

Chapter 8

QUALITY OF LIFE AND BODY IMAGE: A PSYCHOSOCIAL PROGRAM FOR CANCER PATIENTS

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ABSTRACT

Introduction: “Salute allo Specchio” (“A reflection of Health”) is a psychosocial program for cancer patients, whose aim is to improve well-being and quality of life. The focus of the program is the creation of group sessions during which a team of fashion and aesthetic consultants illustrates techniques and strategies to manage the effects of the disease and its treatments (hair loss, pale and waxy skin tone). After “beauty treatments” patients are involved in groups led by the psychologists, as the program is considered a part of a wider psychological supportive care. *Method:* “Salute allo Specchio” (“A reflection of Health”) project is addressed to female patients with a cancer diagnosis who are undergoing cancer treatment (chemotherapy, radiotherapy) at one of the largest hospitals in the north of Italy. Up to now, 24 patients have taken part in the program. Anxiety (STAI-Y), depression (BDI), quality of life (EORTC QLQ-30), body image perception (BIS), and self-esteem (SE) are assessed at the beginning (t_0), at the end of each session (t_1) and after 3 months (t_2). *Expected results:* Based on previous literature, we expect that the beauty treatments, in combination with psychological support and routine care, will have a positive impact on body image perception, increase self-esteem and reduce anxiety and depression, thus improving patients’ general well-being.

Keywords: psycho-oncology, female cancer, aesthetic, psychosocial program, quality of life.

1. INTRODUCTION

Of the many diseases that threaten life, cancer is one of the most stressful and traumatic. In spite of technological progress in the field of oncology, the subjective reality of cancer and its individual interpretation remain that of an insidious and uncontrollable disease that invades, transforms and slowly brings an end to life. The International Psycho-Oncology Society standard of quality cancer care states that:

- 1) Quality cancer care must integrate the psychosocial domain into routine care;
- 2) Distress should be measured as the Sixth Vital Sign after temperature, blood pressure, pulse, respiration and pain.

Few other diseases have so many evident consequences for the sufferer, or interfere with so many different dimensions of the patient’s life: the relationship with one’s body (brought to the forefront by this disease in its limited nature and fragility), the meaning of life, the suffering, family, social and professional relationships, one’s identity and role. The anxiety links to a feeling of profound insecurity weighs the patient down and destabilises their entire existence. With this illness, it is essential to implement all of the physical, mental and affective resources available to help the patient find an area of thought and possibility, free of the anxiety and the limitations that the disease imposes.

Faced with the comprehensive nature of the oncological disease, which interferes with multiple spheres in the patient’s life, the need to couple traditional medical treatment with psychosocial intervention becomes increasingly apparent. Feelings and thoughts in fact neither cause nor cure cancer, but they are integral aspects of the whole person (LeShan, 1994) which can’t be left aside in a perspective of patients’ integrate care. Such interventions aim to provide an opportunity to resolve problems of a not strictly medical nature that patients experience in

their course of treatment (psychological, social and practical problems, for example). They respond to the need for an overall management of the patient, with the goal of not only reinstating, where possible, a condition free of illness but also the protection of a state of psycho-physical well-being. If health corresponds to a “state of complete physical, mental and social well-being that does not coincide with the simple absence of disease or infirmity” (World Health Organization, 1948), nobody working in the clinical world is exempt from considering the patient in their entirety. This means taking into consideration those aspects that are not strictly concerned with the pathology, regarding the patient as a person (LeShan, 1994).

1.1. The experience of the oncological patient

From the psychological point of view, cancer is a highly traumatic event in the life of the individual who has become ill. Initial reactions and signs of suffering may appear in response to the first symptoms or suspicions of disease which then explode with intensity when the diagnosis is made (Stanton & Snider, 1993). The elaboration of the disease must, however, be seen as a process; it is not a single event but rather a complex and varied adaptation divided over time.

Reactions to the news of cancer tend to follow a similar pattern with some individual variations. The first stage is *shock* (incredulity and protest at the “catastrophe” that has occurred); in this phase, the patient often uses defence mechanisms such as “denial” which help to postpone the moment of confrontation. The *transitional* stage (fluctuating states which alternate between anger, desperation, anguish and fear) occurs when the reality of the situation really sets in. Here, the defense mechanisms implemented are often varied and contradictory (for example, “regression” and “projection”) (Lingiardi & Madeddu, 2002). The true psychological impact of the diagnosis and treatment are of extreme importance in this stage (Bolund, 1990). In the transitional stage, the patient is forced to continually re-adapt and re-evaluate the situation by the different steps of treatment. Lastly, the *reorganisation* phase (efforts to establish a balance) involves adaptation and acceptance of events.

The great variability of these stages largely depends on the coping strategies (cognitive and behavioural adaptation to a stressful situation) adopted by the patient and the defense system used to reduce the state of anxiety and tension. The quality and intensity of the reactions can, therefore, also be very different, although still within a normal range. However, almost 40% of these physiological manifestations of discomfort and suffering assume a pervasive and maladaptive nature, to the point that a true disorder can be diagnosed psychiatrically (Grassi, Biondi, & Costantini, 2003). Factors favouring the appearance of true psychological-psychiatric symptoms are certainly medically variable (disabling symptoms, aggressive medical treatment, advanced stage of the disease, etc.), psychological (preceding psychiatric history, perception of little control over events, tendency to repress emotions, etc.) and relational (poor family or social support, low social-economic level, etc.). The most frequent disorders found are depression (in 16% of patients), anxiety (10%), and adaptation (19%) (Mitchell et al., 2011).

1.2. Quality of life

One of the aspects most considered today in the treatment of the oncological patient is the quality of life during and after treatment. Currently, with the transformation of cancer from an inevitably fatal disease to a disease that is increasingly chronic (Varni, Katz, Colegrove, & Dolgin, 1995), it becomes essential to assess the ratio between benefits (increase in survival) and costs (short- and long-term side effects) of each therapeutic choice, emphasizing the well-being of the sick person.

The term quality of life (QoL) lends itself to various possible definitions; it can generally be defined as an overall state of well-being felt and evaluated by individuals through subjective and objective measurements, global functioning, health and satisfaction with the dimensions of life that they consider most important (Hunt, McEwen, & McKenna, 1985). In relation to health, quality of life is divided into some fundamental dimensions: physical function, social function, mental and emotional state, the gravity and weight of the symptoms and the feeling of overall well-being perceived by the patient (Stewart & Ware, 1992).

The conclusions of the research regarding the impact of the oncological disease and its treatment on the quality of life of patients are not always consistent (Rosenfeld, Roth, Gandhi, & Penson, 2004) mainly because of different definitions of the construct and its dimensions. However, beyond these differences, it is recognized that anxiety and depression are significantly correlated with impaired QoL (Frick, Tyroller, & Panzer, 2007); the quality of life of the patient is also an independent positive prognostic factor (Ganz, Lee, & Siau, 1991) and is particularly influenced by the important physical changes that the patient often rapidly undergoes starting from the first therapeutic interventions (Przedziecki et al., 2013).

1.3. Body image and cancer

The concept of body image, previously considered almost exclusively in other sectors, has acquired relevance in the oncological sphere, both in terms of research and also as the specific focus of intervention. When we talk of body image, we need to think of a multi-dimensional mental construct, dynamically moulded throughout life and established on biological and psychological bases. Its definition is still under discussion. However, despite the ambiguities, researchers generally agree on defining it as the mental representation relating to perceptions, feelings, thoughts and attitudes concerning one's body (Cash, 2004; Grogan, 2006).

The experience of cancer causes significant changes to body image. The body is the first aspect to be struck by the disease and the treatments associated with it - alopecia, changes in weight, mutilations, oedema, pallor, nausea, sickness, alterations of taste, loss of energy, and compromise of physical abilities, bring to the forefront the image of a changed, suffering body that is often no longer recognised or felt as one's own (Rosenberg, et al., 2013). In turn, these changes can generate difficulties in daily life and interfere with social life, lifestyle, and moods. The changes relating to how a person sees themselves and how others see them threaten the identity, the sense of oneself and integrity (Grassi et al., 2003).

Studies on body image in oncological patients concentrate on different and specific areas of study, according to the objectives. Researches on the relationship between body image and cancer, for example, highlight how compromises in the former have a negative effect on the quality of life, psycho-social adaptation, sexuality and self-esteem of patients (Erol, Can, & Aydiner, 2012; Arora et al., 2001; Härtl et al., 2003; Anagnostopoulos & Myrzianni, 2009). Some authors have likewise explored investment in body image (i.e. "how much it counts" for the individual) as determinant in the development of a positive or negative psychological adaptation. On this point, the literature shows that a consistent change in the condition and integrity of one's body is experienced more negatively when the investment in body image is particularly intense and high and that a person's self-esteem very much depends on their physical appearance (Carver et al., 1998).

Lastly, as early as the 1970s, some studies in the psycho-oncological area showed how part of psychiatric morbidity in oncology is linked to problems relating to body image. Some cases of social phobia arise as a result of the therapy, especially if it mutilates or changes the exterior appearance of the person. The fear of being judged and the feeling of being watched and pitied can lead to isolation, and bring out feelings of abandonment and solitude. Avoidance behaviour, can also occur as a consequence of the fact that some changes typically linked to treatment (such as, loss of hair) are for many proclamations of their disease status and a constant reference for themselves and others to their stigmatised, easily recognisable condition as "*a person with cancer*".

1.3.1. Body image in female cancer patients. The need to redefine one's image and psycho-corporeal identity is more evident if a woman becomes ill with an oncological disease. The concept of female body image is particularly complex. Throughout life, the female body undergoes changes that are not linear: menarche, the development of secondary sexual characteristics, pregnancy, birth and menopause represent radical changes that necessitate continuous restructuring of a woman's self-perception and of her 'bodily self'. In this sense, the conquest of femininity follows a complex pathway marked by a certain fluidity and continuous comparison with the change and the new (Pigozzi, 2004). Thus, when a female patient becomes ill, the fear of losing her beauty, her integrity, the sense of herself as a woman (self-image,

sexuality, fertility, etc.) add to her fear of the disease itself. It is clear that for all these reasons, the approach to female neoplasia cannot be based exclusively on medical considerations but must include an evaluation and management of psychological and aesthetic problems (an integral part of the disease).

2. BACKGROUND

A simple analysis of the data for 2012 shows that the incidence of cancer in Italy is approximately 354,500. Of these cases, almost 192,200 are male and 162,300 are female. Data for 2012 in Europe shows 3,442,300 new cancer cases; 1,611,700 are female (Globocan, 2012).

As described in the previous paragraphs, the experience of being diagnosed and subsequently treated for cancer is a time of deep personal crisis and the cause of severe physical and psychological stress for the vast majority of patients. This stress is exacerbated for many patients by additional concerns over changes in body image or self-perceptions about physical appearance (Morasso & Tomamichel, 2005). The main changes that patients experience concerning their appearance are loss of hair, eyelashes and eyebrows, pale skin and increase or loss of weight (in addition to any physical impairments related to surgeries). These changes have a detrimental impact on perceived quality of life, self-esteem and level of emotional and social functioning (Quintard & Lakdja, 2008).

In recent years, closer attention to body image and quality of life in oncological patients has led to the creation of specific psychosocial programs in addition to traditional medical care; their impact has been investigated by empirical studies. An early study of 2008 (Quintard & Lakdja, 2008) confirms the usefulness of a program aimed at providing advice and beauty treatments to patients with breast cancer. Patients who took part in the program showed significantly higher scores in the perception of their body image within six months of surgery (which was associated with routine care). A second study of 2009 (Taggard & Ozolins, 2009), evaluates the effectiveness of the program “*Look Good Feel Better*” on a group of cancer patients admitted to a hospital in the UK. At the end of the program, patients showed significant improvements in anxiety, body image and perceived support.

“*Salute allo Specchio*” (“A Reflection of Health”) is a psychosocial program for cancer patients which has been developed as a result of these studies. Its aim is to improve well-being and quality of life through the creation of group sessions in which a team of fashion and oncology aesthetic consultants illustrate techniques and strategies to manage the effects of the disease and its treatments. All patients are personally involved in this experience, all becoming “models” of a set and “customers” of a prestigious spa, both recreated inside the hospital. During these “beauty session” they are instructed not only about make-up, wigs’ management and skin care, but also about how to wear coloured clothes and choose dressy accessories such as foulards, scarves, earrings and necklaces. In a playful atmosphere, consultants give theoretical and practical suggestions often with the help of pictures taken from magazines and famous paintings: by using these images, they are able to establish a link between healthy and ill women. Stressing these aspects, patients’ femininity, often threatened by illness and body changes, could be improved, allowing them to feel more comfortable with themselves and with others; this could ultimately result in a better adaptation to the disease and to the treatment. Moreover, through the participation to this session, patients could recover the pleasure of taking time for themselves, giving greater importance to body care as one of the way to enrich personal wellbeing; “*I learned the importance of dedicating less time to the disease, to the work, to the duties and more time to myself, as a woman*” said a patient at the end of a group. After treatment, patients are involved into discussion groups, led by the team psychologists, where participants can share their experiences and emotions. The program in fact is considered part of a wider psychological supportive care effort, and the group is a fundamental psychological support device (Yalom & Leszcz, 1997).

“The best thing for a cancer patient is to share the disease with other cancer patients. Only who is sick can really understand what I mean. Here I found some special friends”.

3. METHODS AND RESULTS

3.1. Sample selection and recruitment

Patients with a cancer diagnosis undergoing cancer treatment (chemotherapy, radiotherapy or surgery) at one of the largest hospitals in the north of Italy were invited to take part in the program. Women eligible were over 18, Italian speaking, with at least an elementary school education. Approval from the Medical Ethical Committee and informed patient's consent were obtained.

3.2. Measures

The demographic and clinical information of all participants was collected before the beginning of the program (baseline). The following instruments were distributed:

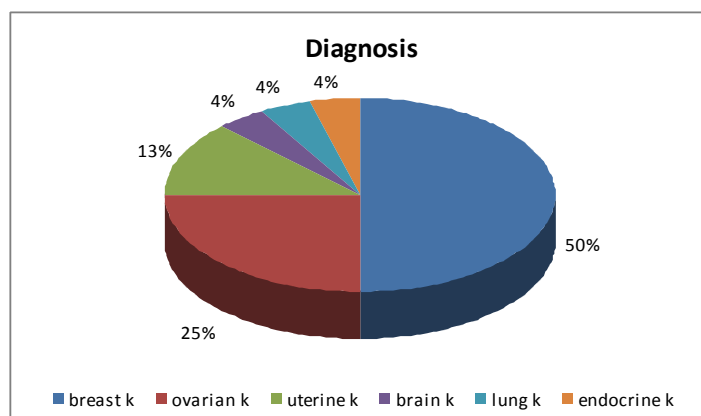
- Self-Report Questionnaire, which includes date of birth, socio-demographic information, date and type of diagnosis, nature of therapy, main 'aesthetic' side effects.
- State-Trait Anxiety Inventory (STAI) (Spielberger, Gorsuch, & Lushene, 1970). This consists of 40 items (rated on a 4-point scale) and measures state and trait anxiety. Total scores range from 20 to 80 for each subscale; higher scores indicates higher levels of anxiety.
- Beck Depression Inventory–Revised (BDI-II) (Beck, Brown, & Steer, 1996). This contains 21 questions (each answer scored on a scale value of 0 to 3) and is one of the most widely used instruments for measuring the level of depression. Higher scores indicate greater severity.
- Rosenberg Self-Esteem Scale (SE) (Rosenberg, 1965). This consists of 10 items (answered on a four point scale) and is considered a reliable and valid quantitative tool for the assessment of self-esteem. Total scores range from 10 to 40; higher scores indicate higher self-esteem.
- Body Image Scale (BIS) (Hopwood, Fletcher, Lee, & Al Ghazal, 2001). This is a brief scale (10 items scored from 0 to 3) which is used to assess body image perception in patients with different types of cancer. Total scores range from 0 to 30, with higher scores denoting a worse body image perception.
- European Organization on Research and Treatment of Cancer QLQ-C30 (EORTC QLQ-C30) (Aaronson et al., 1993). This is a 30-item questionnaire developed to assess the quality of life of cancer patients consisting of five functional scales, nine symptom scales and a global health and quality of life scale. All the scales range in scores from 0 to 100. A high score for a functional and global health status scale represents a healthy level of functioning, while a high score for a symptom scale represents a high level of dysfunction.

A second assessment will be conducted at the end of each session (time 1) and a final follow up will be carried out after 3 months (time 2).

3.3. Available results

To date, 24 patients have been recruited for the program and have completed the baseline assessment. The mean age of the patients is 53.63 years (sd: 10.79; range: 32-74). Time elapsed since diagnosis is on average 19.13 months (sd: 32.85; range: 1-150). All patients are treated with chemotherapy; 5 of them are also treated with radiotherapy (21%). Diagnoses are distributed as follows (Figure 1):

Figure 1. Diagnosis distribution.



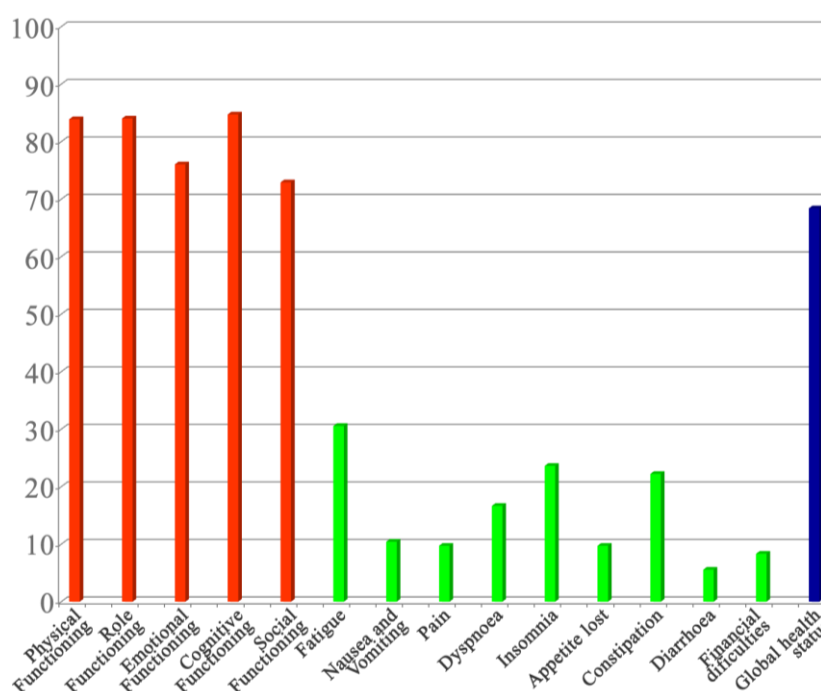
Score ranges, means and standard deviation for STAI, BDI, BIS and SE are reported in the following table (Table 1).

Table 1. Score ranges, means and sd.

Variable	min	Max	Mean	standard deviation
STAI state	22	66	44.42	10.79
STAI trait	28	63	38.75	8.28
BDI total score	1	27	11.83	7.60
BIS total score	0	28	11.75	7.49
SE total score	23	40	33.13	4.52

EORTC QOL-30 results are distributed as follows (Figure 2):

Figure 2. EORTC QLQ-30.



4. FUTURE RESEARCH DIRECTIONS

As this is a preliminary study, the data available has some limitations. First of all, we have conducted only descriptive analyses of the data from which only the initial distribution of the variables in the sample (anxiety, depression, body image, self-esteem and quality of life) and their starting levels can be deduced. At present, there are no repeated measurements in time which would enable the real impact of the project to be assessed and the existence of significant changes in the variables to be considered. In order to obtain generalised results it would be helpful to increase the sample which is rather small at present ($n = 24$). In future, it would also be important to extend the variety of diagnoses so that the results obtained can be better generalised.

Lastly, it would be interesting to extend the assessment of the impact of the project from the patient involved to her family. At present, qualitative observations and clinical feedback demonstrate a lower level of stress and tension expressed by caregivers as well as a climate of greater harmony and positivity in the days following the “Salute allo Specchio” (“A Reflection of Health”) meetings. These aspects certainly deserve further investigation from both an empirical and a research point of view.

5. CONCLUSION/DISCUSSION

Based on previous literature, we expect the “Salute allo Specchio” (“A Reflection of Health”) project will reduce the levels of anxiety and depression, improve perception of body image, increase self-esteem and have an overall positive impact on patients’ quality of life. In addition, the active participation of psychologists and the staff involved (voluntary workers, doctors and professionals) in the groups of each cycle provided the opportunity to observe in vivo the extent that meeting with other women going through similar experiences created a secure context for the patients; they shared their feelings and thoughts and received support. These elements contrasted with the isolation and solitude that cancer patients often experience in their daily lives.

Finally, the ambition of this project is to become an integral part of medical treatment for oncological patients and be a useful tool to favour compliance with the therapies to promote faster adaptation to the condition of this illness.

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