The lived experience of younger women with vulval cancer: the impact of delayed diagnosis

More young women are being affected by vulval cancer but a lack of knowledge about the symptoms of the condition can lead to significant delays in referral

**BACKGROUND**

Cancer of the vulva is a rare condition, accounting for 3-5% of gynaecological malignancies in the UK (Coleman and Santoso, 2000). It commonly affects women aged over 70 but, in recent years, more younger women have also been affected.

An increasing number of younger women are being diagnosed with multifocal preinvasive disease, as higher numbers are becoming infected with the human papillomavirus (HPV). This virus can lead to a precancerous condition known as vulval intraepithelial neoplasia (VIN 3), which may develop into carcinoma in situ and invasive cancer over time. Joura et al (2000) noted that the incidence of VIN in women under 50 has soared by 392% in the past decade. A previous history of genital warts increases risk of VIN (Al-Ghamdi et al, 2002). Lichen sclerosis is another precancerous condition, characterised by a diffuse white change to the skin, which may lead to vulval cancer.

**BOX 1. RISK FACTORS**

- Precancerous conditions such as vulval intraepithelial neoplasia and lichen sclerosis.
- Multiple sexual partners.
- Herpes simplex virus.
- Smoking.
- Genital warts.
- Lower socioeconomic status.

The most common symptom associated with vulval cancer is pruritus, which occurs in 80% of patients. Less common symptoms are pain, burning, soreness, bleeding, an ulcer or a lump. There may be colour changes in the affected area.

Ninety per cent of all vulval cancers have a visible lesion at first presentation, which may look superficial, or deep and ulcerated, raised, warty or appear as a firm lump. Metastatic disease presenting as a lump in the groin may also be seen at presentation. Most squamous cell malignancies arise as unilateral lesions on the labia majora, but other primary sites include the labia minora, clitoris or mons pubis. Multifocal lesions occur in 10-30% of cases (Modesitt et al, 1998). Fig 1 shows a malignant tumour on the labia minora.

Treatment for vulval cancer and related precancerous conditions is surgery to remove the affected area, together with a 1cm area of healthy tissue. The extent of surgery depends on the depth of the tumour’s invasion.

The International Federation of Gynecology and Obstetrics (FIGO) uses surgical information to stage the tumour (Table 1). The stage indicates a prognosis and also helps in making decisions about adjuvant therapy postoperatively.

**LITERATURE REVIEW**

Since vulval cancer is rare, a literature review revealed a paucity of studies and produced limited insights into its wider impact. It found only 14 studies in total; the number of women in each was small and the total involved in all studies overall was under 300. Three studies sought to gain a picture of the consequences of surgery (for example, Corney et al, 1992). Two sought to assess the effect on quality of life postoperatively (for example, Janda et al, 2004).

The remaining nine focused specifically on sexual functioning, comparing preoperative with postoperative functioning and the impact this had on women and their husband/partner (for example, Likes et al, 2007; Green et al, 2000). The earlier study also assessed change in body image. Five studies included an assessment of women’s partners’ experiences (such as Willibrord et al, 1990). Although there are weaknesses in the studies’ design and analytical methods, and a lack of clarity in the data analysis, the literature review helped to build up a picture of the challenges these women face postoperatively. The only British research on women with vulval cancer was a comparative study which incorporated women who had either a total pelvic exenteration or a Wertheim’s hysterectomy (Corney et al, 1992). As it was published several years ago, it does not reflect contemporary healthcare. A research study was therefore undertaken to address this gap in nursing knowledge.

**AIM**

As a clinical nurse specialist caring for women with gynaecological cancer, I noticed that increasing numbers of younger women...
work of Heidegger (2005) and van Manen (1990) was adopted. The local research ethics committee granted ethical approval.

METHOD
Given the paucity of literature about women with vulval cancer in the UK, an interpretative phenomenological approach based on the work of Heidegger (2005) and van Manen (1990) was adopted. The local research ethics committee granted ethical approval. Semi-structured interviews using 33 questions were conducted with 13 women identified by purposive sampling, all of whom had positive diagnoses of vulval cancer. Participants were aged under 50, reflecting the increased incidence of vulval cancer. Participants were given other names to preserve confidentiality.

RESULTS
One concept that emerged was “searching”, which referred to participants’ feelings of “looking for help”, “repeated visits to the doctor” and “seeking advice”. It included the way in which they searched to control symptoms by their own efforts and by asking for help from their GPs. Participants were given other names to preserve confidentiality.

RESULTS
One concept that emerged was “searching”, which referred to participants’ feelings of “looking for help”, “repeated visits to the doctor” and “seeking advice”. It included the way in which they searched to control symptoms by their own efforts and by asking for help from their GPs on several occasions. The issue of searching is examined fully in this article. A delay in diagnosis has been explored with other patients with cancer (Scott et al, 2006).

Delays in the referral process
The findings showed that nine out of 13 participants experienced a delay between the time they first noticed symptoms and the time they were referred to a cancer centre. Although the DH (2000) stipulates that all those with suspected cancer should be seen within two weeks of seeing their GP, women had experienced symptoms ranging from several months to many years before they were referred to a consultant gynaecologist:

"It was about nine months before I was eventually diagnosed" (Denise);

"It was four years from the time of my first symptoms [before I was diagnosed]" (Donna).

The reasons for delays in diagnosis may be due to women’s lack of awareness that their symptoms may indicate a malignancy. Seven participants said they presumed their symptoms of vulval itching were caused by an infection and had visited their GP to ask for a prescription:

"I thought it was thrush all the time” (Eve).

Some tried to resolve their symptoms by searching for products in the local pharmacy. Leigh had bought medication:
"I'd been given Diflucan and sorts of things like that. I had tried the products on the market you can find to stop itching and things like that, so I had tried to apply various stuff to stop the itching, but nothing worked" (Leigh).

Josie had tried complementary therapies:

"I decided to try homeopathy. So I went to see Dr A, and I mean she's a proper doctor, but she specialised in homeopathy as well. So I went to see her privately and she was trying different things" (Josie).

Women with chronic vaginal symptoms are increasingly rejecting antibiotic treatment in favour of alternative remedies (Nyirjesy et al, 1997). This study reported that 42% of women used alternative therapies, such as yogurt and tea tree oil (Melaleuca alternifolia). Josie also sought advice from skin specialists and a doctor qualified in Chinese medicine:

"With visits in between to the skin specialists who again just did the same thing: just gave me different steroid creams, a bit stronger and stronger creams, but nothing helped. Somebody gave me a name of a doctor who worked at X university and also did clinics [in Chinese medication] on the side privately" (Josie).

Other women presented to their GP with a vulval swelling:

"It was just like a pea size lump on my vulva, on the right hand side. I thought it was one of those pimple things, like a Bartholin's cyst. I thought it was one of them…. He [GP] said: ‘your lymph glands swell up because of the infection’" (Kay).

This may illustrate participants’ dependence on their doctor, as the majority appeared to return to the same doctor for further appointments.

The cause of the swelling was thought to be an infection of the Bartholin’s gland. These glands produce a small amount of fluid that lubricates the vaginal lips. Swelling and infection are caused if a flap of skin grows over the opening of the glands and the fluid remains inside it, causing pain.

Eleven women saw their GP several times:

"Because I was pregnant, it was an automatic assumption I had thrush, so I had the Canesten. Went home, put that on religiously, no improvement so I went back and it was probably three or four months of just going back and forward to the doctor getting no response whatsoever" (Ria).

Josie had tried homeopathy:

"I think some of the doctors haven’t seen it before as it is so rare" (Kay).

This finding supports a study by Coleman and Santosro (2000), who noted that unfamiliarity with the disease and doctors’ reluctance to perform an examination can add to delays.

Some women’s GPs reassured them that their symptoms were probably due to a benign, non-cancerous condition. Sarah and Kay remarked:

"He [the GP] said: ‘I don’t think it is anything, it might be a cyst or something.’ He said: ‘You’ve got nothing to worry about, it is just a wart or a cyst’" (Sarah);

"But my GP said it was a cyst, he gave me some antibiotics and sent me away" (Kay).

"I had a lump. And I had a lot of trouble, I was in and out of hospital for months up here in X, they didn’t know what was wrong, couldn’t find nothing [sic] wrong (Julie);

"I think the male doctor’s lack of empathy for her symptoms of itching by saying:

"And it’s very difficult to talk to a [male] doctor or whoever if they don’t understand what you’re saying…. It’s hard to describe to a, to somebody who’s, especially a man who’s not got the bit there to itch anyway” (Stella).

Josie commented:

"Like I said to the skin specialist, you know I’d say to anybody: ‘You see how long you can go without scratching. You know if you have something that’s really irritating you.” (Josie).

These comments highlight a lack of understanding and empathy from healthcare professionals. Donna felt she was being laughed at:

"I said I felt something was wrong but he [consultant gynaecologist] said it was all in my mind, and there was nothing wrong with me. He just laughed at me” (Donna).

Consequently, some participants felt ill prepared for their eventual diagnosis of cancer. Receiving a diagnosis of cancer can be shocking and overwhelming, and this may have been exacerbated because women had been told they had a benign condition:

"I was expecting something minor as the doctor at the other hospital said it was all in my mind. I felt angry, really angry” (Donna);

"He [consultant gynaecologist] did a biopsy and the next thing I knew I had a phone call from the secretary asking me
to go there [to the cancer centre]. But nothing was said at the time that he [sic], it could have been what it was” (Denise).

The NHS cancer plan (DH, 2000) stipulated that people with cancer should be treated within 62 days of their first referral, or 31 days of being told of their diagnosis. But two participants experienced a further delay between having a biopsy taken and being told they had a diagnosis of vulval cancer:

“I saw a doctor who said I needed a biopsy straight away so they admitted me in to X in the November and then it was the March when I went back and they said it was a cancerous lump” (Julie);

“I had the biopsy in August: my appointment was in the October” (Leigh).

DISCUSSION
This study is based on interviews with 13 women, 11 of whom were treated in the NHS and two in the private sector in the same geographical area of the UK, giving a perspective on two healthcare systems.

The purposive sampling identified white women; while knowledge of spoken English was necessary for the study, other ethnic groups may have had other concerns which were not identified. The sample size was small so these findings may not apply to all women diagnosed with vulval cancer. Neither is it known if the delay in diagnosis had an impact on prognosis. It did lead, in some cases, to the women developing a lack of faith in clinicians involved in their care.

Despite the study’s limitations, patterns have emerged that may contribute to the provision and delivery of care in the future.

Recommendations
Participants highlighted a lack of awareness of vulval cancer among healthcare professionals and in society in general. Nurses should encourage women with chronic symptoms that indicate thrush to discuss referral to the local cancer centre with their GP. A biopsy of the area can then be taken and, if malignant, treatment started as soon as possible.

A campaign should be developed to raise awareness of the condition among the public, for example, by posters or leaflets in GP surgeries, well woman and GUM clinics. It could draw attention to symptoms, for example, persistent symptoms of thrush like illness despite treatment, or an ulcer or lesion that does not heal.

The campaign could also mention 40% of vulval cancer cases may be related to HPV (Munoz et al, 2006). Since the virus is linked to cervical cancer, this knowledge may prompt women to address concerns about symptoms with their GP or practice nurse.

As the condition is rare, a list of symptoms should be made available to GPs, which could be similar to a “risk of malignancy index” (Royal College of Obstetricians and Gynaecologists, 2003). This index is designed to prompt GPs to refer women who present with ovarian cancer symptoms to a consultant gynaecologist immediately.

Some participants who attended cancer centres were unaware of their diagnosis (even after being diagnosed in hospital and referred) or potential diagnosis, and felt they had been given insufficient information.

Although healthcare professionals making referrals may not know the treatment involved, patients could be given a leaflet detailing the name of the consultant, the clinical nurse specialist’s name, a contact telephone number, and the likely radiological investigations. It would also be helpful to give patients the date and time of their appointment at the cancer centre before leaving the referring hospital.

CONCLUSION
This article has discussed the delay in diagnosis of vulval cancer for nine out of 13 study participants. The delay may be attributed to lack of awareness of symptoms among women and healthcare professionals. As a result of the delay, women tried to “search” for remedies to alleviate symptoms. While it is not known whether the delay affected prognosis, participants felt unprepared for their cancer diagnosis. Some changes to practice are recommended to increase awareness among nursing and medical staff and the general public.

The thesis on which this article is based has been shortlisted for the Akinsanya Award 2010 for Innovation in Doctoral Studies in Nursing, run by the Royal College of Nursing.