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Patients' experiences of vulvar cancer diagnosis and treatment: results from a consumer-guided qualitative study

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ABSTRACT


Background: Despite increased attention for the use of sentinel node biopsy (SNB) for the management of vulvar cancer as a less invasive technique compared with lymph node dissection (LND), patient views on this technique are unknown. This study explored patients' experiences of being diagnosed and treated for vulvar cancer and to enhance our understanding of the patient view of SNB.

Methods: Ten women who had received surgery (with or without lymph node removal) for vulvar cancer in the previous five years participated in a semi-structured qualitative interview in 2022. A consumer-led research group guided thematic analysis of the data.

Results: Ten women were interviewed ranging in age (41–82 years). Treatment included either lymph node removal during initial surgery ($n = 4$), or following a routine scan identifying a change ($n = 2$); four vulvar cancer patients were being monitored with ultrasound at the time of the interview. Five main themes were identified: (1) difficult diagnostic experiences; (2) lack of support and information; (3) challenges with treatment decision-making; (4) patients' perspectives of LND and SNB with monitoring; (5) trauma of treatment.

Conclusions: SNB seems acceptable to patients and potentially offers a less invasive alternative to standard treatment, which should be further investigated.

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Introduction

Vulvar cancer is rare and due to its intimate nature, is also largely hidden from public discourse. With an incidence of 2.5 cases per 100,000 females, approximately 400 Australian women are diagnosed every year [1]. It develops from vulvar skin and can spread locally to adjacent structures (vagina, urethra, anus) and via lymphatic channels to regional lymph nodes in the groin [2].

Clinical practice management guidelines mandate surgical excision of the primary tumor plus surgical evaluation of the draining groin lymph nodes [3,4]. Involvement of groin nodes indicates a worse prognosis compared to tumors confined to local involvement [2]. Unfortunately clinical examination and medical imaging don't reliably detect groin node involvement [2]. Hence all patients (except those with Stage 1A disease) require surgical evaluation of groin nodes [3,4]. In 30% of cases this reveals positive nodes [5,6], and a need for postoperative radiation treatment. If positive groin nodes are not detected and become enlarged and clinically palpable, >90% of patients die within 12 months, despite subsequent treatment [2]. Conversely, if groin node involvement is detected early while still small, survival outcomes are expected to be excellent [2].

While standard treatment is often curative, groin node dissection is associated with debilitating outcomes for many patients (e.g. wound breakdown, cellulitis, limb swelling) causing substantial reductions in quality of life [7–10]. To limit the morbidity associated with groin node surgery, sentinel node biopsy (SNB) has been implemented into standard care [11–13]. It involves the injection of a radioactive tracer next to the primary vulvar tumor. The tracer gets transported via lymphatic channels to the draining groin lymph nodes. The first node into which the vulvar lymph fluid drains is known as the sentinel node. Compared to an inguino-femoral lymph node dissection, with SNB only one or two targeted lymph nodes are removed and if the sentinel node is tumor-free, it is assumed that all other nodes are tumor-free also. Involvement of the sentinel node assumes that the patient has advanced disease and requires adjuvant treatment [2]. As strict guidelines restrict SNB to patients with unifocal tumors less than 4 cm in diameter, 50% of patients are not eligible for the SNB procedure. Recently, substituting groin node surgery with groin node surveillance and groin ultrasound has been offered to patients on an ad-hoc basis with encouraging results [14].

Very limited evidence is available on the patients' views and preferences of treatment. One study reported that women's preferences for a less invasive SNB was 97% (34/35) among those who had received it, versus 62% (17/

270) among women who had experienced a full LND, if the false negative rate was 1% [15]. Conversely, an Australian survey ($n = 60$) found that while women preferred full LND if the risk of missing a positive lymph node was higher than 1 in 100, almost one third of respondents favored less invasive approaches if the risk of missing a positive lymph node was less than 1 in 100 [16].

This study was guided by consumers and aims to describe the patient experience of being diagnosed and treated for vulvar cancer and to enhance our understanding of the patient view of groin node surgery from qualitative interviews in women who have had surgery for vulvar cancer.

Methods

This qualitative study used semi-structured interviews to explore vulvar cancer patient experiences of diagnosis and treatment. The COREQ checklist for reporting qualitative research [17], and the GRIPP2 checklist for reporting of patient and public involvement in research [18], were followed. This research was approved by The University of Queensland Human Research Ethics Committee.

Participants

Participants were recruited from three gynecological oncology practices in Brisbane, Australia. Patients were eligible if they were aged 18+ years and had received surgery (with or without lymph node removal) for vulvar cancer in the previous five years. The standard treatment is groin LND through sentinel node biopsy for patients with unifocal tumors < 4 cm or full groin LND for the remainder of the patients. This treatment was offered to all patients. However, if and when patients made it clear that they are not satisfied (“Doctor, is there another option?”) then a non-surgical, ultrasound-based surveillance option was discussed on an ad-hoc basis. Potential participants were identified by practice managers and sent an invitation to participate with an information sheet and consent form. A clinical nurse consultant (AM) telephoned those who replied with a signed consent form to arrange a suitable time for the interview. In total, 16 patients who met the inclusion criteria were sent a study information package; three patients declined (too busy, $n = 1$; unable to contact, $n = 2$) and 13 patients consented. After interviewing 10 participants, the issues women described were repeated and further interviews were not scheduled to reduce unnecessary burden on patients [19]. The authors discussed the interviews and agreed that there was rich and important information, and that the themes emerging from the interviews were sufficiently often repeated to ascertain that no new themes were arising.

The research team

The research team has expertise in gynecological oncology, psychology, nursing, qualitative research, epidemiology and public health, biostatistics, and biomedical sciences. An established consumer-led research group ($n = 6$) guided the data analysis, interpreting results, and contributed to writing of the paper. All members of the consumer-led research group have a lived experience with gynecological cancer either as a survivor or caregiver, therefore involvement aimed to provide a deeper understanding of the experiences shared by participants.

Interviews

The semi-structured interview guide (Supplementary material 1) was developed with advice from a gynecologic oncologist, gynecological oncology nurse, psychologist, and qualitative researchers to ensure its applicability and appropriateness to the participant group. Participants were asked to comment on their experiences of being diagnosed and treated for vulval cancer. Stage of the disease was determined by the surgeons. All semi-structured interviews were conducted by AM (a female clinical nurse consultant with extensive experience in gynecological oncology nursing and qualitative data collection) over the telephone or zoom. The interviewer had no part in the participants' clinical care. Only the interviewer and participant were present for the interview. Interviews continued until no new themes were identified. Interviews were audiotaped and transcribed verbatim by a professional transcription service. Interviews were conducted between October 2022 and December 2022 via telephone ($n = 2$), zoom with camera off ($n = 4$) or zoom with camera on ($n = 4$) and lasted on average of 29 min (range 19–36 min).

Data analysis

Data analysis and interpretation was led by our consumer-led research group. Thematic analysis of the entire data set was conducted by two independent consumer-researchers (TD, MJo) to identify themes within the qualitative data. Each researcher familiarized themselves with the content of the transcripts followed by manually generating initial codes and themes [20]. They (TD, MJo) reviewed and discussed the preliminary themes to modify and expand on the analysis. Coding of transcripts continued to develop an understanding of the role and meaning of experiences in the narratives. Our analysis balanced deductive and inductive orientations, guided by both the predetermined aims and themes from the interview guide, and adding new themes as they were discovered in the data itself.

Themes were presented to the consumer-led research group at each step for refinement and interpretation, providing novel insights and practical recommendations for discussion.

Results

Participants ranged in age from 41 to 82 years (median 68 years) at the time of the interview, resided in either major city or inner regional areas of Queensland [21], and were diagnosed with vulvar cancer between 2017 and 2022. Nine participants were diagnosed with stage IB vulvar cancer and one participant with stage IA. Treatment included either lymph node removal at the time of initial surgery only ($n = 4$), or lymph node removal following a routine scan identifying a change ($n = 2$); four vulvar cancer patients were being monitored with ultrasound at the time of the interview.

Five main themes were identified from the analysis of the qualitative interview data. Themes are outlined below with illustrative quotes detailed in Table 1.

Diagnostic experiences

Participants described experiencing various symptoms prior to diagnosis including a lump in the vulvar area; feeling itchy, uncomfortable, or irritable in the vulvar area; sting when urinating; unusual bleeding; or pink discharge after intercourse. At the time of first noticing them, women did not associate these symptoms with cancer but rather thought about a variety of possible causes such as scar tissue from giving birth, discomfort due to aging, or a consequence of going through menopause. One participant described a three-year interval, experiencing symptoms and consulting doctors, before being diagnosed. Other accounts conveyed short intervals between initial consultation with a General Practitioner to diagnosis.

Support and information

Support, in the form of emotional support and information, was critical throughout diagnosis, treatment, and post-treatment phases. All participants spoke about family and friends as their main source of support. Participants highlighted the importance of having someone with them at consultations to help remember the conversation and information provided. While participants ($n = 6$) recalled receiving information during consultations with their doctors, they were uncertain if written information was provided.

Besides family and friends, many participants were their own advocate in finding support and information. Participants reported different approaches to their self-directed research which seemed to be influenced by some of the

**Table 1.** Themes and illustrative quotations from participants.

Themes	Illustrative quotes
Diagnostic experiences	<p>I'd been quite uncomfortable down there for a fair while and I did feel a lump which I just thought was scar tissue from when I had the kids. (02)</p> <p>It never entered my head and yet I had this lump. It was just itchy in there and I thought I've got to go and see about this. I never really thought about cancer. (03)</p> <p>I wasn't sure really what was going on, I just knew that when I weed it was stinging ... and I thought it's just thin skin because I'm getting older. (05)</p> <p>It was the tiniest little lesion ... It didn't have any colouration to it, it was literally just a little tiny raw piece of skin, there was no redness, no nothing to it, so I honestly thought it was just a piece of skin that wasn't healing. (07)</p> <p>I didn't even know what it [vulvar cancer] was until I was diagnosed with it myself, I'd never heard of it. (07)</p>
Support and information	<p>I went by myself. I think when you hear the word cancer and you've got to have surgery, then everything else just goes in one ear and out the other. (01)</p> <p>I would always take somebody with me. Because there is so much to process, and so much to decide. (10)</p> <p>Well, I find that I am a loner with all this that's happening. (01)</p>
Support	<p>People say, "Oh, you've got cancer, what kind of cancer?" how do you say, I've got cancer of the vagina? It's not something that gets spoken about, it's almost – it's an embarrassing kind of cancer to have. It's not something you want to discuss with people. I don't know if there's support groups for that kind of thing, or what not. (07)</p>
Information	<p>I wasn't really, really, happy about having radiotherapy and chemotherapy, but I spoke to my family and weighted up the positives and the negatives, and decided, well, I was relatively fit, I might as well do it, rather than have it spread further. (08)</p> <p>Just verbal [information in regard to the treatment] ... nothing written. (05)</p> <p>Yeah, it was just verbal conversations. I did all my research on Google. (07)</p>
Being your own advocate	<p>I think he spoke to us about it [surgery], but I don't know if we actually go any written anything, but he spoke very well about it, what might happen and sort of thing. (06)</p> <p>I try to stay away from Dr Google. It can be a minefield. (09, nurse)</p> <p>But maybe just information-wise, maybe there's just not quite enough information. And I like to know, I Google everything to find out what's going on, because I figure the more information you have, the better off you are. (02)</p> <p>They were basically medical sites, but I also went to a lymphoedema occupational therapist and she did ... an LED reading. (08 – tech librarian)</p>

(Continued)

Table 1. Continued.

Themes	Illustrative quotes
<p>Treatment decision-making Patient-provider roles</p>	<p>I would have just signed for what he had to do; just would have agreed with what he had to do. (03) Well, I just took his advice. He said that was the best course to take. So I just took his advice, and that's what I did. (04) I just said, "You do what you have to do" sort of thing, and that's what he said, "Well, I advise you to do that [remove the lymph nodes]". We were guided by him. I mean, I put my trust in him. He's the one who knows what he's doing. (06) So, I questioned [the doctor] about whether we could go down the route of doing all these – it was literally going through Doctor Google, pretty much to find out what my options were other than surgery. . . . So I asked [the doctor] for me to go down those routes instead, and she reluctantly agreed, and by doing these things it came back showing that there was nothing wrong with nodes at all. I was pleased that I put my foot down to the surgery because had they gone in they wouldn't have found anything and they would have taken everything away, which would have left me with quite possible severe side effects for the rest of my life. (07) But given that there were clear nodes and everything had been – pelvis and lymph glands and everything were all normal, we decided between the two of us that this was an option to take and that there were studies being done on this course of treatment [ultrasound and monitoring]. I'm grateful that he was willing to entertain an alternative or a slightly different course from what the usual would be. (09, nurse) So, from me going to see my doctor, for the second time, to having the surgery was all within a month, I believe, it was really, really quick, I didn't have time to process anything. (07)</p>
<p>Quick interval from diagnosis to surgery</p>	<p>I saw him one week, and the following week I was on the operating table. (10) [Lymphoedema] was a big concern to me. I've always been really active, and I could picture it totally changing my lifestyle if that were to happen. (02)</p>
<p>Preferences</p>	<p>So, I said no to the surgery . . . I'm not going to have that happen for the fact that I'm only 41 . . . I've got a three-year-old, I'm not going to take the risk to end up with . . . lymphoedema with the fluid in the leg from taking all those nodes away. (07) He [the doctor] said, "Oh, well, these are the options," and I said straight up – because I'm very active in my lifestyle and my work, I just said, "lymph gland dissection is not an option." So we've gone with this two-monthly ultrasound, and he reviews it and – for at least two years . . . , but he said there's about – I think a 3% chance that it might recur and I said, "Yeah, well, I'm happy to take that chance." (09) We both agreed that we wanted to go this way because of my physical activity, and the career that I have, which is in ballet. And so, I just felt I couldn't take the chance of having lymphoedema or other, so I said, "I'm prepared to do this" and I just trusted him that he would be watching. (10)</p>
<p>Perspectives of lymph node dissection and sentinel node biopsy with monitoring Knowledge of lymph node dissection and fear of lymphoedema</p>	<p>So, then he said, "We didn't get it all and we'll have to take your lymph glands as well." That made me panic more than actually being told that I had the cancer. Yeah, so then I said, "Well, I don't want that to happen," because I know that having lymph glands being removed is all about, the swelling and all that sort of stuff. He said, "Well if you don't, you're going to die." (01)</p>

(Continued)

**Table 1.** Continued.

Themes	Illustrative quotes
Perspectives on sentinel node biopsy with monitoring	<p>I decided not to have my lymph nodes removed, just to have the monitoring with ultrasounds and seeing [Prof] regularly, mainly for the fact that I was worried about getting, I'm probably not going to say it properly, lymphoedema. (02)</p> <p>I was terrified to have them [lymph nodes] removed because of lymphoedema. (05)</p> <p>I knew it was a somewhat risky decision but the alternate of losing all the lymph nodes in one leg wasn't very appealing to me. I was concerned about lymphoedema at, at that stage, I was still working. I did a lot of research about lymphoedema before surgery, because I knew it was a risk. (08)</p> <p>Well, I was a nurse in a past life. So we talked about lymphoedema and I, yeah, was aware of pressure bandage and all that sort of thing. (09)</p> <p>Well, I still think I did the right thing by not having them [lymph nodes] removed initially, even when I had the two taken out later on, there was nothing wrong, there was no cancer in them. (05)</p> <p>It's very frightening [having regular scans] because every two months I think, "oh gosh." I mean, I haven't – I don't feel anything but that doesn't mean that there hasn't been some sort of minor change ... (09)</p>
Trauma of treatment Complications of treatment	<p>I Google a lot of stuff for the problems I'm having with the lymph glands being removed and the swelling and what to expect, and the garments, all that type of stuff. Yeah, so I google it all and I also go onto YouTube and watch videos on how to actually do home massaging as well. (01)</p> <p>When I was at the hospital one of the nurses came in, gave me this sheet of paper with the lymphoedema things, and I just put it away for a while, I couldn't be bothered reading it because I thought well, this is my life. It was all American-based, all the stuff that you read. Yeah, so I left the hospital thinking okay, who do I call? What do I do? That type of thing. That's why I've done it all alone. (01)</p> <p>I got an infection in the drains ... I ended up in hospital at Christmas that year with sepsis. So I was in hospital for a month. (04)</p> <p>I've been uncomfortable for years. To sit down, it's still sore. Where I had the radiation, it's made the skin really hard in places, and then inside it never feels like it's fully healed. (04)</p> <p>I actually found the radiation incredibly difficult. I had burning, I had bowel problems, at the end of that time I was anaemic, and I'd never had any trouble with iron levels. I was just exhausted, physically exhausted, and it took a long time to build that up. I also had ongoing nerve problems. (08)</p>
Experiences of lymphoedema	<p>Since the last operation at the end of last year I've really suffered mentally talking about the lymphoedema and all this was terrible. (06)</p> <p>Mildly [lymphoedema]. I have to keep on top of it. I go to the lymphoedema clinic once every six months or so, and I do have lymphoedema massages. I should probably wear compression stockings but I can't stand them, literally can't stand them, so I don't wear them. (08)</p>
Expectations of recovery	<p>I thought I'd be back to my normal life, the normal life within a very short amount of time. And I'm here passed the 12-month mark ... (02)</p>

participants having high health literacy (e.g. nurse and library technician). Google was often cited as a source for information, while two participants preferred evidence from medical sources. Additionally, the idea of being a *loner* (01) was described with most women not knowing anyone else diagnosed with vulvar cancer. A diagnosis of vulvar cancer was isolating, and this was compounded by the taboo nature of the disease.

Treatment decision-making

The time interval between diagnosis and needing to make a treatment decision was short. This was compounded by the (perceived) lack of information and support at this time (see theme above). The extent of involvement in treatment decision-making varied and seemed to rely heavily on how the patient viewed their role in the patient-provider relationship. Two women expected their clinician, as the trusted authority, to tell them what was best. Other patients were proactive and wanted to be involved in the decision-making with their clinician. Treatment preferences were significantly based on maintaining current lifestyles, and minimising complications.

Perspectives of LND and SNB with monitoring

In the short time required to decide on treatment (see treatment decision-making theme) knowledge of LND and associated complications made women fearful to an even greater extent than the cancer itself and they therefore wanted to avoid LND. Five women had explicit knowledge of lymphoedema prior to surgery. There was an interest and preference for less invasive treatment options. Five women would have been interested in receiving less invasive treatment alternatives, such as serial ultrasounds instead of lymph node removal, if this was an option. Participants were accepting of the schedule for monitoring and the possibility of treatment in the future over and above the undesired risk and potential impact of lymphoedema on their quality of life.

Trauma of treatment

Patient experiences of the side-effects of treatment varied. Some ($n = 3$) participants described almost no side-effects while others experienced mild to severe side-effects following treatment for vulvar cancer. Complications due to radiotherapy (e.g. burning, blistering, swelling, pain) and drainage issues (e.g. infections/sepsis) were discussed. Experiences of lymphoedema also varied, including for support and information. Participants spoke about their struggles accessing the right information, care, garments, and treatment for lymphoedema, which placed an emotional toll on patients. Overall, some ($n = 4$) participants expressed frustration towards the

changes to lifestyle, quality of life, and not being able to do what they did before diagnosis and treatment of vulvar cancer – with recovery taking longer than expected.

Discussion

We identified five key themes among patients diagnosed and treated for vulvar cancer that included (1) difficult diagnostic experiences; (2) lack of support and information; (3) challenges with treatment decision-making; (4) patients' perspectives of lymph node dissection and sentinel node biopsy with monitoring; (5) trauma of treatment.

Our participants did not associate the gynecological symptoms that they experienced pre-diagnosis with cancer. This finding concurs with a qualitative study conducted among women from the general public in the United States that found that most participants were unfamiliar with vulvar cancer and with gynecological cancer symptoms (such as changes in the color of the skin of the vulva or a rash, sores, or warts on the vulva) [22]. A lack of awareness of symptoms and a lack of specific symptoms are commonly reported for rare cancers; this makes rare cancer more difficult to diagnose than common cancers in addition to other contributing factors including the lack of early detection screening tests, access to clinical expertise, including additional barriers to accessing services for people living in regional and rural areas [23].

Consistent with a previous Australian qualitative study [24], we found a diagnosis of vulvar cancer to be an isolating experience with high unmet support and information needs. This was a recurring issue within each theme and throughout diagnosis, treatment, and post-treatment phases. It is important for patients to be able to find up-to-date resources that they can understand and trust. We know that many (85%) gynecological cancer patients use the internet as a resource to learn about their diagnosis, although often find it somewhat hard to understand [25]. The consumer-led research group recognized that patients' needs for information vary, with some not wanting information beyond that provided by their treating team, whilst others would benefit from external support (e.g. support groups, counseling) and information from trusted sources. Therefore, consumers suggested that the treating team may be well-placed to recommend reliable services, resources, and websites. This idea is further supported by the finding that information plays a role in regaining a sense of control following a cancer diagnosis, in treatment decision-making, and for understanding the consequences of disease and treatment [26].

While implementation of new surgical techniques into practice will largely be driven by gynecological oncologists, the knowledge and experiences of patients is poorly understood. Results from a vignette study

showed differences in the factors of importance between gynecologists (i.e. survival gain) and patients (i.e. survival gain, travel time, complications) when considering SNB for low-intermediate risk of endometrial cancer [27]. Of key importance among our study participants was to avoid complications and the potential impact of treatment on post-treatment *quality* of life. Participants cited personal reasons for prioritising quality of life, most commonly to reduce the risk of developing lymphoedema and the subsequent effect on their lifestyle (i.e. career, family, physical activity). Little is known about the tradeoffs and factors associated with vulvar cancer patients' choice between *quality* and *quantity* of life.

While our study participants were interested and stated a preference for less invasive treatment options, it is not known if women fully understood the pros and cons of SNB. A study of the patient experience of SNB for melanoma found that 32% of patients incorrectly assumed that SNB would prevent disease spread and 76% correctly recognized that the procedure establishes if the cancer may have already spread locally [28]. Furthermore, one study among vulvar cancer patients found no difference in overall quality of life between those who received SNB compared to those who underwent a full LND; however this study was limited by a small sample size [15]. As there appears to be an individual level of risk that each woman can define regarding her preference for SNB [16], our consumer-led research group considered the value of a treatment decision aid. For patients with no distant metastases or spread to adjacent organs, the decision aid would present the risks of recurrence and death with and without LND, and the risk of lymphoedema with LND, for patients to weigh up the benefits and harms of LND. The patient's own values with respect to the importance of lymphoedema compared with recurrence could then be incorporated into the decision.

SNB holds the promise of more accurate staging and fewer complications than more extensive LND [29]. Nodal assessment via ultrasound is already routine in head and neck, breast, and other cancers, where it consistently yields high sensitivity rates (>90%) [11,12,30,31]. Lessons learned from research among other cancer patients where an option exists for SNB can be applied. High levels of acceptance by patients for SNB as an alternative to axillary nodal clearance was reported among women being treated for breast cancer long before this technique became standard practice [32]. Variations in adherence to guidelines also indicated surgeon preferences for conservative surgical options [33].

Strengths and limitations

Ten qualitative interviews were conducted and, although the results may not be generalizable to all vulvar cancer patients, the sample was heterogeneous

in terms of age distribution (median 68 years; range 41–82 years) and residential area (major city, inner regional) thereby potentially capturing diverse experiences. The average age of our sample reflects the average age at diagnosis for vulvar cancer in Australia (i.e. 70 years) [1].

Involvement of a consumer-led research group and interviews conducted by a gynecological oncology nurse consultant was very effective for providing a deeper understanding of patients' experiences and perspectives on SNB, with additional novel insights and practical recommendations. The group was already established and the pre-existing relationships between consumers/researchers allowed for genuine collaboration. A limitation of this study is that participants were interviewed up to five years following treatment, which may impact on recall and alter perceptions of the treatment experience. Conversely, this also allowed us to capture longer-term experiences and perspectives.

Implications moving forward

These results suggest several implications for research and practice. It would be useful to extend the current findings by exploring in detail the pathways to vulvar cancer diagnosis and treatment; most accounts in our study move swiftly from a symptom to diagnosis and surgery, therefore lacking details on duration and factors contributing along the pathway to treatment.

Our study has shown an unmet need for information and support services throughout diagnosis, treatment, and post-treatment. Whilst patients depend on family and friends for support during diagnosis and treatment, it is critical that health professionals provide the information resources required for women to make fully informed decisions regarding their treatment options. Without this information, women are unable to provide informed consent. Support and information provided to women could come in a variety of formats (i.e. written decision aids, recommended websites, support groups). Specifically, clinicians should consider the use of a decision aid (as described above) during shared treatment decision making discussions. Similar to previous research among patients treated for cancer [34], our findings suggest that preferences for involvement in treatment decision making varies. Evidence is suggestive of a positive association between shared decision making in cancer treatment and quality of life outcomes [35].

Patients expressed a strong preference for less invasive treatment options demonstrating support for continued research and translation of SNB into clinical practice. Recent overseas research shows promising results for survival following SNB compared with full LND in vulvar cancer patients without distant metastasis and adjacent organ invasion [36]. A clinical trial of groin ultrasound surveillance to de-escalate the degree of surgical intervention of vulvar cancer is warranted and, based on our findings, should consider the

aspects for (i) a personalized surgical approach with careful assessment of risk-benefit and patient preference; (ii) information resources and decision aids to assist women to make an informed choice, and (iii) counseling needs to balance the clinical (adjuvant radiotherapy, regular scans, recurrence, survival) and non-clinical (complications, lymphoedema, quality of life) factors.

Conclusions

There are approximately 1400 survivors of vulvar cancer in Australia, diagnosed in the five-year period 2014–2018 [1]. While current standard treatment offers only surgical groin node dissection, patients prefer being given a choice and prefer less invasive treatments. Most vulvar cancer patients will live with the detrimental, life-long impacts of their cancer treatment because there are currently no alternatives to mitigate these impacts. SNB with groin ultrasound surveillance is acceptable to patients and potentially offers an alternative to standard treatment, which should be further investigated.

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Author contributions

Andreas Obermair and Monika Janda contributed to the study conception and design. Andreas Obermair, Monika Janda and Anne Mellon contributed to the preparation of study materials. Data collection was performed by Anne Mellon. Analysis was performed by Tracey DiSipio and Meredith Johnston. All authors contributed to the interpretation of data. The first draft of the manuscript was written by Tracey DiSipio and all authors commented on each version of the manuscript. All authors read and approved the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent to publish

Participants signed informed consent regarding publishing their data.

Ethics approval

Approval was obtained from the Human Research Ethics Committee of The University of Queensland (2022/HE000123). The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Data availability

The participants of this study did not give written consent for their data to be shared publicly, do due to the sensitive nature of the research supporting data are not available.

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