

# The impact of epithelial ovarian cancer diagnosis on women's life: a qualitative study

L. Mangone<sup>1</sup>, V.D. Mandato<sup>2</sup>, R. Gandolfi<sup>3</sup>, C. Tromellini<sup>3</sup>, M. Abrate<sup>2</sup>

<sup>1</sup>Statistics, Quality, and Clinical Studies Unit, IRCCS - Arcispedale Santa Maria Nuova, Reggio Emilia

<sup>2</sup>Department of Obstetrics and Gynecology, IRCCS-Arcispedale Santa Maria Nuova, Reggio Emilia

<sup>3</sup>Association "La Melagrana", Reggio Emilia (Italy)

## Summary

**Purpose of investigation:** To describe the experience of ovarian cancer patients from symptoms complained before diagnosis until the impact of ovarian cancer diagnosis perceived by women. **Materials and Methods:** The authors used the Psychological General Well being Index (PGWBI) and a semi-structured interview to measure the overall well being of 39 women diagnosed with ovarian cancer in the period 2005-2010 at a secondary care hospital in northern Italy. **Results:** The PGWBI showed that the majority of the women reported general stress. On the semi-structured interview, 95% of women reported having symptoms and 69% reported a stressful event prior to diagnosis. More than 50% of women reported changes concerning life course. Almost all reported that their primary concerns had to do with the surgical scar, weight gain, and hair loss. **Conclusions:** Ovarian cancer diagnosis has a very stressful effect on the quality of life. Early assessment of psychological problems must be an integral part of the therapeutic pathway. Gynaecologists must provide clear and useful information regarding the disease itself as well as regarding correlated symptom relief.

**Key words:** Ovarian cancer; Survival; Quality of life; Patterns of care.

## Introduction

Epithelial ovarian cancer (EOC) is the most lethal gynaecological tumour, with 224,747 new cases yearly worldwide and an estimated 140,163 disease-related deaths [1]. In Europe, approximately 66,700 new ovarian cancer cases are diagnosed yearly, with the highest incidence in northern European countries and the UK [2,3]. In the Emilia-Romagna Region, a region of Northern Italy, there is a yearly average of 17.6 new EOC per 100,000 females (about 401 new cases) [4]. The majority of women (about 65%) are diagnosed at advanced International Federation of Gynecology and Obstetrics (FIGO) Stage III-IV [5]. The most recent report shows overall European age-standardized five-year relative survival at 36.1 % [6]. Survival in Italy is also below 40%, with a marked age gradient: in older women, the higher frequency of advanced stage disease and the presence of comorbidities compromise the benefits of radical interventions and chemotherapy [7].

Due to the advanced stage at diagnosis, side-effects, radical surgery, and chemotherapy, physical, and psychological sequelae emerge which can radically change a patient's life.

The aim of this study was to describe the experience of EOC patients in order to raise the awareness of general practitioners and specialists regarding these patients' emotional and psychological needs. EOC patients were asked to describe their experiences with diagnosis and treatment, as well as the relationships with their general practitioner, gynaecologist, oncologist, and nurses.

## Materials and Methods

The study was approved by the provincial Ethical Committee. The study design was observational in that it describes the characteristics of the women with ovarian cancer who underwent surgery at the Department of Gynaecologic Oncology and Surgery of the IRCCS-Arcispedale Santa Maria Nuova in Reggio Emilia, Italy during the period 2005-2010.

The Department Chief contacted 77 women to explain the details of the study and to ascertain whether they would be willing to participate in a psychological interview. Of these 77 patients, 20 refused, ten had had recurrence, and one had died. A psychologist then contacted the remaining 46 women, of whom seven refused to participate in the interview and 39 accepted; these latter completed the questionnaire.

Two tools were used to collect data: the Psychological General Well being Index (PGWBI) and a semi-structured interview.

The PGWBI, a self-administered questionnaire that measures the level of well being or distress related to the emotional/affective sphere, was developed in the United States in the 1970s. The present study used the Italian version of this tool [8]. Chosen for its simplicity and for its reliability, the PGWBI is made up of 22 items covering the six dimensions of anxiety, depressed mood, positive well being, self-control, general health, and vitality. The items referred to the four weeks prior to completing the questionnaire and is self-administered at the beginning of the meeting with the psychologist.

The semi-structured interview was developed *ad hoc* to investigate the patient's experiences with reference to:

- 1) symptoms and experiences prior to diagnosis;
- 2) experiences during clinical pathway
- 3) experiences after treatment
- 4) plans and expectations for the future.
- 5) psychological well being

Both tools are included in the Annex to this study.

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Table 1. — Characteristics of ovarian cancer patients in the Reggio Emilia province, during the period 2005-2010.

	n.	%
<b>Age in years</b>		
25-49	12	30.8%
50-69	22	56.4%
70-79	5	12.8%
<b>Marital status</b>		
Married	32	82.1%
Separated/ divorced	3	7.7%
Widow	2	5.1%
Single	2	5.1%
<b>Education</b>		
Middle school	14	35.9%
High school	23	59.0%
College	2	5.1%
<b>Profession</b>		
Housewife	16	41.0%
Employed	8	20.5%
Retired	7	17.9%
Other	8	20.5%
<b>Year of operation</b>		
2005	4	10.3%
2006	3	7.7%
2007	5	12.8%
2008	5	12.8%
2009	16	41.0%
2010	6	15.4%
Total	39	100.0%

#### The meetings with the psychologist

A psychologist met with each patient participating in the study; meetings lasted between 35 minutes and two hours and included a detailed explanation of the research study. The participants were given forms pertaining to the protection of privacy. Also, they signed a release authorising the recording of the conversation in its entirety and the use of the data for purposes strictly related to the study. Each meeting began with a self-administered PGWBI, followed by a semi-structured interview.

## Results

Characteristics of the study participants are illustrated in Table 1. The mean age was 55.8 years (range 39-74), 82% of the women were married, 59% had a secondary school education, and 41% were housewives. While the study period was from 2005 to 2010, most of the participants were operated after 2007. Interviews were conducted in 2009-2010.

#### 1) Symptoms and experiences prior to diagnosis

The presence, type, and timing of symptoms are reported in Figure 1. A mean of three symptoms was reported (range 0-9 symptoms), with 65% of the patients reporting symp-

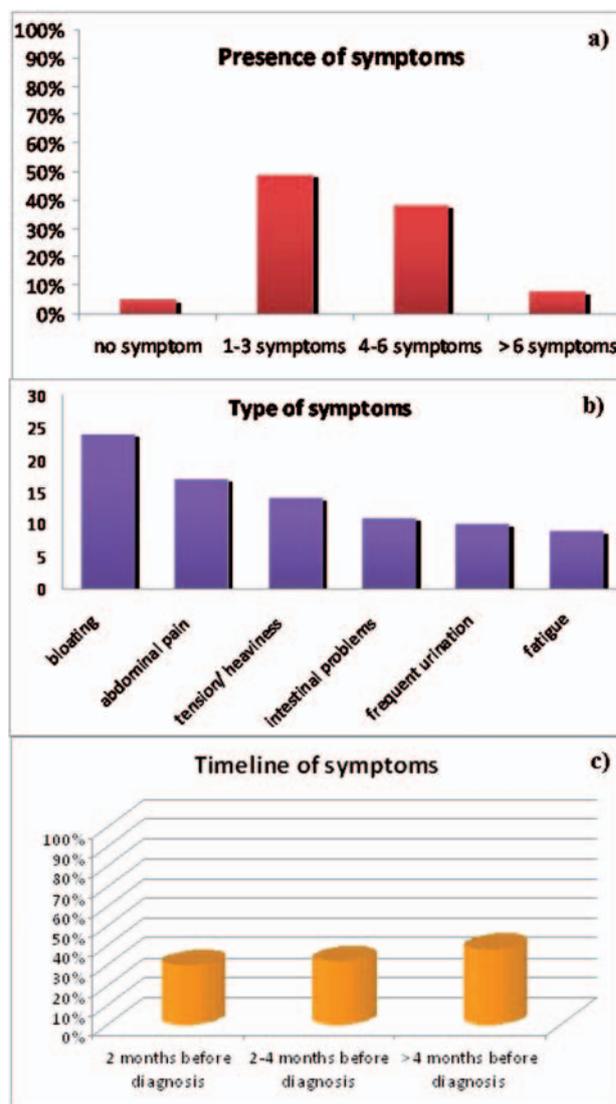


Figure 1. — Ovarian cancer patients in the Reggio Emilia province, 2005-2010: a) presence; b) type; c) timeline of symptoms.

toms of high intensity. The most common symptoms were bloating, pelvic pain, lower abdominal distension, intestinal disorders, frequent urination, severe fatigue, weight loss, and stomach disorders. Less common symptoms included groin pain, lower back pain, menstrual disorders, “sensation of a ball in the lower abdomen”, and pain/heaviness in the legs. Symptoms appeared more than four months before diagnosis in 38% of women. Of the 39 participants, 29 reported symptoms to their general practitioner. In 41% of these, the attending GP did not request further diagnostic testing. “My doctor played it down and told me that it was nothing, that it was menopause. I felt abandoned”. Regarding any stressful events in the months prior to diagnosis, 69% reported at least one (Figure 2).

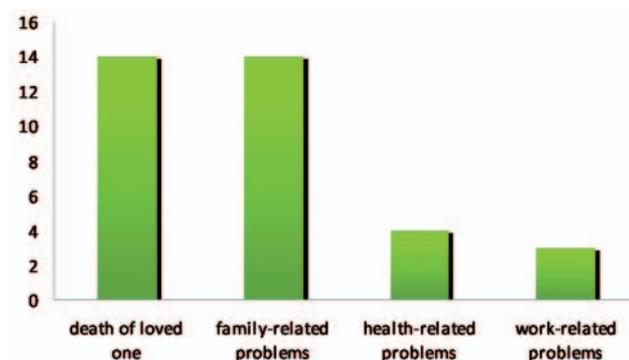


Figure 2. — Ovarian cancer patients in the Reggio Emilia province, 2005-2010: number of stressful events prior to diagnosis.

### 2) Experiences during clinical pathway

All the women interviewed reported that the most critical moment was at the communication of the diagnosis. *“At first I couldn't grasp what was happening to me. It was a tremendous shock. – It was a storm. A typhoon – It was like crashing into a wall. – It was the greatest blow I could ever imagine receiving in my life”*. After the communication of the diagnosis, the most common mood reported was fear (79.5%), the most common fears being of death, recurrence, physical suffering, and chemotherapy. However, as the women's moods did fluctuate between negative and positive states, they also reported feeling tranquillity, inner strength, and optimism.

### 3) Experiences after treatment:

The main physical changes after diagnosis are reported in Figure 3. *“I put on weight because I ate more desserts. I used to be slimmer; I've put on eight kg (17 lbs) and can't seem to lose them. – I started eating more. I put on seven to eight kg (15- 17 lbs). – When I look at myself I look completely different, ruined, unrecognizable. I've put on 12 kg (26 lbs)”*.

Fifty-one percent of the women reported changes in their relationships with their partner, especially in terms of sexual activity. *“Sexually, I was totally unprepared. They could have prepared us a bit more for this. – Stupidly, I thought it would be like it was before. Instead, I can no longer have intercourse. – Over time we stopped having sex. – My partner and I don't have sex anymore. The first few months, it was because of physical problems; now, it's probably a psychological block”*.

The women reported other changes as well post-treatment in terms of their life course (e.g., job loss), their daily lives (e.g. greater difficulty doing housework), and interpersonal relationships (e.g. becoming more selective in friendships).

### 4) Plans and expectations for the future:

Sixty-two percent of women reported having plans for the future, the most common being travelling, buying a

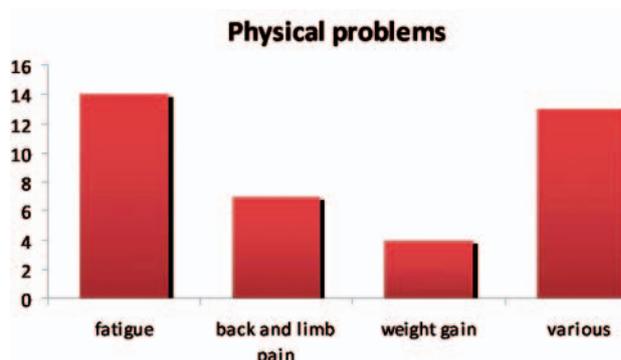


Figure 3. — Ovarian cancer patients in the Reggio Emilia province, 2005-2010: number of physical problems after disease onset.

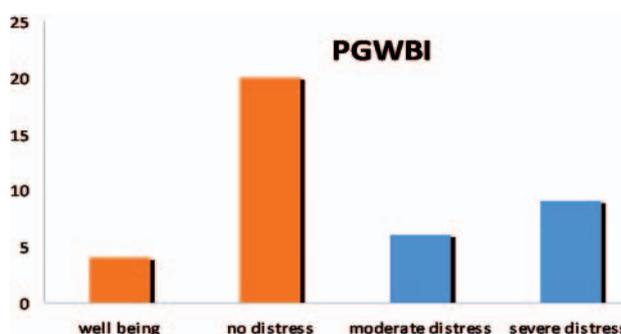


Figure 4. — Ovarian cancer patients in the Reggio Emilia province, 2005-2010: PGWBI Test results.

house, and returning to work. Some, however, especially the older women, preferred focusing on the present. *“I plan to continue doing what I did before. – I don't make plans anymore. I want to learn how to live day to day”*.

### 5) Psychological well being

The PGWBI provides self-reported status in terms of well being or distress related to the emotional and affective spheres and whether this status is higher or lower than the “normal” level, i.e., a stress-free state. The higher the score obtained in each of the six dimensions measured, the greater the degree of well being. Scores are reported in Figures 4 and 5.

Most women did not show any particular psychological distress: for each dimension examined, results were average, or even above average when compared to a group of healthy women the same age, except for the last scale – General Health. In this case only, almost half of the women interviewed (44%) scored below average but this was due to the fact that 23 women out of 39 (59%) reported having physical problems unrelated to their cancer.

Despite these positive results, it must be noted that 39% of cases reported stress, and in 23% of these, stress was severe, meaning with psychopathological features. These

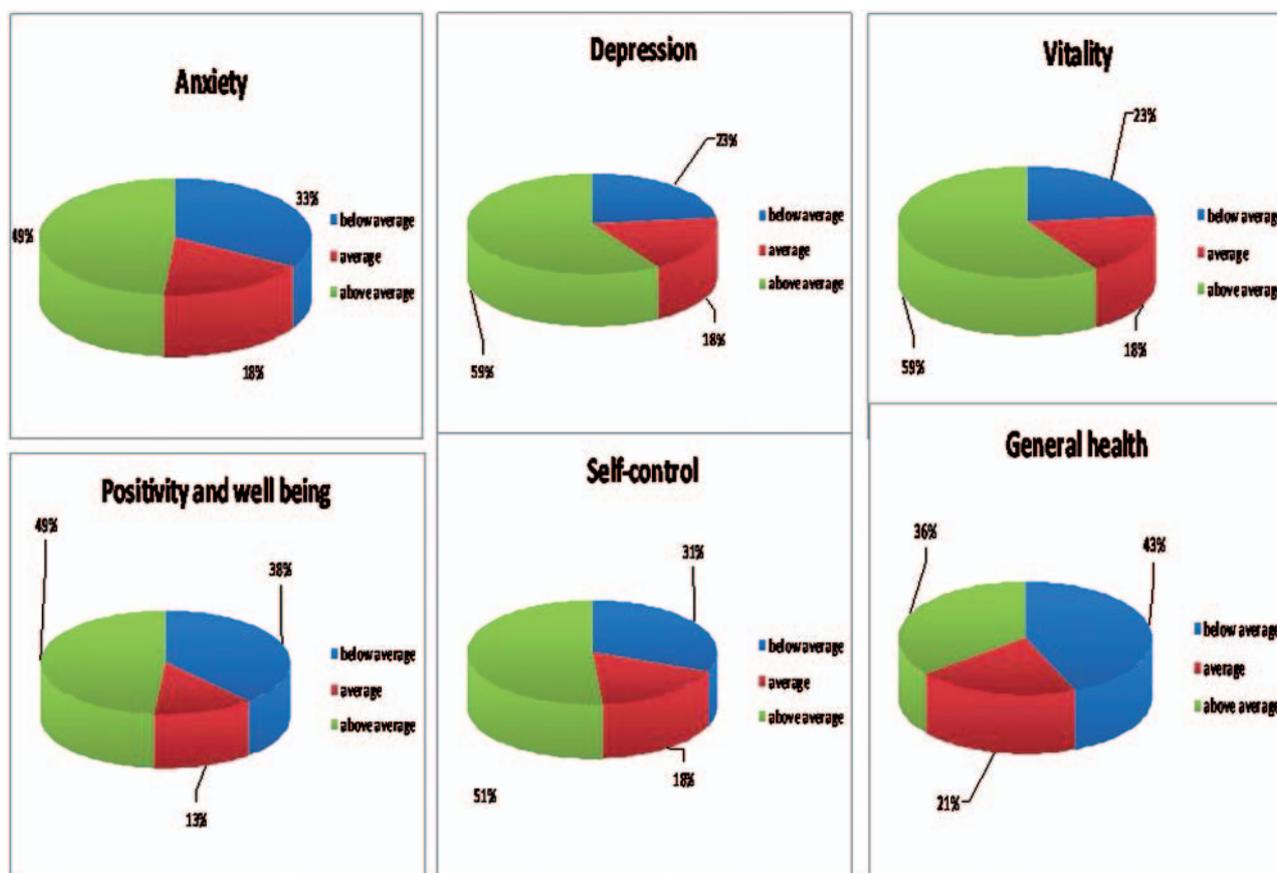


Figure 5. — Ovarian cancer patients in the Reggio Emilia province, 2005-2010: PGWBI results for 6 dimensions.

cases were exclusively among those women who participated in the interview less than one year after the end of treatment; for those women, instead, who had finished treatment two to three years before the interview, the psychological situation was definitely better. In any case it would be opportune to evaluate the need for psychological support in those cases where distress appears to be severe, where a social network is lacking or is inadequate, and/or when there are other concomitant critical events.

## Discussion

Ovarian cancer survival has risen from 32.4% in the 1990s to 36.3% in the 2000s: only younger women had higher survival rates [6]. The fact that these survival rates do not describe the psychophysical well being of these women has been widely reported in the literature [9-11]. Thus, healthcare must include both the tumour and the person.

The quality of life of women with ovarian cancer has been widely studied. Early assessment of psychological problems must be an integral part of the therapeutic pathway [12-15], which begins with the general practitioner's examination; assessment results must be useful to the GP

as well [15]. Many instruments have been used to assess the problems of ovarian cancer patients [17, 18], some of which are applicable to all cancers while others are more specific [19]. There is not yet, however, an ideal instrument [20].

Physicians must quickly understand whether the patient is in physical or psychological distress, and whether the woman is bearing the burden of her distress alone or has someone with whom she can share it [21]: In the present study, 80% of the women shared their moods and fears with others. However, the quality of this sharing was not always such that the women could bear their anxieties and fears. Nevertheless, being able to talk about one's moods and feelings positively affects the women's ability to cope with their disease.

Age was also a strong determinant of the general health of these patients: younger women had more family- and work-related problems [22, 23]. Although younger women may have a wider social network than older women, and as in the present study, may receive more support from their partner, the disease is more likely to impact on their everyday life. Further, the possibility of recurrence or death upsets the patient and those around her, such as her partner and/or her children [24]. Although

61% of the women in this study did not report stress after diagnosis, their PGWBI scores would suggest otherwise. On the one hand, the women reported feeling vitality, positive well being, and self-control, while on the other, they also reported anxiety, depressed mood, and poor general health. However, what appears to be a contradiction has been reported in the literature [21] and is partially explained by the frequent psychophysical fluctuations these women are subject to.

Although symptoms are vague and non-specific, recognizing them as such and giving them due consideration appear to be crucial to early diagnosis. Only five percent of the women in the present study did not report having any symptom prior to diagnosis; of the remaining 95%, 49% reported having one to three symptoms, 38% four to six symptoms, and eight percent more than six symptoms. The association between frequency and severity of symptoms must not be underestimated [25].

As far as clinical pathway satisfaction is concerned, 88% of the women reported positively: *“I was very pleased with everything, and with the gynaecology department, in particular: the care, the professional competence, their kindness, attention, and consideration – everything someone in my position could possibly want. – I was pleased with both the gynaecology and the oncology departments and the hospital. The doctors and nurses were all very kind”*.

Instead, their reports on the kind of information they received from the gynaecologists is less positive: *“They told me everything about the operation but in technical terms. What I wanted to know was what it was going to be like afterwards, so as to be more psychologically prepared”*.

After the operation, the women perceived their bodies as being irreparably damaged, especially if the operation was very invasive: *“I’ve got this huge tear up to here. Physically, I make myself sick. – I have a scar as big as a house. I see it every time I look at myself. – Every time I get undressed I remember what happened”*.

Chemotherapy also contributes to exacerbating this experience, and thus negatively affected the psychological condition of these women. Chemotherapy often contributes to lowering self-esteem and to making sexual activity more stressful: *“When they told me that I would have to do chemo, I felt as if I had a weight on my chest, that I couldn’t breathe. I cried for three days. You’ve got to experience it yourself to know what it’s like. And ... your hair. That’s your first thought. At least for a woman. – The worst moment for me was the six cycles of chemo I did. Crossing that threshold to be injected with poison. For me, losing my hair was terrible, even though I was prepared for it. – Thinking about chemotherapy made me lose it. I was afraid of feeling sick physically, of feeling bad psychologically, of losing my hair. – The most traumatic thing for me was losing all my hair”*.

In a study on the psychosocial distress of EOC patients, participants clearly expressed the need for more informa-

tion and emotional support right from the moment of diagnosis, and throughout the treatment process. Telephone interventions rather than face-to-face contact were proposed as the most likely to be effective for providing psychosocial counselling specifically but also for specific disease-related information. It is strongly recommended that health care organizations explore setting up a telephone-based service for EOC patients which includes EOC survivors as counsellors, ideally with the collaboration of patient groups and advocates [26].

Gynaecologists/ surgeons should explain how the surgical procedure will be performed (preferably using visual aids such as drawings or diagrams) and should describe what the surgical scar will look like, i.e., that it will be about 30 cm long, more or less from the pelvic bone to the sternum. If the scar is particularly unsightly, the GP or specialist could provide some practical suggestions on how best to deal with it.

Before chemotherapy is commenced, the oncologist should inform the patient of the possible side effects (e.g., nausea, vomiting, nail disorders, and so on) and must absolutely deal with the side effect that most concerns women: hair loss. Hair loss is inevitable but temporary, lasting about six to eight months from the beginning of chemotherapy. Specialists should suggest some options and practical solutions here as well, such as cutting your hair very short before the start of chemotherapy and buying a wig that is as close to your natural colour and style as possible (ideally also providing information about costs and where to buy a wig in the local area). As hair loss also includes eyebrows and eyelashes, practical suggestions could include getting eyebrow tattoos and using black eyeliner to “cover” the lack of eyelashes, and/ or wearing eye-glasses with frames that “accessorise”.

Another important issue concerns weight gain: women with cancer often react to the stress by eating more, and in particular by eating more sweets and desserts. Associated with this is the fact that cortisone and other drugs induce fluid retention, which alone leads to an immediate weight gain of two to three kg. Weight gain results in changes in the woman’s appearance and can thus negatively affect her self-image and her mood. Specialists must therefore not only tell women to be very careful about weight gain, they could also provide patients with a list of suggested low-calorie and/ or sugar-free snacks to have on hand to relieve hunger pangs. Further, specialists and GPs must explain the importance of getting regular exercise, providing practical information concerning kinds of appropriate exercise and how much is necessary (e.g. “walk 30 minutes a day, every day, at a brisk pace”) so that patients can realistically implement a program as soon as possible. This will improve both the patient’s health and her mood [27]. Involving family members throughout the entire clinical pathway could be helpful [28] in dealing with all aspects of this disease.

Monitoring the entire pathway is essential, especially for those women undergoing chemotherapy. [29]. Today, it should be mandatory to carefully assess all EOC patients for symptoms of anxiety and depression, to ensure social and, if necessary, specialist support. It is reported that social support is associated with survival advantage for EOC patients [30].

Finally, GPs and specialists should encourage and facilitate help and support provided by “former” patients who are willing to talk about their experiences with patients newly diagnosed with the same kind of cancer. Hearing other women talking about their personal experiences may be more convincing and thus more helpful than any scientific information from a specialist would be: “*You change because afterwards you don't feel the same, and whoever has had this kind of experience has a different perspective on things, on their importance. – I feel more fragile, but I'm also more attentive to respecting myself. I am more in tune with myself. – I feel I've become a better person, much more understanding – My illness has helped me change. It sounds strange, but it's helped me calm down and enjoy every moment. – My illness helped me become wiser and has built up my self-esteem. – It's been positive; I never would have believed I could be so strong, that I could stand the pain without complaining, that I could deal with my anxieties without unloading them on others. – I feel I've changed for the better. Now I care only about what's really important. I feel more confident and more serene.*”

It would benefit these women if they formed support EOC groups or associations like those that have become more and more common among breast cancer patients in order to help each other throughout their illness.

It would benefit these women if they formed support EOC groups or associations like those that have become more and more common among breast cancer patient in order to help each other throughout their illness. It has been seen that positive stimuli can be found in other women's experiences. While each woman's experience may be longer or shorter, the important thing is that not one day is wasted and that each is a *special day*.

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Address reprint request to:  
V.D. MANDATO, M.D., Ph.D.  
Department of Obstetrics and Gynecology,  
Arcispedale Santa Maria Nuova di Reggio Emilia,  
IRCCS, Viale Risorgimento 80,  
Reggio Emilia (Italy)  
e-mail: dariomandato@virgilio.it