

# **The lived experience of younger women with cancer of the vulva: a phenomenological study.**

## **Background**

This study is an exploration of the lived experience of 13 women, who were less than 50 years of age, and were diagnosed with cancer of the vulva and underwent surgical treatment. As a Gynaecology Oncology CNS I have cared for a number of these women for many years, and in particular the care of a 28 year old patient with advanced disease had a lasting impact on me. I began to reflect about these women with a specific question in mind: 'What must it be like to be diagnosed and treated for cancer of the vulva?' I understood the physical effects of the surgery involved, but I started to consider how this might affect them from a psychological, emotional and social point of view.

A review of the literature showed a paucity of studies (Andersen and Hacker 1983, van de Wiel 1990, and Green et al 2004) with only 14 studies in all, involving less than 300 women. This is not surprising as cancer of the vulva affects only 1,000 women each year, but it does mean that there are limited insights into the wider impact of this disease.

## **Aim**

The purpose of this study was to add to the body of nursing knowledge and inform the development of clinical nursing, by investigating the experiences of women following the onset of symptoms, diagnosis and treatment of vulval cancer. The wider context of their experience within their family and work environment was also explored.

## **Method**

Given the paucity of literature regarding women in the UK, a decision was made to generate this insight utilising an interpretative phenomenological approach based on the work of Heidegger (Heidegger 2005) and van Manen (1990). Van Manen (1990) describes the four fundamental components that make up the structure of the lived world in which we live, Lived Time, Lived Space, Lived Body and Lived Relationship and these were used as a guide to reflection in the research process.

Following ethical approval by the Local NHS Research Ethics Committee, 13 women aged less than 50 years were purposively sampled following attendance at a regional Cancer centre. They had all had surgery between 6 months to 5 years previously. A semi structured interview was conducted as it helped to frame the questions for optimal feedback when asking women who had been diagnosed with vulval cancer to tell me their stories about what it is like, what their feelings are, and their understanding of the events following their diagnosis or in other words ‘What was it like for *you*?’ In all, 33 questions were used to collect the data, which focussed on issues identified in the literature and through professional experience and were used as a checklist. The interviews were recorded and transcribed in full. Confidentiality and anonymity for the participants was maintained.

## **Results**

The data was analysed using framework analysis (Ritchie and Spencer 1994) which involves a systematic process of sifting, charting and sorting data into key issues and themes. Concepts were developed which used words or phrases to build up a description

of this phenomenon. One concept arose out of the women's feelings of 'looking for help', 'repeated visits to the doctor', 'seeking advice', 'being on the look out for any remedies that may alleviate their symptoms'. The word '**Searching**' was used to describe the manner in which the women searched to control their symptoms by their own efforts and by undergoing surgery, the search to understand the truth about their condition and the search for help to access information. The tempo in which the search was undertaken is also noted.

Another concept involved a sense of separation as the women described their loss of sexual function following the onset of their symptoms of vulval cancer and subsequent treatment, and their inability to enjoy the sexual relationship they had previously. The women also felt that there was a lack of knowledge about this condition and a perceived lack of understanding. The word chosen to describe these sentiments was '**Aloneness**', as it appeared to summarise the women's sense of loneliness and the women's sense of isolation due to the geographical distance between their home and the hospital.

A further concept arose from the women's sense that they felt different after their diagnosis and treatment. This included both physical and psychological changes and also impacted on their feelings regarding their body image. It had both positive and negative aspects and led to a sense of powerlessness and uncertainty. 'Everything' appeared to be different for the women after their diagnosis of cancer. The phrase that appeared to sum up these experiences was '**All Change**'. This concept also included the women's perspective of the future with a fear of recurrence.

An additional concept was concerned with the relationship between the women and the health care professionals involved in their care during the journey from diagnosis to rehabilitation within the context of the health care system. There was a lack of empirical knowledge, and a range of care and advice. The word used to describe the concept relating to the relationship between the women and her health care professionals was **'Professional Connectivity'**. The four key concepts emerged from the data, Searching, Aloneness, All Change and Professional Connectivity, and were shown to be incorporated within the four existentials of the every day world, Lived Body, Lived Relationship, Lived Time and Lived Space (Van Manen 1990).

## **Discussion**

The lived experience was described in its entirety by the concept of **Invisibility** which reflects the challenges the women faced in living with a condition that is not recognised or widely discussed, a factor that impacts on the way in which these women can share their experience with family, friends and the health care professionals.

## **Conclusion**

The study concluded by making tentative suggestions as to how the insights gained could be used to improve the care of these women, by raising awareness within the healthcare profession and the general public, improving written information and the development of more robust pre and post operative support.

## References

Andersen, B. and Hacker, N. (1983) Psychosexual adjustment after vulval surgery. **Obstetrics and Gynecology**, 62: 457-62

Green, M., Wendel Naumann, R. and Elliott, M. et al. (2000) Sexual dysfunction following vulvectomy. **Gynecologic Oncology**, 77: 73-77

Heidegger, M. (2005) **The Essence of Human Freedom**. (Trans. Sadler, T.). London: Continuum

Mulhall, S. (1996) **Heidegger and Being and Time**. London and New York: Routledge

Ritchie, J. and Spencer, L. (1994) "Qualitative data analysis for applied policy research."

In Bryman, A. and Burgess, R.G. (eds.) **Analysing Qualitative Data**. London: Routledge

Van de Wiel, H., Weijmar Schultz, W. and Hallensleben, A. et al. (1990) Sexual functioning of women treated for cancer of the vulva. **Sexual and Marital Therapy**, 5: 73-82

Van Manen, M. (1990) **Researching Lived experience. Human science for an action sensitive pedagogy**. New York: State University of New York Press