



## ORIGINAL ARTICLE

# Challenges and controversies patients and (health care) professionals experience in managing vaginal, vulvar, penile or anal cancer: The SILENCE study

Jessy van Dongen<sup>1</sup>  | Eline de Heus<sup>1,2</sup>  | Lauren Eickholt<sup>1</sup> | Marga Schrieks<sup>3</sup> |  
Ilaniek Zantingh<sup>4</sup> | Oscar R. Brouwer<sup>5</sup> | Maaïke H. M. Oonk<sup>6</sup> |  
Brechtje A. Grotenhuis<sup>7</sup> | Nicole P. M. Ezendam<sup>1,8</sup> | Saskia F. A. Duijts<sup>1,9</sup>

<sup>1</sup>Department of Research and Development, Netherlands Comprehensive Cancer Organisation (Integraal Kankercentrum Nederland, IKNL), Utrecht, Netherlands

<sup>2</sup>Department of Medical Oncology, Radboud University Medical Center, Nijmegen, Netherlands

<sup>3</sup>Dutch Federation of Cancer Patients Organisations (Nederlandse Federatie van Kankerpatiëntenorganisaties, NFK), Utrecht, Netherlands

<sup>4</sup>Center for Quality of Life, The Netherlands Cancer Institute – Antoni van Leeuwenhoek Hospital (NKI-AvL), Amsterdam, The Netherlands

<sup>5</sup>Department of Urology, The Netherlands Cancer Institute – Antoni van Leeuwenhoek Hospital (NKI-AvL), Amsterdam, Netherlands

<sup>6</sup>Department of Obstetrics and Gynecology, University Medical Center Groningen, Groningen, Netherlands

<sup>7</sup>Department of Surgical Oncology, The Netherlands Cancer Institute – Antoni van Leeuwenhoek (NKI-AvL), Amsterdam, Netherlands

<sup>8</sup>Department of Medical and Clinical Psychology, Center of Research on Psychology in Somatic diseases, Tilburg University, Tilburg, Netherlands

<sup>9</sup>Department of Medical Psychology, Cancer Center Amsterdam, Amsterdam Public Health Research Institute, Amsterdam UMC, University of Amsterdam, Amsterdam, Netherlands

## Correspondence

Saskia F.A. Duijts, Department of Research and Development, Netherlands Comprehensive Cancer Organisation (IKNL), Godebaldkwartier 419, Utrecht 3511 DT, Netherlands.  
Email: [s.duijts@iknl.nl](mailto:s.duijts@iknl.nl)

## Funding information

The authors declare that no funds, grants or other support were received during the performance of this study.

## Abstract

**Objective:** Patients with vaginal, vulvar, penile or anal cancer experience deteriorated psychosocial functioning and decreased Quality of Life (QoL). The aims of this study were to explore (1) the challenges and controversies patients experience in managing vaginal, vulvar, penile or anal cancer; their unmet needs; and how this affects their psychosocial functioning and (2) the gaps health care professionals (HCPs) experience in providing psychosocial support and potential improvements in care.

**Methods:** Semi-structured interviews with patients with vaginal, vulvar, penile or anal cancer and with HCPs were conducted. All interviews were transcribed verbatim and thematically analysed.

**Results:** Fourteen patients (86% female; mean age 55.5) and 12 HCPs (75% female; mean age 46.4) participated. Four themes were identified: (1) recognisable symptoms but unfamiliar diagnosis, (2) ‘double hit’ has severe impact on psychosocial functioning, (3) personal and tailored information is important but not guaranteed and (4) all-encompassing care to improve psychosocial functioning and QoL.

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**Conclusion:** Patients with vaginal, vulvar, penile or anal cancer encounter a lack of awareness and knowledge about their rare cancer type, difficulties regarding communication and long-term changes in body image and sexuality. Awareness of symptoms should be raised and psychosocial care should be offered on a structural basis.

**KEYWORDS**

anal, penile, psychosocial care, sexuality, vaginal, vulvar

## 1 | INTRODUCTION

While most patients suffer from a common cancer type, one in five patients in Europe is diagnosed with a rare type of cancer (Gatta et al., 2011; Gatta, Capocaccia, et al., 2017). Rare cancers are defined as those with an annual incidence of less than 6 per 100.000 people (Gatta, Capocaccia, et al., 2017). In Europe, about 5.0 million inhabitants are currently living with the consequences of being diagnosed with and treated for a rare cancer (RARECARENet, n.d.; Gatta et al., 2011; Gatta, Capocaccia, et al., 2017). Rare cancer patients have a worse prognosis and face more difficulties than patients diagnosed with common cancer. This is due to factors such as poor awareness among the general public and clinicians, which may result in symptom misinterpretation and in diagnostic and/or treatment delay, and insufficient knowledge about and experience with effective treatments (Blaauwgeers et al., 2018; Komatsubara & Carvajal, 2016; Pillai & Jayasree, 2017).

Based on the definition of rare cancers, a total of 223 types of cancer (86%) can be considered rare in the Netherlands (Blaauwgeers et al., 2018). The annual Dutch incidence for vaginal cancer is 50, for vulvar cancer 430, for penile cancer 200 and for anal cancer 275 patients (IKNL, 2021). Patients with one of these rare cancer types may experience additional difficulties, mainly because they face a 'double hit'. That is, being diagnosed with cancer itself has a huge impact, plus these cancers are located at body parts considered taboo (Butame et al., 2017). Related to this, these types of cancer can be caused by the Human Papilloma Virus and might therefore be associated with sexual activity (Mortensen & Jakobsen, 2013). Previous studies already showed that patients, diagnosed with these rare cancers, experience a decreased Quality of Life (QoL) and deteriorated psychosocial functioning, which can persist for many years after treatment (Bentzen et al., 2013; Boden & Willis, 2019; Dräger et al., 2017; Gane et al., 2018; Sterner et al., 2019). For example, patients may face problems related to sexuality and body image, when parts of the vulva or penis have been removed as part of the treatment (Mortensen & Jakobsen, 2013).

As these diagnoses and related symptoms might be poorly understood by people, including some (health care) professionals, patients with vaginal, vulvar, penile and anal cancer expressed the need for better psychosocial care to deal with challenges and controversies they are confronted with (Boden & Willis, 2019; Paterson et al., 2020; Philp et al., 2017). Moreover, the necessity of attention for psychosocial support for these patients has been stated by (health care)

professionals and other relevant stakeholders (together abbreviated to 'HCPs') as well. That is, HCPs indicated in a previous study that they sometimes experience barriers in providing psychosocial care to patients with these rare cancers, e.g., because of a lack of confidence to discuss sensitive issues during their consultations (Hendry et al., 2017). Further, since the trajectory and prognosis of these rare cancers can be uncertain, HCPs consider it important that sufficient psychosocial care is offered and that improvements in care for existing gaps are realised.

Currently, studies about experiences of patients with vaginal, vulvar, penile or anal cancer and of relevant HCPs, regarding faced challenges and controversies and regarding their experiences with psychosocial support and care, are lacking. Therefore, the aims of this study were to investigate (1) the challenges and controversies patients experience in managing vaginal, vulvar, penile or anal cancer; their unmet needs; and how this affects their psychosocial functioning and (2) the gaps HCPs experience in providing psychosocial support and potential improvements in care.

## 2 | METHODS

### 2.1 | Study design

A qualitative exploratory research design was used. Semi-structured interviews were conducted with patients with vaginal, vulvar, penile or anal cancer and with relevant HCPs. The Medical Ethics Committee of Amsterdam University Medical Centers had assessed the study and declared that the Dutch Medical Research Involving Human Subjects Act (WMO) does not apply, and that extensive approval of this study was not required (2020.0748). The consolidated criteria for reporting qualitative studies (COREQ) have been applied (Tong et al., 2007).

### 2.2 | Study sample and recruitment

Patients were eligible for participation if (1) they had been diagnosed with vaginal, vulvar, penile or anal cancer in the past 6 years and (2) they did not have any severe psychological problems. HCPs were eligible for participation if they had experience with psychosocial care for patients diagnosed with vaginal, vulvar, penile or anal cancer for at least 1 year. Both patients and HCPs needed to be able to communicate in Dutch and/or English.

Purposive sampling was used to recruit participants. Recruitment of patients took place via medical specialists with expertise on these rare cancer types, via relevant stakeholders, e.g., representatives of the Dutch Federation of Cancer Patients Organizations (NFK), and via social media. Patients could express interest in the study to their treating medical specialist or by sending an email to the responsible researcher (JvD). If a patient was interested, a package with an information letter, informed consent, short questionnaire and return envelope was handed to them by their medical specialist or sent by postal mail by the researcher (JvD). When patients decided to participate in the study, they could return the filled-in forms to the research team.

HCPs were recruited via the network of the research team. They received a package with an information letter, informed consent and short questionnaire, by mail from LE. HCPs were asked to return their completed form. If patients and HCPs were eligible to participate in the study, an interview was scheduled. Recruitment of the participants continued until data saturation was reached.

## 2.3 | Data collection

Semi-structured interviews were conducted by JvD (patients) and LE (HCPs) between March and June 2021 by Microsoft Teams or phone, due to COVID-19. Generated topic lists, used during the interviews, contained questions about experiences regarding, e.g., diagnosis, stigma, communication, relationships, sexuality and body image, and psychosocial care. Topic lists were evaluated by a range of experts in the field prior to the first interview and subsequently adjusted. Minor additional adjustments were made after a few interviews had been conducted. Interviews lasted between 30 and 60 min and were audio recorded. Two researchers (JvD and LE) were present during all interviews.

## 2.4 | Data analysis

Data from the interviews were transcribed verbatim and anonymized. Data were processed by means of thematic analyses, based on the six phases described by Braun and Clarke (2006). Two randomly selected interview transcriptions, i.e., one patient and one HCP, were open coded by a second researcher (JvD or LE) to ensure reliability of the coding procedure. All other transcripts of patients were coded by JvD and those of HCPs by LE. A consensus meeting between the two researchers was held to compare the codes, and a third researcher (SD) was consulted in case of disagreement. A meeting with the research team was held to reach consensus on the final themes. An independent researcher (EdH) was consulted in case of disagreement. Crucial phrases were translated from Dutch to English and used as quotes. All analyses on interview data were performed using ATLAS.ti 8.4.

## 3 | RESULTS

### 3.1 | Sample characteristics

Fourteen patients and 12 HCPs participated in the study. The mean age of the patients was 55.5 years, and 12 patients were female (86%). Three patients were diagnosed with vaginal cancer (21%), five with vulvar cancer (36%), two with penile cancer (14%) and four with anal cancer (29%). The mean age of HCPs was 46.4 years. The occupations of HCPs included, e.g., a psychologist, a sexologist and an urologist. Characteristics of the patients and HCPs are presented in Tables 1 and 2.

### 3.2 | Themes

#### 3.2.1 | Recognisable symptoms, but unfamiliar diagnosis

**Patients:** All patients stated that they recognised symptoms like itching, pain and/or loss of blood, before going to the general practitioner (GP). However, they frequently linked these symptoms to more common diseases, e.g., haemorrhoids, since they were unfamiliar with and did not expect it to be cancer.

At one point, the whole toilet was full of blood, so I thought: 'well, now I really have to go [to the GP], because something needs to be done about my hemorrhoid'. P2

Most patients experienced difficulties in the diagnostic trajectory. Some of them had to consult the GP several times before being referred to a medical specialist. In some cases, it even took a long period of time before the GP examined the particular body parts. As a result, some patients received incorrect treatments for an extensive period of time.

**HCPs:** Participants stated that the overall knowledge about these rare cancers is lacking, because they only see a limited number of patients with these specific rare cancers during their career. For some HCPs, it is difficult to increase knowledge and expertise. Consequently, these rare cancers are often not recognised by HCPs, causing delays in the diagnostic trajectory.

That is exactly the problem, because anal cancer, I think, occurs approximately 200 times a year and is treated in about 60 hospitals, so if you only see a few patients per year, then you cannot focus on what it means to have this particular cancer, which may lead to many associated problems. HCP4

**Patients:** The type of hospital patients was referred to play a crucial role in the diagnostic trajectory. Patients who were directly

**TABLE 1** Patient characteristics

No.	Age	Gender	Marital status	Education	Type of cancer	Time since diagnosis	Metastases	Type of treatment
1	61	Female	Living with partner	Higher professional education	Anal	4 years	No	Radiotherapy + chemotherapy
2	54	Female	Living with partner	Higher professional education	Anal	4.5 years	No	Radiotherapy + chemotherapy
3	72	Female	Married	Higher professional education	Anal	5.5 years	Yes, lymph node	Radiotherapy + chemotherapy
4	54	Female	Living with partner	Secondary vocational education	Vulvar	3 years	No	Surgery
5	52	Female	Married, getting divorced	Higher professional education	Vaginal	4 months	No	Surgery + radiotherapy
6	53	Female	Married, children living at home	Secondary vocational education	Vulvar	1.5 years	No	Surgery
7	53	Male	Married, children living at home	University	Penile	1 year	No	Surgery
8	61	Male	Married	Lower vocational education	Penile	2 years	No	Surgery + reconstruction
9	59	Female	Married	Secondary vocational education	Vaginal	5 years	No	Surgery + radiotherapy
10	56	Female	Divorced	General secondary vocational education	Vulvar	2 years	No	Surgery
11	53	Female	Married, children living at home	Secondary vocational education	Vulvar	2 years	No	Surgery
12	57	Female	Divorced	General secondary education	Anal	5 years	Yes, lymph node	Radiotherapy + chemotherapy
13	55	Female	Married	Lower vocational education	Vulvar	3 <sup>3</sup> / <sub>4</sub> years	Yes, urethra	Radiotherapy + chemotherapy + surgery + reconstruction + oxygen therapy
14	37	Female	Living apart together, children living at home	Higher professional education	Vaginal	1 week	Yes, lymph node	To be decided

referred to a Center of Expertise (CoE) seem to have obtained their diagnosis faster than patients diagnosed and treated in a regional hospital.

So I thought, if there are only three or four women a year in my age category, then she [gynecologist in regional hospital] probably never saw someone with this diagnosis. So, how can you diagnose a patient, when you have never seen someone with this particular diagnosis before? P14

### 3.2.2 | Double hit has severe impact on psychosocial functioning

*Patients:* Patients frequently stated that the location of the tumour hampers communication. Most patients were struggling with their feelings about the existing taboo on those body parts frequently associated with sexual activity and their cancer being located in that

intimate area. All participants stated that it would have been less complicated if they were diagnosed with a common cancer, since these are well known and more accepted in society. Nevertheless, the majority of the patients decided to tell their close friends and family members about the location of their cancer:

I have been very open about it from the beginning. I mean, yeah, it is located in my vagina. Okay, I noticed I felt a kind of barrier, but at the same time, I did not want to respond to that, because otherwise I need to censor myself from now on, and I do not want to do that. P5

According to the patients, the majority of their loved ones considered the tumour's location subordinate to the fact that someone they love was diagnosed with cancer. Patients indicated that everyone reacted shocked at first but were predominantly supportive later on.

*HCPs:* All participants indicated that they are aware of the immense impact of these particular rare cancers on patients, especially

**TABLE 2** HCP characteristics

No.	Gender	Current occupation	Years working in current occupation
1	Male	Sexologist	Retired
2	Female	Sexologist and psychologist	1 year and 2 months
3	Female	Radiation-oncologist	4 years
4	Female	Representative of patient organisation	2 years and 2 months
5	Female	Nurse specialist	5 years and 6 months
6	Male	Urologist	2 years and 10 months
7	Female	Occupational therapist	8 years and 6 months
8	Male	Gynaecological oncologist	25 years
9	Female	Urologist	5 months
10	Female	Oncological surgeon	1 year and 6 months
11	Female	Representative of patient organisation	5 years
12	Female	Psychologist	17 years

due to the 'double hit' patients are facing. Apart from the actual diagnosis of cancer, the location of the tumour in the genital area brings along additional consequences related to their self-esteem and sexual functioning.

Being diagnosed with cancer is very unpleasant in the first place, and this type of cancer brings along extra complexities. HCP12

HCPs mentioned that feelings of insecurity, embarrassment and stigmatisation were frequently experienced by the patients.

Well, I often hear about shame and insecurity, and I even hear people say they've been diagnosed with a different tumor. People with penile cancer who say: 'I'm just saying I have prostate cancer', because they're just so embarrassed about it. HCP4

*Patients:* Although the majority of the patients were cured from cancer at the time of the study, they indicated that the changes that occurred with regard to body image and sexuality still have great impact on their psychosocial functioning and QoL. Changes in body image varied from feeling mutilated to feeling less masculine or feminine.

... when you see my stomach. I got a stoma, a urostomy. I am just mutilated. I cannot look at myself in the mirror. Let alone that my husband can see me. I do not undress within his presence anymore. P13

Some patients were unable to have sexual intercourse after treatment due to the pain, which severely affected married couples as well as single participants.

*HCPs:* According to HCPs, the impact of the diagnosis on the patients' psychosocial functioning depends on various factors, such as age, personality and tumour severity. They explained that a resilient

and open personality helps patients dealing with the disease and that the impact is greater for younger people and when the prognosis is worse.

Someone who needs to have his entire penis amputated is of course very different from someone who only needs to use an ointment for a small spot. HCP6

### 3.2.3 | Personal and tailored information is important but not guaranteed

*Patients:* Most patients stated the necessity of clear information about the disease, treatment, residual symptoms and available psychosocial care. The received information partly depended on the type of hospital where they were treated. While information was frequently not sufficient in a regional hospital, most patients treated in a CoE did not share this experience. Patients often assumed that HCPs working in a CoE have more knowledge about these rare cancers than HCPs working in a regional hospital.

Because, I also had the feeling that they knew what they were talking about. You cannot wish for a better treatment than to get it from someone with knowledge, someone who is internationally well-known for this. P3

*HCPs:* Some participants stated that it is difficult to assess the patients' (information) needs, since these are very diverse and depend on various factors, e.g., age and personality. However, most participants emphasised the importance of clarity about what to expect throughout the patient journey in order to avoid uncertainties.

*Patients:* Overall, patients were satisfied with the 'technical information', e.g., factual medical information about the treatment and

possible side effects. Nevertheless, they frequently indicated that there was minimal attention for the emotional consequences. For instance, regarding sexuality, many participants stated that they knew things would change, but no HCP asked them how they, and their partners, felt about and dealt with these changes:

It strikes me that they are proactive on the physical and medical part. So for example, they told me about the diarrhea inhibitors and vaginal dilators. But, the psychological side, as I mentioned before, someone visited me in the hospital once, and that was it. P5

*HCPs:* The majority of the participants considered the provided psychosocial care as insufficiently tailored. They stated that there is no unambiguous policy for providing information about the treatment and consequences. Furthermore, participants indicated that it also depends on whether patients are supported by their partner and family members, on the style of communication by HCPs, and the type of hospital whether information about psychosocial care is provided. Participants often noticed that male patients are less likely to accept psychosocial care, because they might have a more reserved personality.

They [penile cancer patients] just don't want to talk about their disease. I guide many different patient groups, but I cannot find these penile cancer patients. Yet, I do have women with anal cancer in the support groups. HCP4

Most participants indicated that communication plays a role in offering information about psychosocial care. Overall, they considered their communicative skills as very adequate. They feel responsible for breaking taboos that may exist. However, talking about sexuality is often perceived as difficult and is therefore often omitted. Some participants indicated that they make assumptions about sexuality, resulting in inappropriate offered psychosocial care.

I think that many health care professionals do not ask the question: 'Is penetration still important for you when having sexual intercourse?' I think that, very often, that question is not asked because it is assumed, for example, that when a woman is a widow and no longer has a partner, we can sew the whole thing up, right? HCP1

Participants strongly emphasised the differences between a regional hospital and a CoE, where adequate psychosocial care for patients with these specific types or rare cancer is often integrated in care and offered on a regular basis. In addition, nurse specialists play an important role in providing information about psychosocial care.

### 3.2.4 | All-encompassing care to improve psychosocial functioning and QoL

*Patients:* Patients were divided in their answers about whether they needed psychosocial care. While some patients did not feel the need to discuss their feelings with a psychologist or a sexologist, the majority did. However, they did not always know where to go for psychosocial care.

*HCPs:* Most participants mentioned that referrals to psychologists or sexologists do not take place sufficiently. Since HCPs are usually the decision-makers in referring patients to psychosocial care, it does not happen at all when both patient and HCP do not consider or mention it. Some participants stated that offering patients psychosocial care or referring them could be a problem when the physicians do not regard these actions as part of their role.

No, I don't think you should expect that either. Because, some people are very good at surgery and they are not 'people' persons at all, you do not even want to talk to them about sex, you just want them to cure someone, so to speak. HCP9

*Patients:* All patients indicated that tailored psychosocial care should be offered on a structural basis: earlier in the process and frequently during and after treatment. Patients especially stated that sexual support should be the focus, since everyone experiences changes in sexuality due to the location of the tumour.

*HCPs:* While, according to all participants, patients often do not feel the need for psychosocial care at the beginning of their treatment, they strongly recommended to discuss and offer psychosocial care on a structural basis, so referrals are less dependent on the attending physician. Some participants proposed the idea of fixed appointments with psychologists or sexologists in the care pathway.

When I ask them: 'Do you want to be referred to a sexologist?' Most people say: 'Pff no'. But if they do come to me, one way or another, they really appreciated it. HCP2

Participants also emphasised the need of offering psychosocial care during follow-up, when patients might experience consequences in daily life, and of involving the partner, if applicable, in the process.

## 4 | DISCUSSION

### 4.1 | Main findings

The majority of vaginal, vulvar, penile and anal cancer patients experience difficulties in the diagnostic trajectory. The experienced symptoms are recognisable for both patients and HCPs, but a lack of knowledge about these rare cancers complicates linking the symptoms to cancer. Both patients and HCPs emphasised the 'double hit'

patients are facing. That is, next to the diagnosis of cancer, the location of the tumour complicates communication and entails additional consequences related to body image and sexuality. Most patients and HCPs stated that provided psychosocial care is insufficiently tailored, and more attention to and information about the emotional consequences should be given. Participants recommended to offer psychosocial care on a structural basis, since referrals to a psychologist or sexologist are insufficient, even when psychosocial care is integrated in the care pathway.

## 4.2 | Interpretation of findings

Our study showed that most patients and HCPs recognise the symptoms patients experience, but they seem to link these symptoms to more common diseases, due to unfamiliarity with vaginal, vulvar, penile and anal cancer. This is in line with a study by Cooper et al. (2013), who showed that women only considered vaginal bleeding and vulvar skin changes as something serious, while symptoms as urine loss were not associated with something as severe as cancer. Similarly, in a study by Chiu et al. (2015), it has been described that physicians had difficulties differentiating benign diseases from anal cancer when patients with anorectal complaints consulted them. Furthermore, our study showed that a correct diagnosis was earlier realised in CoEs than in regional hospitals. The rarity of these types of cancer makes it difficult for HCPs to develop expertise, which was also stated by Gatta, Trama, et al. (2017). However, CoEs are expected to be more accurate in diagnosis and treatment, because HCPs in these centres treat larger patient numbers (Sandrucci et al., 2019). Therefore, it is recommended to promptly refer rare cancer patients to a CoE (Gatta, Trama, et al., 2017).

In our study, we found that patients experienced difficulties in talking about their disease, because the tumour's location is frequently associated with sexuality. In concordance with these findings, DeMaria et al. (2019) found that women are embarrassed to discuss their genitals, since they experience social taboos, concerning these body parts, and they perceive it as a private matter. Yet patients in our study felt generally supported by their loved ones when telling their diagnosis. In a study by Jefferies and Clifford (2011), results were reported that contrasted our findings. Patients with vulvar cancer felt lonely and isolated by the lack of awareness and knowledge about their disease among friends and family (Jefferies & Clifford, 2011). However, the fact that patients in our study were open about their diagnosis might have made it easier for their social environment to accept the location of the tumour and to focus on supporting their loved one (Rueeggsegger et al., 2018; Witty et al., 2013). Furthermore, HCPs emphasised the 'double hit' patients are facing. This is confirmed by a systematic review (Sekse et al., 2019) on the QoL of patients with gynaecological cancer, in which it was stated that patients encounter problems with communication about the diagnosis, sexuality and body image. Patients, both in our study and in previous studies, indicated that the changes that occurred regarding their body image and sexuality have great impact on their psychosocial

functioning and QoL (Eardley, 2016; Iżycki et al., 2016; Kpoghomou et al., 2021).

Further, patients and HCPs considered provided psychosocial care as insufficiently tailored. Yet HCPs in our study considered their communication about psychosocial care as adequate. This can be explained by the fact that HCPs in our study were mostly working in CoEs, where psychosocial care is better integrated, according to our findings. However, HCPs stated that discussing sexuality, as part of offering psychosocial care, often feels awkward. This has been described in previous studies as well (Dilworth et al., 2014; Krouwel et al., 2015).

While the majority of the patients stated that they needed psychosocial care, referrals to psychologists or sexologists did not take place sufficiently. Physicians do not always consider themselves as the designated person to discuss psychosocial care and evident care pathways are lacking (Dilworth et al., 2014). Such indistinct care pathways are regularly seen in rare cancer care. Lastly, according to patients and HCPs, it is important that psychosocial care is offered to every patient on a structural basis during the whole trajectory. This is in concordance with previous findings, stating that recurrent provision of psychosocial care is part of high-quality cancer care (Boden & Willis, 2019; Hodgkinson et al., 2007; Sekse et al., 2019).

## 4.3 | Strengths and limitations

This is the first explorative study to investigate the experiences of patients with vaginal, vulvar, penile or anal cancer and of relevant HCPs with psychosocial support and care. Limitations of the study are the small sample size, the lack of men among the participants and the fact that most included HCPs worked in the same hospital. Moreover, patients that participated in our study were relatively comfortable with talking about their disease and associated consequences, which impedes their representativeness for other patients with these rare cancers. Therefore, results should be interpreted with caution. Also, while data saturation has been achieved on discussed topics as a whole, it was not reached independently for vaginal, vulvar, penile and anal cancer patients and involved HCPs, as we should have included more patients per cancer type to accomplish that. The limited number of patients per tumour type emphasises once more the difficulties in communication these patients experience. Lastly, all interviews were conducted online or by phone, due to COVID-19, which might have led to wrong interpretation of non-verbal expressions.

## 4.4 | Implications for research and practice

In future research, it is recommended to include more men with anal or penile cancer and HCPs from various hospitals, in order to enhance transferability. In addition, research in caretakers of patients with these rare cancers may contribute to a broader understanding of this topic.

With regard to clinical practice, psychosocial care should be offered on a structural basis throughout the whole trajectory to every patient. Furthermore, every patient with vaginal, vulvar, penile or anal cancer should be referred to a CoE in order to get access to a high level of expertise regarding their specific tumour and provision of sufficient psychosocial care. Finally, in order to increase knowledge and awareness about symptoms of vaginal, vulvar, penile and anal cancer in society, more media attention should be given to these cancers, which might also contribute to reducing taboo, stigmatisation, challenges and controversies.

## 5 | CONCLUSION

Patients with vaginal, vulvar, penile or anal cancer face many challenges and controversies that have long-term negative effects on their psychosocial functioning and QoL. According to both patients and HCPs, awareness about possible symptoms related to these rare cancers should be raised, and tailored psychosocial care should be offered to patients on a structural basis, throughout the whole disease trajectory to increase their QoL.

### ACKNOWLEDGEMENTS

We would like to express our gratitude to all patients and health care professionals who participated in this study. Also, we would like to acknowledge the time and effort put into patient recruitment by various health care professionals involved in the Dutch rare cancer field.

### CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author (SD) upon reasonable request.

### ORCID

Jessy van Dongen  <https://orcid.org/0000-0002-0949-9173>

Eline de Heus  <https://orcid.org/0000-0002-0019-7259>

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**How to cite this article:** van Dongen, J., de Heus, E., Eickholt, L., Schrieks, M., Zantigh, I., Brouwer, O. R., Oonk, M. H. M., Grotenhuis, B. A., Ezendam, N. P. M., & Duijts, S. F. A. (2022). Challenges and controversies patients and (health care) professionals experience in managing vaginal, vulvar, penile or anal cancer: The SILENCE study. *European Journal of Cancer Care*, 31(6), e13676. <https://doi.org/10.1111/ecc.13676>