitional questions	The participants' experiences with the period up to conisation	<p>5. How did you react when you heard that you had cervical dysplasia?</p> <p>6. Can you describe the period prior to conisation?</p> <p>7. How did you react to being told that you needed conisation?</p>
Key questions	The effect of cervical dysplasia on their quality of life after conisation	<p>8. What are your main thoughts on the disease today?</p> <p>Cues: change in perception of cervical dysplasia, termination of or stage in the course of disease, future medical supervision, worries about the future</p> <p>9. Do you feel any physical symptoms or effects from having had cervical dysplasia?</p> <p>10. Does the dysplasia still affect you psychologically? –If yes, how?</p> <p>Cues: frame of mind (fear, shame, guilt, anger, depression), perception of self and body, thoughts on the meaning of life, regrets (previous non-attendance for cervical smear testing), worries about the future, disease phobia?</p> <p>11. Has cervical dysplasia affected your social life? – If yes, how?</p> <p>Cues: Level of support, taboos, concerns about stigma</p> <p>12. Has the dysplasia affected your love life? – If yes, how?</p> <p>Cues: worries about infidelity, being contagious, conflicts with and support from partner, disrupted sex life, fear of rejection</p> <p>13. Has there been a change in the way in which cervical dysplasia affects you today compared with when you were diagnosed?</p>
Closing questions		<p>14. In conclusion, how do you assess the communication you had with medical practitioners throughout the course of the disease?</p> <p>15. Is there anything you think we ought to have discussed but did not?</p>

Responses to reviewers' comments on Ms No: JOPH-D-09-00071

Reviewer #1: The manuscript covers a topic of public health importance and is well presented. It should be considered for publication in the Journal of Public Health as it is of great value to its readership. The manuscript only needs minor revisions.

Comment 1.1: The title could be more specific.

Response 1.1: The title has been changed to be more specific

Introduction

Comment 1.2: What is the percentage of infections that regress spontaneously? (page 2, line 14)

Response 1.2: the estimate that is generally used is 90% and this has been added into the introduction.

Comment 1.3: As the focus of the Journal of Public Health is international rather than European, data on the international burden of disease should be introduced. (page 2, line 34)

Response 1.3: The data on the international burden have been introduced

Comment 1.4: What is the role of HPV tests taken from the cervix? Are they performed at all in Denmark?

Response 1.4: HPV testing is not routinely done in Denmark, and this information has been added in the manuscript

Methods:

Comment 1.5: Patient information, was it standardized? Did all practitioners involved educate patients according to any guidelines? Did you investigate how practitioners informed their patients just from the patients' point of view? How many practitioners have been involved?

Response 1.5: We have given more information in the methods section to provide the information requested by this reviewer; however it was not an aim in the protocol to collect the women's experience with the recruitment process

Comment 1.6: I do not totally agree with the statement that "data on the specific stage of cervical dysplasia [...] were not required [...]" (page 4, line 44-47) as the stage of disease would provide information on the participants. Whether conisation has been performed or not may be a proxy, but if the information on the stage of disease exists, it should be added.

Response 1.6: We have rewritten this sentence which should now explain more clearly that what was important was the women's perception of their dysplasia and not the exact diagnosis. We wanted to recruit more women who had undergone conisation because they could relate their experiences before and after the intervention – it was not considered as a proxy for the severity of their disease. We have rewritten this in the manuscript, so we think this is clearer now.

Comment 1.7: Results: page 6, line 26: Is it that patients had to wait for the results of colposcopy? Or rather the results of cytology?

Response 1.7: This has been corrected

Comment 1.8: References: Please also consider the paper by Bunge M, Mühlhäuser I, Steckelberg A: What constitutes evidence-based patient information? Overview of discussed criteria. Patient Educ Couns (2009): doi: 10.1016/j.pec.2009.10.029

Response 1.8: This has been added into the manuscript

Comment 1.9: Figure 1: Readability of the figure will be increased by replacing the cell types (ASC/AGC - LSIL - HSIL) by the severity of disease (mild - moderate - severe) or by at least adding the severity of disease.

Response 1.9: We have modified the figure to include both classifications.

Comment 1.10: Figure 2 is redundant as the focus of the Journal of Public Health is not gynecology and the majority of its readership may not benefit from the information presented!

Response 1.10: We have removed this

Comment 1.11: Please consider adding a table on patient characteristics and / or a table that summarizes the results somehow.

Response 1.11: We have added a table to provide information about the women.

Reviewer #2: Comments on manuscript number JOPH-D-09-00071 "Women's experiences with cervical dysplasia"

Overall, this is a sound contribution taking up an interesting and important issue. After some minor revisions, I would therefore very much like to see it published in the Journal of Public Health.

Introduction

Comment 2.1: *P. 2 line 27-30: Please rephrase the sentence ("In Denmark, although.")

Response 2.1: This has been rewritten and should now be clearer

Comment 2.2: *P. 2 line 44 and Figure 2: Isn't Figure 2 rather a table?

Response 2.2: In response to a comment from reviewer 1 this has now been removed from the manuscript.

Comment 2.3: *P. 3 line 18: Please set "watchful waiting" in quotation marks in line with the usage in the rest of the paper

Response 2.3: OK

Comment 2.4: *P. 3 line 29-30: The use of "be contributed to" is unclear here, please check and rephrase the sentence

Response 2.4: This has been rewritten

Methods

Comment 2.5: *Recruitment of study participants; I would like to see some more information on the selection criteria of the interviewed women. How large was the universe of the women fulfilling the selection criteria? How was the response rate (how many women rejected to be interviewed, how many approved to)? Or were only

women interviewed, who volunteered? Please discuss shortly the possible selection bias and its consequences for the results

Response 2.5: We have provided more information in the methods section, but we do not have information about how many women did not accept to participate. In qualitative studies, recruitment is commonly continued until a sufficient number of participants are reached. The aim is to recruit participants with the right characteristics rather than trying to obtain a representative sample, in a quantitative sense. In the discussion we have raised the issue of possible selection bias, and how that could have an impact on the results.

Results

Comment 2.6: *P. 6 line 16-17: The second half of the sentence (".and rather on the.") is unclear; please rephrase

Response 2.6: This has been rewritten.

Comment 2.7: *P. 6 line 23-34: The authors might like to present the setting of the interviewed women described here in a table. This would make the different backgrounds of the cases more clear

Response 2.7: We have added a table (Table 1) to provide this information.

Comment 2.8: *P. 6 line 36-41: please explain more detailed, why the focus-groups were generated in this way. Were all women BOTH interviewed in focus-groups AND individually?

Response 2.8: We have provided more information in the methods section, so it should now be clear that women were either interviewed individually or in a focus group, but not in both.

Comment 2.9: *P. 7 line 54: "THE longer" instead of "they longer"?

Response 2.9: OK

Comment 2.10: *P. 9 line 20: The sentence "Women who had poor." fits better to the next chapter on the effects of information on HPV. The part "Effects of information on HPV." needs some clarification, too; it seems to me as if it is more about the cause of cervical dysplasia (HPV) being sexually transmitted than simply on HPV (see also page 12, line 33-49). Please specify.

Response 2.10: This has been rewritten and should now be clearer.

Comment 2.11: *P. 10 line 26: "And THEN she said." instead of "the"?

Response 2.11: OK

Discussion

Comment 2.12: *P. 12 line: 33-49 please see above

Response 2.12: This has been rewritten and should now be clearer

Comment 2.13: *P. 12 line 52: Please rephrase the sentence "In Denmark, HPV vaccination."

Response 2.13: This has been rewritten