

A Qualitative assessment of Patient Experience during pathway to Diagnosis for Vulval Disease in the North East of England

A McCormick¹, M Gallagher², M Russell¹, K Short², J Goodfellow¹, D Mansour⁴,
K Clement⁴, L Sharp⁴, RL O'Donnell^{1,5}

1. Department of Gynaecology, Royal Victoria Infirmary, Newcastle Upon Tyne

2. Department of Gynaecology, Royal Infirmary of Edinburgh, Edinburgh

3. Dermatology of Community Gynaecology, New Croft Centre, Newcastle Upon Tyne

4. Institute for Health and Society, Newcastle University

5. Translational and Clinical Research Institute, Newcastle University

Introduction

Service design for management of vulval disease varies greatly nationally. With little available data to determine place of care, we are forced to assume that the majority of patients are cared for in primary care or within general gynaecology clinics. Despite a growing number of specialist vulva clinics, pathways to tertiary and quaternary specialist centres are often disordered and prolonged.

This study aimed to assess the effect of this variation of care and the role of specialist vulva clinics.

Methods

Purposive sampling of all patients attending the Specialist Vulva Clinic with more than a 6 month history of a vulval condition was undertaken. Patient's were consented for participation in a semi-structured telephone interview. A topic guide was iteratively developed by the study group to understand patient experience during pathway to diagnosis and impact of the vulva clinic. Thematic analysis of transcripts was undertaken.

Six patients with established diagnoses of dermatological and functional vulval conditions underwent interviews (20 – 60 minutes).

Results

❖ Patients were seen on average by 7 (range 5 – 15) doctors prior to referral to the Specialist Vulval clinic with prolonged pathways, some lasting 10 years. Leading to a high levels of anxiety and frustration.

"itching is unbearable, but what is worse if the anxiety of not knowing and the risk of cancer... for years. I lost my mum to cancer.... Makes it all worse"

"no support at work at all, women's health is just pushed away"

❖ Thematic analysis revealed patient frustration with cyclical repetition of investigations and trials of topical preparations leading to a perception of limited knowledge and disinterest by health care professionals was a clear theme.

"GP just looked through the internet in front of me"

"15 doctors, new tests, new pessaries, new creams, washing powder advise.... Came away thinking "they have no idea" and one male GP just said "sometimes this just happens"....."

"The gynaecologist had no idea what he was dealing with, gynaecologists should know about the vulva... surely?"

❖ A theme of avoidance and reluctance, especially from male doctors, to discuss the psychological aspects of vulval conditions emerged.

"male doctors aren't prepared to go into any kind of discussion, just keen to offer a cream"

"he said he was a vulval expert (gynaecologist), but he wasn't interested, didn't explain and at the end of the consultation just said - "right I won't see you again"... left me in tears, feeling nowhere to turn to"

❖ All patients reported sexual dysfunction resulting in avoidance or complete cessation of intercourse and intimacy highlighting the importance of addressing psychosexual care.

"we have incorporated vaginal dilators into our sex life.... have to learn to laugh at it (laughs)... wish I'd started dilators earlier - wouldn't have had 5 years of not wearing pants! (laughs)"

"Intimacy has been killed off over the years, more than I'd like to admit. It is putting a strain on the relationship.... Yeah.... Just not really talked about because of having small children.... Crazy world with small children."

❖ All participants reported a positive impact of the Specialist vulval clinic with importance placed on time to listen and the feeling of a coordinated journey rather than an isolated appointment.

"I really liked her (Consultant) felt this was the start of the road... totally different compared to the private doctor, who left me high and dry"

"An entirely different appointment (specialist vulval clinic), she just listened to me, took the time, didn't just look and go "ok"..."

Conclusions

The level of distress that was reported in association with the experience was considerable in all participants and sheds a new light on the limitations of the current vulval care provided. Feeling unable to control or influence their health status may in turn reduce a patient's ability to manage symptoms and perform maintenance behaviours (Aujoulat, I. et al 2007, Cross et al., 2006).

We concluded that knowledge of vulval conditions and specialist care may be limited in primary and secondary care resulting in negative experiences, repeated appointments and frustration for patients. Streamlined pathways to specialist services are needed.

References:

- Aujoulat, I. Et al (2007). *Qualitative Health Research*, 17, 772–785.
Cross, M.J. et al (2006). *Rheumatology (Oxford)*, 45, 92–96.