Introduction
Cervical cancer is the fourth most frequent cancer among women worldwide with an estimated 569,847 new cases and 311,365 deaths in 2018.\(^1\) In the majority of cases, cervical cancer and its precursors are induced by a persistent human papillomavirus (HPV) infection.\(^2\) Nearly 80% of all women have been estimated to have at least one HPV infection in their lifetime, and the infection becomes persistent in 10–15% of cases and may lead to development of high-grade cervical intraepithelial neoplasia (CIN2+).\(^3\) CIN enjoys a high spontaneous regression rate, but up to 31.3% of CIN3+ cases may...
Development of cervical cancer may be prevented and many countries have therefore introduced population-based cervical cancer screening programs. However, the incidence of cervical cancer peaks around the age of 75 years, and elderly patients are more frequently diagnosed with advanced-stage cervical cancer and have poorer prognosis than younger patients. In most cases, follow-up in patients with abnormal cervical test results consists of colposcopic examination of the transformation zone and samples obtained from the cervix and the cervical canal (CBC). However, this procedure may be challenged by age-related anatomical changes in elderly (postmenopausal) patients due to retraction of the transformation into the cervical canal. Consequently, cervical biopsies may represent the exocervix only, and some patients have to undergo several colposcopies to ensure valid biopsies.

Repeated colposcopies are considered very unpleasant by some patients, and research indicates both pre- and post-colposcopy anxiety associated with the risk of having high-grade CIN or cervical cancer, as well as distress due to the colposcopy examination itself. One strategy to reduce the number of colposcopies in postmenopausal patients with an insufficient CBC examination is the “see-and-treat” approach, which combines diagnosis with instant treatment as cone biopsy is performed immediately after unsuccessful colposcopy. However, for some patients, this approach turns out to be overtreatment because infection or cervical lesion will never develop into high-grade CIN. We hence see an important gap in the knowledge about preferences in this selected group of patients, which we expect will grow much larger in the future thanks to longer lifespans and extensions of cervical cancer screening programs in some countries. This calls for investigation of elderly patients’ deliberations about risks and benefits of follow-up after abnormal cervical test results. The aim of the present study was to explore elderly patients’ experiences with HPV testing, colposcopy and cone biopsy, and to identify their preferences for follow-up.

Materials and Methods
Setting
The study took place in Central Denmark Region, which is the second largest region in Denmark with approximately 2.3 million inhabitants. Most healthcare services in Denmark are tax-funded and free of charge, including population-based screening, diagnostic procedures, treatment and follow-up after cervical cancer.

Cervical cancer screening is offered to women aged 23–64 years. Cytology-based screening is offered to women aged 23–59 years. HPV-based screening is offered to women aged 60–64 years; and in 2017, the Danish Health Authorities invited women born before 1948 for a one-time HPV-based screening offer. Patients with abnormal cytology or a positive HPV test are referred for colposcopy and cervical biopsy at a gynaecological outpatient clinic or at a private gynaecologist.

Design and Participants
Qualitative methods in general and focus groups in particular are considered appropriate for exploring topics that are sparsely described in the literature. The study was designed as a focus group interview study and this method was chosen to collect data from group interaction, assuming that data quality would benefit from a confidential setting where participants could reflect on and respond to each other’s experiences with HPV testing, cytology, colposcopy, biopsies and for some a cone biopsy. In studies with relatively homogenous groups, two to four focus groups are considered sufficient to assess theoretical saturation and information power.

The participants were patients above 60 years of age who had a positive HPV test and/or abnormal cytology and had undergone biopsy and colposcopy. They were recruited at four outpatient clinics and at two private gynaecologists in Central Denmark Region. Healthcare staff was instructed by the researchers to disseminate a document to patients in the target group immediately after colposcopy. The document included a short presentation of the study and a consent form to be filled out by the patient herself with her name and telephone number if she wanted to hear more about the project. Then she was contacted by telephone by a researcher (PK) for further information about the study. If the patient agreed to participate, the researcher sent detailed written information and an invitation to participate in a focus group interview on a prescheduled date. Thus, written and oral consent was obtained from all participants. The participants were informed that participation was voluntary and that any travel expenses would be reimbursed. The interviews took place from November 2018 to January 2019. All original identifiers were removed from transcripts and replaced by pseudonyms.

Data and Analysis
A funnel-structured research cycle of ongoing questions, data production and analysis was adopted, and we used an explanatory phenomenological approach based on the interpretive
Thus, the interpretation began with the formulation of research questions based on Danish clinicians’ empirical experiences with the patient group and on existing (however sparse) literature, and continued through the data production in a continuous dialogue with new insights from each interview. The approach was constructivist with an emphasis on phenomenology, aiming to explore how people make sense of their experiences in a specific context. This approach was reflected in the focus group interview guide which was designed to cover the patients’ experiences with HPV testing, cytology and colposcopy; knowledge about cervical cancer screening, HPV, CIN and cervical cancer; attitudes to under- or over-diagnosis, overtreatment and complications; and preferences for follow-up after a positive HPV test and/or abnormal cervical cytology. The focus group interview guide comprised open-ended questions about experiences and knowledge, and hypothetical scenarios about over-treatment and options for follow-up, including see-and-treat (Figure 1). In the beginning of each focus group interview, all participants filled out a questionnaire with questions about eg education/job, marital status, HPV and cervical status after (most recent) colposcopy, screening participation, and self-rated health (Table 1). Two researchers moderated the focus groups (PK and LG). Questions about experiences with HPV testing, cytology and colposcopy were moderated by PK, who is an experienced interviewer and researcher using qualitative methodology. The hypothetical risk and benefit scenarios were presented by LG, who is a gynaecologist and experienced in clinical communication with patients. The participants had the opportunity to ask questions before discussing preferences with each other in the focus group. PK and LG moderated views and attitudes to the options.

The interviews were digitally recorded and transcribed verbatim by an experienced secretary, supervised by PK. Before each focus group interview, the transcription of the previous interview was read carefully and any questions emerging from the data were added to the dynamic focus group interview guide. PK conducted the initial coding and meaning condensation and presented it for discussion with the co-authors to establish preliminary themes and narrow down the focus of the themes. When interpretations were agreed upon by the authors, the analysis was crystallized into a coherent set of themes, and existing literature about people’s experiences in comparable contexts were selected to provide a meaningful contextualization of the findings.

Ethics
According to EU’s General Data Protection Regulation (article 30), the project was listed at the record of processing activities for research projects in Central Denmark Region (journal no. 1–16-02-363-19). The study complied with the Statements on Ethics of the American Anthropological Association. It did not require further ethical approval in accordance with Danish legislation, ie the Act on Research Ethics Review of Health.

Results
Twenty-eight patients were contacted by telephone of whom 17 were interviewed in four focus groups with 3–5 participants (Table 1). The focus group interviews took between one and a half and two hours. Participants were 60–79 years old (mean 69 years). Six had attained higher education, four had attained middle-level education and four had attained lower-level education (one missing entry). Eight were married or co-habiting, nine were living alone (divorced or widowed). Their self-rated health ranged from 1 to 4, mean 1.8 (1=very good, 5=very bad). Fourteen reported that they had participated regularly in the cervical cancer screening program. Eleven reported that they had abnormal cervical cytology and 12 reported that they had undergone cone biopsy. The following themes were identified in the interviews: 1) information sources and emotional responses to a positive HPV result; 2) attitudes to overtreatment and preferences for follow-up; and 3) preferences for delivery of follow-up options.

Information sources and emotional responses to a positive HPV result
Most patients said that they knew that HPV is a sexually transmitted, asymptomatic infection. Some said that in most cases, HPV may do no harm; but in some cases, the virus is aggressive and may cause cervical cancer. They had been informed about HPV by their general practitioner (GP) or in the hospital when they had a colposcopy, although they did not recall much of what they had been told about the virus in that setting. Instead, they reported that they had acquired knowledge about HPV through a Danish television program showing the lives of girls who had been vaccinated against HPV and subsequently allegedly fallen ill due to the vaccine. The TV program led to a substantial decline in HPV vaccine uptake among young girls in the target group. They reported that they had heard about the long-lasting debate that followed on Danish social media. It left them with the
Focus group interview guide

1. Why did you visit your general practitioner to get a cytology, and why did you visit the gynaecological department or the private gynaecologist to get a colposcopy? What happened?
2. What were you feelings and thoughts about it then? How do you feel and what do you think about it now?
3. Do you know somebody who has experienced the same as you regarding abnormal results?
4. What do you know about x (HPV infection, cervical neoplasia, cervical cancer, cervical cancer screening), and how did you gain this knowledge?

5. Scenario one: HPV 16/18 are known to be responsible for about 70% of all cervical cancer cases. In most cases, up to 90%, the HPV infection passes without medical intervention. If you stay positive for several years, there is a 40% risk of getting high-grade CIN or cervical cancer. 30% of women who are not treated for high-grade CIN will develop cervical cancer. Imagine you were tested positive for HPV 16/18, but there is no CIN or cervical cancer. Would you prefer to get a biopsy at a hospital or a private gynaecologist immediately (despite a negative cervical cytology) or get regular cervical cytology at your general practitioner?

6. Scenario two: 30% of women with high-grade CIN will develop cervical cancer if untreated. All women with high-grade CIN are offered cone biopsy, which carries a small risk of side-effects such as bleeding and stenosis. This means that about two out of three women are treated with unnecessary cone biopsy. Imagine that you have high-grade CIN. Would you prefer to get a cone biopsy or get regular cytologies or control at the gynaecological department if treatment would benefit a) one out of ten and nine out of ten would be overtreated/not benefit from the cone biopsy, b) one out of 20 and 19 would be overtreated/not benefit from the cone biopsy, c) one out of 50 and 49 would be overtreated/not benefit from the cone biopsy, or d) one out of 100, and 99 would be overtreated/not benefit from the cone biopsy.

7. Scenario three: Imagine that you tested positive for HPV 16/18, but the gynaecologist was unable to obtain representative samples during smear to determine the presence of cervical dysplasia. Would you prefer to get regular cytologies/active surveillance of dysplasia status in general practice, or get a cone biopsy immediately at the gynaecological department, which may include a small risk of bleeding and stenosis? Would you prefer to get a cone biopsy immediately if the doctor assumes that it is very hard to obtain representative samples during colposcopy ('see-and-treat'), or would you prefer to wait and see if the samples may turn out to be representative?

8. How may health authorities and healthcare staff improve communication about HPV infection, cervical dysplasia, cervical cancer and cervical cancer screening?
impression that HPV was a “young woman’s disease’. Therefore, they did not feel at risk of HPV themselves:

I know that they (young girls) get the HPV vaccination, but I never imagined I could have HPV. (ID12)

They called for better information and clearer communication about dormant and persistent HPV infection through life and the possible consequences for elderly women.

Patients who had participated in the Danish cervical cancer screening program with primary HPV testing said that they participated without much concern about the possibility and consequence of having an abnormal result. They had participated because it was an opportunity for them to visit their GP; because they appreciated the healthcare system’s offer to get an extra health check for cancer; or because they felt morally obliged towards society and themselves to participate:

I just accepted the offer because I thought I should accept it, like everything you can get for free, right, and also for my own sake. (ID6)

Some patients said that they felt unprepared for the bad news and did not know what to do with the information

| ID | Focus Group No. | Age | Occupation | Educational Level | Marital Status | Self-Rated Health | Cervical Cancer Screening | Cervical Dysplasia | HPV | Colposcopy | Cone Biopsy |
|----|-----------------|-----|------------|------------------|----------------|-------------------|--------------------------|-------------------|-----|------------|------------|
| 1  | 1               | 62  | Employed  | Middle           | Cohabiting     | 2                 | Yes since 2008           | Yes               | Hospital | Yes several times |
| 2  | 1               | 62  | Employed  | Higher           | Cohabiting     | 1                 | Yes                      | Yes               | Hospital | Yes         |
| 3  | 1               | 64  | Employed  | Higher           | Living alone/ divorced | 3                 | No                       | Yes               | Hospital | Yes in 2018 |
| 4  | 1               | 64  | Employed  | Middle           | Married        | 1                 | Yes                      | Yes               | Hospital | Yes many years ago |
| 5  | 2               | 72  | Retired   | Low              | Living alone/ divorced | 1                 | Yes in 2016              | Yes in 2016       | Private gyn | Yes in 2017 |
| 6  | 2               | 71  | Retired   | Low              | Living alone/ divorced | 2                 | Yes                      | Yes               | Hospital | Yes in 1980 |
| 7  | 2               | 79  | Retired   | Middle           | Living alone/ widowed | 1                 | No                       | Yes 1974           | No      | Private gyn | Yes in 1974 |
| 8  | 2               | 66  | Retired   | Higher           | Living alone/ divorced | 1                 | No                       | Yes 1978           | Yes in 2017 | Private gyn | Yes in 2017 |
| 9  | 2               | 64  | Self-employed | Low          | Living alone/ divorced | 4                 | Yes                      | Yes 2017           | Yes in 2017 | Private gyn | Yes in 2017+2018 |
| 10 | 3               | 77  | (not filled out) | (not filled out) | Living alone/ widowed | 1                 | Yes                      | No                | Yes in 2018 | Hospital | No |
| 11 | 3               | 73  | Retired   | Low              | Married         | 2                 | Yes                      | Yes 2017           | Yes in 2018 | Hospital | Yes in 2018 |
| 12 | 3               | 60  | Employed  | Low              | Married         | 2                 | Yes                      | No                | Yes in 2018 | Hospital | No |
| 13 | 4               | 63  | Employed  | Higher           | Married         | 1                 | Yes                      | No                | Yes in 2018 | Private gyn | No |
| 14 | 4               | 64  | Retired   | Low              | Cohabiting     | 3                 | Yes                      | Yes 2018          | Yes in 2018 | Private gyn | Yes |
| 15 | 4               | 78  | Retired   | Higher           | Living alone/ widowed | 2                 | Yes                      | No                | Yes      | Private gyn | No |
| 16 | 4               | 73  | Retired   | Higher           | Married         | 1                 | Yes                      | No                | Yes in 2017 | Private gyn | No |
| 17 | 4               | 75  | Retired   | Middle           | Living alone/ divorced | 3                 | Yes                      | No                | Yes in 2017 | Private gyn | Yes in 2017 |

Note: *(1= very good; 5=very bad).*
about a positive HPV result. This triggered an undue awareness about abdominal sensations, rumination about possible causes and consequences, and focused attention on oneself:

All of a sudden, I think too much about myself, and I think that’s annoying - I’d rather think about my surroundings . . . I think I get too introvert and too focused on myself. (ID17)

Some patients said that they were taken aback by their positive HPV result:

It was like a bomb because I felt alright. (ID4)

Other patients said that they felt relaxed and unconcerned about their positive HPV result because they had had a long life and knew it would come to an end some day:

By now, I’m so old and there is not a lot of drama, so it has not worried me. (ID15)

### Attitudes to Overtreatment and Preferences for Follow-Up

In the first scenario (Figure 1, question 5), the patients were asked to imagine that they had an HPV infection and a negative cytology and had to choose between regular HPV testing at their GP until the infection had cleared or a direct referral for a colposcopy. Several patients said that they would prefer direct referral for a colposcopy because they felt that it would be safer to be referred than to get a regular cytology/HPV test at their GP:

My piece of mind comes from being watched so it doesn’t get out of control. (ID9)

They felt that a referral and biopsy would give them a more thorough examination. They would prefer this despite the discomfort of the colposcopy and a risk of overtreatment:

I’d feel more secure if I was examined at the hospital and got the whole package. (ID10)

Of course, we all want . . . I want the whole package. (ID11)

In the second scenario, the patients were asked to discuss their attitude to overtreatment with cone biopsy in scenarios with declining benefit (Figure 1, question 6). They were told that the remaining patients would not benefit from treatment because their dysplasia would regress and never develop into cervical cancer, and that regardless of the individual (lack of) benefit of treatment, all who got a cone biopsy might suffer from side-effects such as bleeding and stenosis. Some patients argued that they found it difficult to relate to risk presented in numbers in this way and even irrelevant for their decision-making. For them, treatment was preferred despite the high risk of overtreatment and side-effects. They considered the consequences of no treatment potentially more severe than the risk of overtreatment:

I wouldn’t risk anything . . . I want the last years of my life to be good. (ID11)

Several patients mentioned concern and respect for their families and their potential loss in case of a cervical cancer diagnosis as a main reason for undergoing a cone biopsy even if biopsy might be unnecessary:

It may develop, and 1 out of 100 . . . I mean a lot to my family and my family means a lot to me, so I don’t care about the other 99. (ID12)

Some patients also argued that treatment with cone biopsy could give them a sense of security and safety since they would be “rid of it” (the transformation zone, which may contain abnormal cells now or in the future).

I’d go with the cone biopsy – I’d rather be overtreated than risking a cervical cancer diagnosis in the future. (ID8)

In the third scenario, the patients were asked to imagine that they had had a colposcopy and that the biopsies were insufficient for diagnosis (Figure 1, question 7). Several patients said that they had experienced this in real life. Whether they imagined or drew on actual experience, they preferred to get a cone biopsy the next time instead of a colposcopy (which may produce only insufficient biopsies again). It was better to be overtreated with a safe technique than to develop a cancer:

Safety first – if we want to survive. (ID1)

Then they were asked to imagine that the doctor performing the colposcopy would offer see-and-treat, ie a cone biopsy immediately after colposcopy if the doctor assessed that it would be difficult or impossible to obtain sufficient biopsies. Several patients expressed a need to prepare themselves mentally for a possible cone biopsy; and if they were allowed to do so, they were willing to get a cone biopsy. Some patients emphasized that they would prefer to get a cone biopsy right away (see-and-treat),
while others said that getting a cone biopsy at the first visit to the hospital or gynaecologist would be too drastic:

I think you have to inform about it in the letter that it (see-and-treat) is an option if it is difficult to see it (the transformation zone) . . .; of course, you have to phrase it in a way that doesn't scare us. (ID12)

It was pivotal for the patients that the doctor could describe pros and cons in a clear and direct fashion.

Preferences for Delivery of Follow-Up Options
For all of the patients, thorough information about follow-up options, including see-and-treat, was crucial. This information should include both oral information by the GP and written information in the invitation to be discussed at the outpatient clinic or the private gynaecologist with drawings of the transformation zone and a list of pros and cons of see-and-treat. This was particularly important in case of uncertainty about the best treatment. They expressed a need to feel prepared to make an informed choice by receiving written material and oral information:

Then you get a chance to be at the forefront of it so when they ask the question (about cone biopsy), you can say what you had in mind at home. (ID7)

However, some patients objected to the idea of informed choice and imagined that they would be unable and hesitant to make a decision about see-and-treat if the doctor informed them about the option and then left the decision to them:

The doctor should make the decision – that’s not my job. (ID4)

They wanted a clear recommendation from the doctor instead because they would feel unsafe and insecure by making a decision as a non-medically trained person:

You have to remember that you (the doctors) are the ones with a high and distinguished education. (ID3)

Discussion
In this study, elderly HPV-positive patients perceived HPV as a “young woman’s disease”. They expressed intolerance towards healthcare professionals’ expressions of uncertainty, and most of them wanted treatment and follow-up at the gynaecologist, including see-and-treat, instead of a more conservative approach with continuous follow-up /control visits at their GP.

Strengths and Limitations
Some limitations of our study warrant discussion. First, most patients in the sample had already had a cone biopsy (two of them more than once) before we presented the hypothetical scenarios about see-and-treat for them. Their positive attitude towards see-and-treat may, therefore, reflect the fact that they had already had a cone biopsy and wished to justify it. Second, the sample was recruited by healthcare professionals who may have selected patients whom they assessed would be interested in the topic. We do not know whether or how deselected patients might differ from the sampled patients, nor do we know the characteristics of the 11 patients who did not participate in the focus group interviews. The 17 patients who participated represented socio-demographic variation which we consider a strength to the study. They varied in terms of age, educational level, occupation, and marital status (Table 1).

The choice of method was a strength to the study. Focus groups are designed to facilitate narratives of the interviewees’ unanticipated perspectives on the presented topic and this approach is often the first step for collecting data on experiences and phenomena that are sparsely described in the current literature.12 As shown in the Introduction, previous studies have investigated younger patients’ attitudes to HPV testing, colposcopy and follow-up, but these results do not automatically reflect those of elderly patients.

The social and moral aspects of a certain topic or area become more evident in a focus group compared to an individual interview, owing to group dynamic. Risk of overtreatment and use of healthcare resources are exemplars of this. It means that in focus groups participants may feel a pressure to conform to group norms on a sensitive and private topic. We checked this by underlining that no statement is superior to another and we were interested to hear all presented perspectives. The atmosphere in all the groups was relaxed and trustful.

Comparison with Existing Literature
A systematic review has documented that younger patients may experience psychological distress following a positive HPV result, but studies among elderly patients are lacking.19 The majority of patients in our study reported no severe distress, and our results suggest that elderly patients have different priorities and concerns regarding the meaning and consequences of a positive HPV result. In younger patients, HPV transmission may
be considered shameful or stigmatizing because it may imply multiple partners within a short period of time. The elderly patients in our study were aware of the fact that HPV is a sexually transmitted disease, but they lacked knowledge about persistent HPV in elderly patients and did not perceive their HPV infection status as an outcome of promiscuous behavior. They reasoned that they might have contracted the infection at some point during the 40–60 years (depending on their age) they had been sexually active. Future information to elderly patients about the risk of persistent HPV should consider this and avoid assumptions about stigma related to HPV transmission.

Adverse psychological effects in the form of pre- and post-colposcopy distress and anxiety have been documented, including fear of cancer and concerns about fertility. Exception for a slight increase in vigilance before the procedure due to anticipated discomfort, most patients in our study reported no adverse psychological strain. They derived reassurance from being examined thoroughly with colposcopy instead of being followed in general practice with HPV testing and cytology. This finding mirrors findings in other studies demonstrating a preference for colposcopy to get a “speedy resolution” instead of continuous HPV testing and surveillance with cytology. Getting rid of uncertainty and achieving a sense of closure had high priority in patients included in the present study. They demonstrated considerable intolerance towards health professionals’ display of clinical uncertainty regarding the best follow-up choice. This may provide a frame for understanding their apprehension of (un)timely follow-up and their preference for sensitivity rather than specificity in cancer diagnosis.

Studies have shown that patients with high-grade CIN who had undergone see-and-treat were significantly less anxious and more relieved because there was no delay or extra visit. Moreover, it was more convenient for them that it was over and done with, and they were reassured that they had been thoroughly informed during the consultation. This is in line with the findings in our study, which showed that the patients wanted the medical rationales of the options clearly explained, including a prioritization of the options to support their decision to undergo see-and-treat or control with HPV test and cytology. As far as diagnosis and treatment options were concerned, they wished that the gynaecologist would provide an unambiguous oral recommendation tailored to their individual concerns and circumstances.

**Conclusion**

This exploratory study showed that elderly HPV-positive patients perceived the HPV infection as a “young woman’s disease” of which elderly patients were not at risk. A quick solution to persisting HPV infection and CIN including cone biopsy was called for, despite the high risk of overtreatment compared with continuous follow-up/control visits in general practice. The elderly patients wanted unambiguous recommendations. By examining elderly patients’ perspectives on the trade-off between overtreatment and underdiagnosis, this study makes an important contribution to future interventions regarding elderly patients’ preferences and need for decision support regarding follow-up. The study suggests that elderly patients should be presented carefully to known risks and benefits by clinicians. Decision aids in this regard are warranted.

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**Author Contributions**

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

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being responsible for cervical cancer screening in Central Denmark Region. The authors report no other conflicts of interest in this work.

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