

# Quality Of Life Among Urogynecological Cancer Survivors: A Qualitative Analysis Of The Patient

A. Aishwarya<sup>1</sup>, S. Dharini<sup>1</sup>, M. AnbuPriya<sup>2\*</sup>

<sup>1,2</sup>Student, SRM college of Physiotherapy, <sup>2\*</sup>Assistant Professor, SRM College of Physiotherapy, SRM Institute of Science and Technology, Kattankulathur, Kancheepuram District, Tamilnadu, India

## ABSTRACT

**INTRODUCTION:** Urogynaecological cancers include Cancer of Uterus, Ovary, Fallopian tubes, Cervix, Endometrium, Vagina, and Bladder. The 5 year survival rate in India also has been declined. The complications such as Urinary incontinence, over active bladder, pelvic pain etc., drastically affects the quality of life. Patient centered assessment would provide understanding about impact of the treatment and exploring the areas where little research exists. **AIM:** To assess the quality of life among Urogynaecological cancer survivors using a semi-structured interview. **METHODOLOGY:** Five women with one year history of urogynaecological cancer survivorship were considered and a semi-structured interview based on open ended questions. The interview was audio recorded, transcribed and analysed. Themes were set up by two individual researchers on the basis of the data obtained from the patients. **RESULTS:** The participants who had one year history of urogynaecological cancer survivorship were interviewed and their responses were classified into five themes namely physical, psychological, social, financial and sexual. **CONCLUSION:** The quality of life of the urogynaecological cancer survivors varied in terms of short term pain, fear and courage to some as well. This could help to build up a condition specific-questionnaire for a multidisciplinary approach.

**KEYWORDS:** Urogynaecology, Endometrium, Cervix, Ovary, Uterus

**INTRODUCTION:** Urogynaecology deals with the pelvic floor organs such as bladder, bowel and the female reproductive organ. The endometrium, cervix, fallopian tube, ovary are the sites of occurrence of cancer in a female reproductive organ. According to WHO the global percentage of urogynaecological cancer incidence for the year 2018 of cervical cancer (abnormal cell growth in the cervical lining) is 3.2%, uterine cancers is 2.1% with 80% of the cases are squamous cell carcinomas. <sup>[2][3]</sup>Endometrial cancer (inner layer of the uterus) also has few cases being reported.

The risk factors include things that affect the hormonal levels, intrauterine devices, age, diet, exercise, family history, obesity, ovarian tumours, PCOS, prior pelvic radiation due to other cancers. The symptoms are unusual vaginal bleeding, spotting or discharge, pelvic pain, a mass, weight loss<sup>[1]</sup>, bleeding and pain after sexual activity, excessive tiredness, low back pain, unusual vaginal discharge, vaginal bleeding between periods.

Fallopian tube cancers often arises from the fimbriae and 85% - 90% of the fallopian tube cancers are epithelial carcinomas. <sup>[5]</sup>The median age for developing these cancers is 38 years (21-67 years). Indian percentage for cancer in women as reported by National institute for cancer prevention and research accounts for 47.2% that includes 22.86% cervical cancer and 7 % of ovarian cancer. The relative five year survival rate for women averages to 48.7%. <sup>[7]</sup>

The signs and symptoms of cancer is not the same for all cancers and varies according to the cancer type. The treatment for cancer includes chemotherapy, radiation therapy and surgery like

hysterectomy, bilateral salpingo oophorectomy that leads to complications and has a negative impact of these treatments on quality of life of the patients and the recognition of how they function after a chronic illness needs to be addressed. Understanding the patient's concerns the qualitative research helps in determining the results by the way they differ. Both the clinical and biopsychosocial phenomena can be described as it is a way of looking things from the perspective of those being studied.<sup>[10]</sup>

## METHODS:

**Design:** Qualitative analysis of a semi-structured interviews was done. This design was selected as a best method to explore the varied experiences of the urogynaecological cancer survivors.

**Participants And Setting:** The patients included in this study were females who are urogynaecological cancer survivors (any type) above the age group of 30 and is treatment free for one year. Women who were pregnant, who did not complete the treatment process and follow up, recurrence of cancer were not included this study. Patients were recruited from SRM oncology outpatient department with the guidance from an oncologist. They were interviewed separately and responses were recorded after obtaining an oral consent.

**Interview Content And Procedure:** FivePatients completed a single semi-structured interview in an enclosed room at SRM hospital, Potheri. Interviews were audio-recorded and transcribed. Audios were recorded in the phone. The duration of the interviews ranged from 8 mins to 18 mins. The same member conducted all the interviews.

The interview questions were developed from prior research that reported both negative and positive impacts of urogynaecological cancer.

Participant code	Age	Site of cancer occurred	Last date of treatment	Treatment type	Any physiotherapy treatment for pain
P1	38	Ovary	14/01/2018	Hysterectomy, Chemotherapy combined with drugs (pain relief)	No
P2	38	Ovary	9/12/2017	Chemotherapy combined with drugs (pain relief)	No
P3	40	Endometrium	16/01/2018	Chemotherapy combined with drugs (pain relief)	No
P4	65	Cervix	01/01/2018	Chemotherapy combined with drugs (pain relief)	No
P5	53	Cervix	05/02/2018	Chemotherapy combined with drugs (pain relief)	No
P6	56	Bladder	08/12/2017	Radial cystectomy along with hysterectomy	No

				(risk of invasion)	
--	--	--	--	--------------------	--

**Table 1 represents the demographic data and information about the site of cancer.**

**Analysis:**

Qualitative analysis of transcripts of the patients was done using thematic analysis. Each phrase was coded and sorted by another researcher other than the interviewer. The categories were then grouped together with related other categories. The emerging categories were all grouped under five different themes. Within each theme, the categories explaining the theme is discussed in the results.

QUESTION NUMBER	STIMULUS QUESTIONS
1.	What discomfort or pain did you feel as a symptom of cancer?
2.	What did you feel when you came to know about your illness?
3.	How were you treated by your family, neighbours and friends after hearing of your illness?
4.	How did you manage all the expenses?
5.	How about your sexual life before and after the illness?

**Table 2 represents the stimulus questions of the semi-structured interview.**

**RESULTS:** The samples included diverse types of cancer and patient ages. The responses covered a large proportion of categories and included in the final thematic framework. The final framework is presented in Table 3. The five themes includes Physical, Psychological, Social, Financial, and Sexual. Example quotes for the five themes are presented in Table 4. These quotes are a representative of each theme.

Physical	Psychological	Social	Financial	Sexual
Pain, discomfort	Fear about the disease and pain	Increased dependence	Government funding	sexual activity reduced due to pain and discomfort
Tiredness	Feeling of depression	Supportive family and friends	Use of family members income	No sexually active life
Vomiting, difficulty in eating	Feeling of anxiety	Negative impact on relationships	Experience of poverty due to excessive expenditure on treatment.	Not in a sexual life need
Pain during urination	Strong and confident	Improper family support		
		Isolation		Pain during intercourse

**Table 3 represents the thematic conceptual framework of the life impacts of urogynaecological cancer, including categories representing under each theme work**

<b>PHYSICAL</b>	<b>PSYCHOLOGICAL</b>	<b>SOCIAL</b>	<b>FINANCIAL</b>	<b>SEXUAL</b>
Physical impacts experienced	Psychological impacts experienced	Social impacts experienced	Financial impacts experienced	Sexual impacts experienced
“ pain and bleeding was present and thought it was piles” – p1	“ no fear, cancer is just like fever or headache” – p1	“ had friends and relatives to take care of and was not isolated” – p1	“ initially spent a lot of money, which deteriorated my family position, later spent through government policy” – p1	“ difficult to return back to sexual life because I had pain” – p1
“inability to eat; sleep problem; pain in lower abdominal region during urination” – p2	“I was completely aware about my illness and had no fear about it” – p2	“ all family members were supportive” – p2	“my son and daughter spent all the money they had, so my family situation became unstable” – p2	“ I felt scared to have a sexually active life, because I feared there could be any recurrence of cancer” – p2
“Pain was intolerable, reduced after surgery and only tiredness is present” – p3	“was scared when I came to know about my illness, still I have the same fear, and I am emotionally weak” –p3	“The only support was my daughter. Only she took care of me” – p3	“only source to spend money was through government policy” – p3	“I was not sexually active before my illness, and now do not feel any need for it” – p3
“ had no symptoms of pain, burning or discomfort and slight pain during walking only after treatment” – p4	“was not scared or worried about the disease or treatment; it was like any other disease” – p4	“ neighbours and relatives were not informed about my illness because I had fear to say” – p4	“ poverty hit hard after spending money for cancer treatment” – p4	“My spouse died 15 years back, hence there was no sexual need” – p4
“ slight pain was present initially and post treatment pain during cough is present” – p5	“ had no courage and was scared about the disease and treatment; fear increased due to pain” – p5	“ family members and neighbours were very supportive”-p5	“government policy for the diseased helped me in getting the right treatment” – p5	“my husband died 5 years ago, so I was not in a need of sexual life” – p5
“ pain while passing urine in the lower abdomen, and Vagina” – p6	“I was in a distress since I had frequent urination and was isolated and restricted to use only one bathroom and other members of the family feared to use it”– p6	“excessive intervals of urination was an obstacle for attending family functions” – p6	“money was obtained through government policy and the rest were paid from savings” – p6	“felt pain during the intercourse around the vagina and hence decided not to proceed” – p6

**Table 4 represents the examples of participant quotes for each theme in the conceptual framework**

**Theme 1: Physical:**

Physical effects of Urogynaecological cancer were predominant in both pre and post treatment. Patients described pain in Lower abdomen, back and sometime hip pain and present during coughing or walking as the major impact. For example *“due to injections in the hip region, back pain is present”*. The patients were not aware that the symptoms were depicting cancer. Patients could not eat as much and sometimes resulted in vomiting if the food intake exceeded the limit. Tiredness affected the functional activities of the patients and described *“used to do all activities before”* or *“unable to walk like before”*.

**Theme 2: Psychological:** Psychological and emotional impacts attributed to the cancer and its treatment as reported by the patients were diverse. These included fear of societal acceptance, depression and tiredness due to which they had no courage prior treatment and more scared after the treatment. The latter could be attributed to feeling of intolerable pain.

On the contrary few had courage, and knew about the illness which could primarily be due to the support they received from their family ;“( was) *not scared, it was just like fever or headache*”. The inconsistency in the emotions and feelings is a major aspect to be given utmost importance since this largely impacts the quality of life of the patients.

**Theme 3: Social:** The patients reported contrasting attitude towards the society. Some patients received support from friends and family; *“when my family got to know about the disease they took me for treatment and cared for me”*. It was also observed that patient feared to reveal about their illness since they were worried about the gossips in the society. *“Neighbours and relatives were not informed about my illness because I had fear(ed) to say”* The increased support and care from family and friends in turn helped them undergo treatment with a positive attitude.

**Theme 4: Financial:** The patients reported the financial impacts due to the enormous expenditure for the cancer treatment. Most of the patients received the treatment money from government made policies to help the diseased stating that *“we paid through Kaapedu Thittam”* (p1). Responses focused on the lack of work post the survival due to weakness or pain. It was also reported that the patients were active before cancer and the survival has deteriorated their overall health which made it difficult to return back to work. *“No work, due to pain and feeling of a weak body”*, were the patient’s words.

**Theme 5: Sexual:** The sexual impact being the upper hand of worry for majority of the patients. Whereas, a minority of the patients felt they were not in a need for sexual life. The reasons could be varied, from *“my husband died 5 years ago, so I was not in a need of sexual life”* to *“I was not sexually active before my illness, and now do not feel any need for it”*. Also, patient feared of occurrence of pain hence hesitated to return to normal sexual life. On the contrary, there were reports stating that returning to sexual life increased their vaginal pain. *“Felt pain during the intercourse around the vagina and hence decided not to proceed”*

**DISCUSSION:**

The analysis has successfully identified a wide range of life impacts as reported from the patient’s experience who survived the Urogynaecological cancer. It has been the first study to report the quality of life post cancer survival in a qualitative analysis method since most of the studies used pre designed questionnaire that was quantified and assessed only the sexual component qualitatively.

The five themes included in the frame work were physical, psychological, social, financial and sexual. The themes have helped change the outlook of the disease and treatment by not just focusing on the physical aspects. A patient centered assessment would be a sensible approach in knowing the effects and needs of the patient. There are 2 implications from this study that needs to be thought of. First the

patients were not aware of the symptoms and its seriousness. The second is the diverse negative impacts that can be better dealt with a multidisciplinary approach.

While a lot of them have no clue about the physical therapy or other such methods. Rhoda suubi Muliira (2011) stated that the diagnosis of the cancer itself is a difficult task, as many do not have the access to proper diagnosis. Due to this there is a decrease in the quality of life of the patient which in turn increases the expenses of the treatment.

According to Alejandro J. Miranda-Sousa et al; during the radical cystectomy the nerve fibers and vascular structures located on the lateral walls of the vagina are found to be removed or damaged sometimes due to the removal of the bladder, urethra and anterior vaginal wall. Hence, postoperative sexual dysfunction is common in women who suffered bladder cancer.

Apart from this, educational qualification of the patient and the awareness of the illness contributed to the psychological aspect of the patients. Surprisingly patient with low educational qualification were very confident stating that nothing could ever affect them. A unique observation was found, is that the patients whose one of the family member worked in any cancer related set up, knew about the exact consequences of the illness and also proved effective in influencing the mindset of the patient and hence provided confidence in them. On the whole, these patients experienced were divergent in the site, intensity of pain and as well emotions and feelings towards illness.

### **Strengths And Limitations:**

There are certain limitations and strengths to this qualitative research. First, the samples collected were purposefully confined to a single geographical area, and interview was conducted by an independent interviewer which may have inadvertently could have influenced the topic and nature of the themes. However, a semi-structured interview to some extent could have protected from the source of bias.

The thematic framework could have been unknowingly influenced by the researchers. However, the use of two independent researchers could have attributed to reduce the risk of bias. There could be a chance of the patients hiding certain experiences or emotions due to the feeling of embarrassment to disclose it to the interviewer. Maintenance of good rapport with the patient to a major extent has minimized the error and gained patient's confidence.

**Future Research:** A high priority of future research is the development of a multidisciplinary condition specific questionnaire for assessing the quality of life of urogynaecological cancer survivors. The thematic framework from this investigation will be used as a stimulus material for a questionnaire framework.

Further research should also include investigations to examine the effects during treatment duration on the people. This study can also be applied to a wider geographical area, which would yield even better conclusions.

**CONCLUSION:** The quality of life of the urogynaecological cancer survivors has been varied in terms of short term pain, unknown symptoms, fear and courage to some as well. This could help to build up a condition specific-questionnaire for a multidisciplinary approach.

**Conflict Of Interest:** There are no conflicts of interests.

**Source Of Funding:** This study is Self-funding.

**Ethical Clearance:** Ethical clearance not required for this study.

### **REFERENCES:**

1. What Is Endometrial Cancer? [Internet]. Cancer.org. 2019 [cited 19 February 2019]. Available from: <https://www.cancer.org/cancer/endometrial-cancer/about/what-is-endometrial-cancer.html>

2. Australia C. Understanding Cervical Cancer [Internet]. Cancer.org.au. 2019 [cited 19 February 2019]. Available from: <https://www.cancer.org.au/about-cancer/types-of-cancer/cervical-cancer.html>
3. Latest global cancer data: Cancer burden rises to 18.1 million new cases and 9.6 million cancer deaths in 2018. 2018. Uterine Cancer - Treatment Options [Internet]. Cancer.Net. 2019 [cited 19 February 2019]. Available from: <https://www.cancer.net/cancer-types/uterine-cancer/treatment-options>
4. Ovarian, Fallopian Tube, and Peritoneal Cancer - Treatment Options [Internet]. Cancer.Net. 2019 [cited 19 February 2019]. Available from: <https://www.cancer.net/cancer-types/ovarian-fallopian-tube-and-peritoneal-cancer/treatment-options>
5. Risks and causes | Ovarian cancer | Cancer Research UK [Internet]. Cancerresearchuk.org. 2019 [cited 19 February 2019]. Available from: <https://www.cancerresearchuk.org/about-cancer/ovarian-cancer/risks-causes>
6. Cancer Statistics - India Against Cancer [Internet]. India Against Cancer. 2019 [cited 19 February 2019]. Available from: <http://cancerindia.org.in/cancer-statistics/>
7. Meryl j. Alappattu, PT,DPT, J Womens health phys therap.2013;37(3): 97-102
8. Karin Bergmark, M.D., Elisabeth Avall Lundqvist, Ph.D., Paul W.Dickman,Ph.D., Lars Henningsohn., et al; N Engl J Med 1999, 340;1383-1389
9. Doshani A, Pitchforth E, Mayne C, Tincello DG. The value of qualitative research in urogynaecology. BJOG: An International Journal of Obstetrics & Gynaecology. 2009 Jan;116(1):3-6.
10. Muliira JK, Kisaakye E, Kizza IB, Suubi RR. Perceived cervical cancer risk, knowledge and preventive practices. African Journal of Midwifery and Women's Health. 2011 Apr;5(2):87-93.
11. Miranda-Sousa AJ, Davila HH, Lockhart JL, Ordorica RC, Carrion RE. Sexual function after surgery for prostate or bladder cancer. Cancer Control. 2006 Jul;13(3):179-87.