

# Life Experience of Survivors of Gynecologic Cancers: A Survey Conducted in Italy

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## ABSTRACT

**Background:** The study of health-related quality of life in survivors of gynecologic cancers is becoming increasingly important as 1.5 million survivors of gynecologic cancer in the United States and more are expected due to advances in diagnosis and treatment. This project investigated the perceived needs and lived experiences of survivors of gynecological cancer to help design supportive activities to be implemented in clinical practice.

**Methods:** Patients were recruited in hospitals or through social media and responded to an online survey that was addressed to patients in Italy, specifically in Sicily, Puglia, and Campania. Patients with ovarian, endometrium, or cervix cancer were recruited among women attending Cannizzaro Hospital and Alleanza Contro il Tumore Ovarico (Alliance Against Ovarian Cancer) members.

**Results:** Body image perception was changed in 82.3% of respondents, whereas familial relationships were described as changed by 27.5% of women. In 69.6% of patients, sexual habits were hindered by changes in the body, depression, pain, and awkwardness. Physicians informed patients about sexuality changes related to cancer extensively in 16.7% of cases and briefly in 19.6% of cases. The advice of a clinical sexologist was considered potentially helpful by 31.4% of patients and not potentially helpful by 47.1%, whereas 21.6% of patients had no opinion.

**Conclusions:** Although sexual habits are often changed by cancer, women surviving gynecological cancer rarely seek medical advice in this area. Physicians should be trained to inform patients and to promote referrals to sexologists.

**Keywords:** Gynecological cancer, quality of life, sexual activity

Gynecologic cancers, including ovarian, cervical, endometrial, and vaginal cancers, have a growing incidence worldwide.<sup>1</sup> Accordingly, the number of survivors is growing, being second only to survivors of breast cancer, and women may live for many years after receiving a diagnosis.<sup>2,3</sup> The study of health-related quality of life in survivors of gynecological cancers is becoming increasingly important and is considered a relevant patient-reported outcome, in addition to overall or disease-free survival.<sup>4</sup> Assessment of pre- and posttreatment health-related quality of life is a predictive factor for postoperative complications and a prognostic factor for overall survival and progression-free survival in patients with gynecological cancers.<sup>5</sup> Quality of life after gynecologic cancer also has been found to be related to cancer-related cognitive impairment.<sup>6</sup>

Quality of life for an individual is defined by the CDC as “physical and mental health perceptions and their correlates, including health risks and conditions, functional status, social support, and socioeconomic status.”<sup>4</sup> This broad definition includes all areas of everyday life, such as relationships, work, communication, and self-care. Among other components, the deterioration of sexual health has been repeatedly described in survivors of gynecological cancer.<sup>7-11</sup> Indeed, the treatment of cancers

**TABLE. Health-Related Quality of Life Questionnaire**

Questions	Answers	Respondents (%)
What kind of help or support could make cures easier?	<ul style="list-style-type: none"> <li>▪ Psychologic</li> <li>▪ Social (individual accompanying to therapy, caregiver at home, help for family members)</li> <li>▪ Economic</li> <li>▪ Working</li> </ul>	<ul style="list-style-type: none"> <li>▪ 52.0</li> <li>▪ 32.4</li> <li>▪ 8.8</li> <li>▪ 6.9</li> </ul>
Which area of your life was most impacted by the disease?	<ul style="list-style-type: none"> <li>▪ Work</li> <li>▪ Family</li> <li>▪ Personal (care of yourself, identity)</li> </ul>	<ul style="list-style-type: none"> <li>▪ 12.7</li> <li>▪ 27.5</li> <li>▪ 59.8</li> </ul>
How much did your body image change?	<ul style="list-style-type: none"> <li>▪ Not at all</li> <li>▪ Quite a bit</li> <li>▪ Very much</li> </ul>	<ul style="list-style-type: none"> <li>▪ 17.6</li> <li>▪ 53.9</li> <li>▪ 28.4</li> </ul>
Do you feel different?	<ul style="list-style-type: none"> <li>▪ Not at all</li> <li>▪ Quite</li> <li>▪ Very much</li> </ul>	<ul style="list-style-type: none"> <li>▪ 13.7</li> <li>▪ 54.9</li> <li>▪ 31.4</li> </ul>
Can you recognize your own image in a mirror?	<ul style="list-style-type: none"> <li>▪ Not at all</li> <li>▪ Quite</li> <li>▪ Very much</li> </ul>	<ul style="list-style-type: none"> <li>▪ 29.4</li> <li>▪ 62.7</li> <li>▪ 7.8</li> </ul>
Your mood is...	<ul style="list-style-type: none"> <li>▪ Good</li> <li>▪ Quite good</li> <li>▪ Depressed</li> </ul>	<ul style="list-style-type: none"> <li>▪ 26.5</li> <li>▪ 57.8</li> <li>▪ 15.7</li> </ul>
Who supports you most?	<ul style="list-style-type: none"> <li>▪ Parents and family</li> <li>▪ Husband/partner</li> <li>▪ Friend</li> <li>▪ Other (please specify)</li> </ul>	<ul style="list-style-type: none"> <li>▪ 21.6</li> <li>▪ 47.1</li> <li>▪ 8.8</li> <li>▪ 22.5</li> </ul>
What changed most in your life?	<ul style="list-style-type: none"> <li>▪ Nothing</li> <li>▪ I can no longer plan</li> <li>▪ Everyday life</li> <li>▪ Working life</li> </ul>	<ul style="list-style-type: none"> <li>▪ 9.7</li> <li>▪ 31.0</li> <li>▪ 45.1</li> <li>▪ 14.2</li> </ul>
Do you feel different?	<ul style="list-style-type: none"> <li>▪ No</li> <li>▪ A little</li> <li>▪ Very much</li> </ul>	<ul style="list-style-type: none"> <li>▪ 13.7</li> <li>▪ 54.9</li> <li>▪ 31.4</li> </ul>
Communication with your physician is...	<ul style="list-style-type: none"> <li>▪ Very poor</li> <li>▪ Fairly good</li> <li>▪ Good</li> <li>▪ Very good</li> </ul>	<ul style="list-style-type: none"> <li>▪ 2.0</li> <li>▪ 23.5</li> <li>▪ 35.3</li> <li>▪ 39.2</li> </ul>
Which is the main emotion related to the disease?	<ul style="list-style-type: none"> <li>▪ Anger</li> <li>▪ Disbelief</li> <li>▪ Acceptance</li> <li>▪ Other (specify)</li> </ul>	<ul style="list-style-type: none"> <li>▪ 23.4</li> <li>▪ 22.4</li> <li>▪ 45.8</li> <li>▪ 8.4</li> </ul>
Do you easily talk about the disease with your family?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> <li>▪ Sometimes</li> </ul>	<ul style="list-style-type: none"> <li>▪ 80.4</li> <li>▪ 6.9</li> <li>▪ 12.7</li> </ul>
Are children in your family aware of your disease?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> <li>▪ Partially</li> </ul>	<ul style="list-style-type: none"> <li>▪ 49.0</li> <li>▪ 23.5</li> <li>▪ 27.5</li> </ul>
Are you afraid that anyone in your family may develop the disease?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> <li>▪ A little</li> </ul>	<ul style="list-style-type: none"> <li>▪ 59.8</li> <li>▪ 19.6</li> <li>▪ 20.6</li> </ul>

Do you think a group of patients could support you?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> <li>▪ I do not know</li> </ul>	<ul style="list-style-type: none"> <li>▪ 40.2</li> <li>▪ 14.7</li> <li>▪ 45.1</li> </ul>
Which one of the following could support you better?	<ul style="list-style-type: none"> <li>▪ Talking with a friend</li> <li>▪ Physical activity</li> <li>▪ Cooking</li> <li>▪ Other (specify)</li> </ul>	<ul style="list-style-type: none"> <li>▪ 40.2</li> <li>▪ 11.8</li> <li>▪ 17.6</li> <li>▪ 30.4</li> </ul>
Has the attitude of the people closest to you changed?	<ul style="list-style-type: none"> <li>▪ Yes, it is improved.</li> <li>▪ Yes, it is worse.</li> <li>▪ No, it is unchanged.</li> </ul>	<ul style="list-style-type: none"> <li>▪ 38.8</li> <li>▪ 6.8</li> <li>▪ 54.4</li> </ul>
Did your nutrition change?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> </ul>	<ul style="list-style-type: none"> <li>▪ 61.8</li> <li>▪ 38.2</li> </ul>
Do you want to improve your nutrition?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> </ul>	<ul style="list-style-type: none"> <li>▪ 66.7</li> <li>▪ 33.3</li> </ul>
Do you think that support by a nutritionist with expertise in oncology could help you?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> </ul>	<ul style="list-style-type: none"> <li>▪ 71.6</li> <li>▪ 28.4</li> </ul>
Did you practice sports before the disease?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ If yes, which sport?</li> <li>▪ No</li> </ul>	<ul style="list-style-type: none"> <li>▪ 31.5</li> <li>▪ 25.4</li> <li>▪ 43.1</li> </ul>
Do you practice sports now (even if a mild one)?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ If yes, which sport?</li> <li>▪ No</li> </ul>	<ul style="list-style-type: none"> <li>▪ 24.1</li> <li>▪ 16.4</li> <li>▪ 59.5</li> </ul>
Did sexual habits with your partner change?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> <li>▪ Partially</li> </ul>	<ul style="list-style-type: none"> <li>▪ 44.1</li> <li>▪ 30.4</li> <li>▪ 25.5</li> </ul>
What prevents normal sexual habits?	<ul style="list-style-type: none"> <li>▪ Nothing</li> <li>▪ Changes in the body</li> <li>▪ Depression</li> <li>▪ Pain</li> <li>▪ Awkwardness</li> <li>▪ Inadequate information</li> <li>▪ Sense of guilt</li> </ul>	<ul style="list-style-type: none"> <li>▪ 30.1</li> <li>▪ 25.2</li> <li>▪ 21.1</li> <li>▪ 15.4</li> <li>▪ 6.5</li> <li>▪ 0.8</li> <li>▪ 0.8</li> </ul>
Did your physician give you information about changes in sexual habits?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> <li>▪ A little</li> </ul>	<ul style="list-style-type: none"> <li>▪ 16.7</li> <li>▪ 63.7</li> <li>▪ 19.6</li> </ul>
Is your partner sympathetic about distress in sexual health and dysfunction?	<ul style="list-style-type: none"> <li>▪ Yes</li> <li>▪ No</li> </ul>	<ul style="list-style-type: none"> <li>▪ 75.5</li> <li>▪ 24.5</li> </ul>
Do you think a clinical sexologist could help you?	<ul style="list-style-type: none"> <li>▪ No</li> <li>▪ Yes</li> <li>▪ I do not know</li> </ul>	<ul style="list-style-type: none"> <li>▪ 47.1</li> <li>▪ 31.4</li> <li>▪ 21.6</li> </ul>
More than 1 answer is allowed for each question		

originating in sexual organs inevitably has short- and long-term effects that can interfere with normal sexual function, body image, and sexuality.<sup>7,12</sup> These effects include premature menopause, pain, depression, anxiety,

fatigue, sleep disruption, an increase or decrease in weight, scars, loss of skin sensation, loss of bowel and bladder function (formation of ostomies), lymphoedema, and social isolation.<sup>12</sup>

High frequencies of sexual problems

in this population have been reported: 40% to 100% of patients reported dyspareunia or pain, 60% to 87% reported vaginal dryness, 25% to 61% reported loss of libido or low arousal, and 45% reported low/lack of orgasm.<sup>13-15</sup>

Support for difficulties in life is currently considered important for facilitating survivors' quality of life. Adequate services need to be provided with perspectives tailored to patients' needs and clinical management of cancer. To design supportive activities to be implemented in the clinical practice, perceived needs and the lived experiences of survivors of gynecological cancer should be queried, taking into account cultural properties. To this aim, the life experience of survivors of gynecological cancers was investigated by an online survey created by the investigators to address doubts arising from their clinical practice and addressed to patients in Sicily, Puglia and Campania, Italy.

## Patients and Methods

### Participant Selection

The survey was addressed to adult women affected by gynecological cancer, at any stage and in any phase of the disease, and inhabitants of a socially homogeneous area in Sicily, Puglia and Campania. Patients were included if they lived in Sicily, Puglia, and Campania; and in Sicily, specifically, they were included if they were patients at Cannizzaro Hospital, where the Alleanza Contro il Tumore Ovarico (ACTO; Alliance Against Ovarian Cancer) was founded. Patients in the aforementioned populations who were ACTO members were invited to participate in the survey. Patients could partake in the survey either during control visits or follow-up in Sicily or through social media groups for ACTO Puglia and ACTO Campania.

### Methods

The authors developed a questionnaire from the perspectives of specialized physicians and patients. It contained 27 questions investigating the following areas: changes in everyday life; perception of body image; subjective psychological and physical well-being, including sexuality;

patient-physician communication; and nutrition. The questionnaire, arranged via the Survio software, was delivered online and in paper form.<sup>16</sup>

Open and closed (multiple choice, with either single or multiple permitted answers) questions were included. Survey results were anonymous. Data were analyzed by descriptive statistics and are presented as absolute numbers or percentages.

## Results

Overall, 102 women answered the survey, of whom 88 were outpatients of Cannizzaro Hospital and 14 were members of ACTO Puglia and ACTO Campania. The respondents' ages ranged from 32 to 80 years.

The Table reports the frequency of answers to the questionnaire. Main changes in everyday life after the diagnosis of gynecological cancer were reported about mostly personal areas (care of oneself, identity, body image). This area was of concern for 59.8% of patients, the family area for 27.5%, and the work area for 12.7%. The patients reported that their disease was known to family members and could be mentioned freely by 80.4%, rarely by 12.7%, and not at all by 6.9%. Children were aware of the mother's disease in 49.0% of cases, not fully aware in 27.5%, and not at all in 23.5%.

Perception of body image was of concern for 99.9% of patients; that it had changed very much was reported in 28.4%, changed quite a bit by 53.9%, and was unchanged by 17.6%. Specifically, 31.4% of patients perceived themselves as very transformed, 54.9% as a little transformed, and 13.7% as not transformed. One's image in a mirror could be completely recognizable by 7.8% of women, quite recognizable by 62.7%, and not at all recognizable by 29.4%.

Mood changes seemed not to be a common concern. The mood was

described as depressed by 15.7% of subjects, quite good by 57.8%, and good by 26.5%. The emotion mainly related to the disease was acceptance for 45.8%, anger for 23.4%, disbelief for 22.4%, and other for 8.4%.

Answers about sexual habits showed relevant changes following cancer diagnosis and treatment and some difficulties in addressing them. Sexual habits were noted as changed for 44.1% of patients, partially changed for 25.5%, and unchanged for 30.4%. Factors impacting sexuality were a sense of guilt in 0.8% of cases, limited information in 0.8%, awkwardness in 6.5%, pain in 15.4%, depression in 21.1%, and body changes in 25.2%. No impacting factor was reported by 30.15% of patients. Partners were reported as sympathetic to the sexual distress of patients in 75.5% of cases.

Communication with the referring physician, either an oncologist or a gynecologist, was judged as very good by 39.2%, good by 35.3%, quite good by 23.5%, and bad by 2%. Physicians informed patients about sexuality changes related to cancer in 16.7% of cases; 19.6% of patients received limited information in this area, and 63.7% were not informed. The advice of a clinical sexologist was considered helpful by 31.4% of subjects and not helpful by 47.1%, whereas 21.6% of women had no opinion on this point.

Nutrition was changed after cancer diagnosis in 61.8% of cases. An improvement in nutrition was desired by 66.7% of patients and was not desired by 33.3%. Support by a nutritionist with expertise in the nutrition of patients with cancer was considered helpful by 71.6% and not helpful by 28.4%.

## Discussion

Results showed that perception of changes in oneself was a main concern in patients, more frequent than social relationship impairments. Changes in

family and work were considered a secondary problem to personal changes. Body image perception was changed by cancer experience in approximately 80% of patients, whereas family relationships were described as changed in less than 30% of women.

Notwithstanding this fairly good evaluation of family life, sexual habits with one's partner were changed for 69.6% of patients. Many patients didn't appear to understand what caused this change. For example, 21% of patients answered that sexual changes were due to depression, but only 16% had reported depressed moods. More commonly, body changes were the reported cause of sexual impairment. The partner's disposition toward sexual habits changes was considered sympathetic by 75.5% of survey participants. Indeed, only 31% considered advice from a clinical sexologist as potentially useful. Although the relationship with physicians was reported as good by the majority of patients, the physicians only rarely discussed sexual impairment associated with gynecological cancer.

Overall, the results of this survey showed that women are mainly concerned with changes in one's person, whereas family and work relationships are less concerned in the experience of cancer. For the survey participants, sexual habits were often changed and seemed to be associated with physical problems or mood disorders. Medical advice in this area seemed to be little desired. It is also possible, conversely, that women do not want to share this problem with professionals for lack of confidentiality or confidence in possible effectual help. Finally, sexual changes may be accepted as events without consequences in a couple's relationship. Based on the authors' clinical experience with these patients, they can confirm that even when a strong alliance is established, sexual problems

are seldom mentioned by women during the follow-up. Medical advice meant to improve treatment efficiency is mainly dismissed, whereas women seem to be ashamed or to feel guilty in addressing a secondary priority need.

Such results suggest that patients would need professional aid to communicate their distress in resuming sexual activity after the diagnosis of gynecologic cancer and to face such problems. Physicians who follow up with these patients should be trained to promote confidentiality and to provide assistance in the sexuality area, specifically by referring patients to a sexual health therapist. The opportunity to seek a sexual health therapist's assistance should be actively explained and encouraged.

This study has some limitations, such as the moderate number of participants and their residence in a select part of Italy. A limitation of our study could be that validated instruments for the measurement of quality of life, such as the European Organisation for Research and Treatment of Cancer Quality of Life-C30, PROMIS-29, FACT-G, and QOL-CS, were not used; indeed, we aimed at identifying different areas of discomfort. For this reason, no direct comparison may be made with studies assessing quality of life.<sup>5,6</sup>

After the survey, a focus group was organized with 10 patients to better understand their attitudes toward sexuality and to shape a support group responding to their needs. The results of this intervention will be the subject of a future article.

In conclusion, although this survey confirmed that gynecologic cancer impacts sexual health and dysfunction, further investigation is necessary to identify a possible approach to organizing support services for cancer survivors in the south of Italy. ■

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