

The unmet needs of women with breast cancer: a qualitative research

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Abstract. *Background and aim of the work:* Breast cancer (CM) is the most commonly diagnosed form of cancer in Italy and the most common malignancy in women (25%) with 53,000 new cases. This disease affects all age groups (1 in 40 women <49 years, 1 in 20 between 50 and 69 years, 1 in 25 between 70 and 84 years). The percentage of patients diagnosed with cancer within 5 years of diagnosis is higher than for other cancers, and this conviction rate in these cancer patients has increased, leading to an ever-improving level of attention. The research aims to understand the main needs of women with breast cancer, compare them with those reported in the literature and in particular to identify which of these are still unsatisfied. *Method:* The study is based on the use of the narrative interview conducted by the Case Manager, in the Breast Unit of Melegnano (Milan), selected with a sampling of convenience. The participants who joined the research project were 12 women with breast cancer, aged between 40 and 60, who are in the active treatment phase of the disease. *Results:* As highlighted by literature, various unmet needs have emerged, afferent to well-defined areas: emotional health, continuity of care, information, adverse effects, educational strategies, economics, information and social support. The study showed that, the needs that are most unsatisfied relate to the information area and the psychological area. *Conclusion:* The interviews conducted underlined the importance of the role of the Case Care Manager as a facilitator of the disease path that patients are experiencing both in terms of the clinical and psychological aspects but also as a support in managing daily life. future research should investigate the role of the Case Care manager in meeting these needs. (www.actabiomedica.it)

Key words: Unmet needs, breast cancer, Case/Care Manager Nurse, narrative interview

Introduction

Clinical care pathways for women with breast cancer

According to what was published by AIOM and AIRTUM in 2019, breast cancer (BC) is the most frequent tumor in Italy and is the most frequent malignant neoplasm in women (25%) with 53.000 new cases. This disease affects all age groups (1 in 40 in women <49, 1 in 20 between 50 and 69, 1 in 25 between 70 and 84). On average, for an Italian woman, the risk of getting sick in the course of life is 13%: about 1 in 45

women gets sick by the age of 50, 1 in 19 between 50 and 69 years old, and 1 in 23 women between 70 and 84 years old. As for survival, 5 years after diagnosis, it is equal to 87% and is rather homogeneous among the different age groups: it is equal to 91% in young women (15-44 years), 92% among 45- 54, 91% between 55-64, 89% between 65-74, and 79% among over 75.

The percentage of breast cancer survivors 5 years after diagnosis is higher than that of other cancers and this means that the coexistence time of these patients with the disease is consequently increased, requiring

more and more attention to the needs of these women from health professionals (1). Breast cancer requires, from the care point of view, a path that accompanies women from the moment of diagnosis to the end of therapy, through the assistance's phase, continuing then with follow-up checks' phase (2). The approach that has been proved as the most appropriate is the Breast Units (European Commission, 2006). They are multi-specialist units that represent a model of assistance in the prevention, diagnosis and medical and surgical treatment of breast cancer. In Italy, on 18th December 2014, the State-Regions agreement was signed for the establishment of the Breast Units (3). The ministerial document approved on that occasion defines, in fact, the essential requirements for the diagnostic-therapeutic pathways in the Breast Units. The Breast Unit represents a model of assistance in the screening phase, clinical-instrumental diagnostics in the treatment and psychophysical rehabilitation of women with breast cancer, which the management of the patient's path is entrusted to a multidisciplinary group of dedicated professionals with specific experience in the breast sector.

The Breast Unit therefore functionally brings together all the operating units and services that are involved in the diagnosis and treatment of breast disease: radiodiagnostics, dedicated surgery including reconstructive surgery, pathological anatomy, oncology, radiotherapy, nuclear medicine, pharmacy, medical genetics, physiotherapy, psycho - oncology and palliative care. The presence of surgeons, radiologists, pathologists, oncologists, radiotherapists, nurses, radiology technicians and data managers must therefore be ensured in the Breast Unit (3). Nurses in the Breast Unit (Nurse Case/Care Manager) must also have specific training regarding the pathology, diagnosis and treatment of breast cancer to ensure assistance, education and support for the woman throughout the therapeutic path. Nurse Case/Care Manager, is present both when the diagnosis is communicated to the patient and when the treatment program is discussed and is a reference for the client and for the caregivers, even at the end of therapy, regardless of the stage of the disease.

Therefore, by consulting the guidelines on the organizational and care methods of the network of

breast care centers issued in 2014, it is deduced that it would be essential to include the Nurse Case/Care Manager (NCCM) in each Breast Unit. The work of the NCCM contributes significantly to the well-being of the patients, as it provides psycho-social support, education and training and this helps them to meet their needs, allowing a reduction in psychological morbidity, increasing levels of self-efficacy and of coping, with a positive impact on the quality of life (4). In the study of Fang and Coll. (2018) the NCCM is described as a fundamental figure in the care path of women and could be the figure responsible for planning interventions aimed at satisfying the bio-psycho-socio-relational needs of the patients, becoming a stable reference for patients. Despite this, from a research published in October 2019 in the national newspaper "La Repubblica" (5), and conducted by the SWG Research Institute (6), it appears that one in three women with breast cancer is not actually treated in a Breast Unit, is not followed by a multidisciplinary team, resulting in dissatisfaction and concern related to the disease path, especially because the woman, during the therapeutic path, meets a multiplicity of needs, some of which remain unsatisfied.

Women with breast cancer's needs

Despite the progress made by science regarding breast cancer pathology, allowing the improvement of the prognosis with less invasive and more tolerated treatments and despite the birth of Breast Unit operating units dedicated to the total care of women with breast cancer, there are still many bio-psycho-socio-relational needs that can be unsatisfied.

We can summarize the needs of women with breast cancer in some main categories: physical or adverse effects, relational, psychological or emotional health, information, education, social support, economic and continuity of care. There is in particular the need for support and / or social support, the fear of relapse, needs related to physical symptoms such as alopecia, pharmacologically induced menopause, needs related to the sexual sphere, needs related to anxiety and depression (7). In particular, scientific literature highlights various needs that are still unmet: - emotional health: dysfunctional coping strategies and fear of relapse (1, 6, 8-13); - continuity of care: from access

to follow up (14, 15); - relationships: body image, intimacy and sexuality (16); - social support: fear of social isolation, need for emotional support (17); - economics: forced abstention from work (18); - information: linked to the diagnostic-therapeutic process, complications, side effects of therapies and pathology (6, 19-22); - adverse effects: related to the disease and related treatments (23);

- educational intervention: that can be used at any time regardless of age (24). It therefore, need for educational plans aimed at adopting a correct lifestyle to prevent relapses or the onset of new pathologies. These researches documents that these needs do not all emerge at the same time, but they manifest themselves at different times according to the stage of the disease in which the patient is (23). Initially, the patient manifests physical, information needs related to emotional health and continuity of care; subsequently, needs related to the need for social support, financial worries, relationships and the need for educational plans linked to correct lifestyles to be adopted to prevent relapses or the onset of new pathologies arise. Furthermore, there is a difference between the needs expressed by a young woman and those of an elderly woman: the young woman expresses needs related to the change of her body image while the elderly expresses needs related to the family, her role and the fear that her family members may inherit this pathology (25). Finally, there are further differences based on the country of residence, in consideration of the free treatment and the quality of health services (6). In conclusion, it emerged that women with breast cancer manifest bio-psycho-socio-relational needs that continue to be unsatisfied, which decrease physical tolerance to the disease and related treatments (1). Furthermore, the presence of unmet needs negatively affects the quality of life and the perception of the quality of care (22). From these results primarily arises the need to pay more attention to understanding these needs in the patients' life stories.

Aims

As highlighted by literature, various unmet needs have emerged, afferent to well-defined areas: emotional health, continuity of care, information, adverse

effects, educational strategies, economics, information and social support. The aim of this research was to understand deeply what the unmet needs of the patients were. This led to a research aimed at investigating which of these needs were unmet in women with breast cancer belonging to a Breast Unit in Italy.

Method Research design

The project is a single-center qualitative study.

Setting

The study involves women suffering from breast cancer, in active treatment, belonging to the Breast Unit of Melegnano (MI), selected with a sampling of convenience.

The Core Team includes dedicated specialists in possession of the requisites of training, experience and updating: radiologist, pathologist, breast surgeon, plastic-reconstructive surgeon, radiotherapist, medical oncologist, nurse, psychologist, physiatrist.

A Clinical Pathway is adopted in the Breast Unit and shared by the members belonging to the Core Team who guarantee its drafting, application and updating, in accordance with the knowledge and clinical guidelines of reference, referring to the most updated versions of the Guidelines AIOM, ROL and FONCaM (AIOM, 2018 - FONCaM, 2003 - Eusoma, 2000).

The multi-disciplinary Core Team guarantees the quality and appropriateness of the services provided, ensures continuity and timeliness of assistance throughout the entire process through the joint assessment of cases.

Recruitment of participants

The project aimed to enroll, in the months of January and February 2021, 20 women with breast cancer aged between 40 and 60 years, who were in the active treatment phase.

The number of women is based on an estimate of the people who entered the Clinical Pathway of the Melegnano Breast Unit in the same time period the previous year.

The age group of the patients was chosen on the basis of epidemiological criteria that show that breast cancer is more frequent in this age group than in other ages (26).

Furthermore, the active treatment phase was chosen because literature suggests it is the phase in which unmet needs are most manifested (27).

Ethical considerations

Project approved by the Milan Area 1 Ethics Committee, Experimentation Register no. 2021 / ST / 011.

Data analysis and instruments

Using the phenomenological-hermeneutic paradigm, a patient-centered approach was adopted (28) emphasizing the importance of individuality, interpersonal relationships, the experience of illness as a significant part of assistance. This model uses relational-quantitative tools that help the professional to provide assistance based on the perspective of taking care of the patient (to care) in a perspective of humanization of the sick person, as an expert in illness and sickness. The narrative interview was chosen as a qualitative tool that aims to understand the patient's point of view, the vision of his or her experience of illness and the meanings he attributes to it (29). The narrative interview therefore creates a communication in which the NCCM is activated with an attitude of deep understanding, empathy, towards the other person, who is helped to expose his or her problem and with whom he can share reflections, taking care not to influence the response. The interviewer, in this case the Nurse Case/Care Manager, places himself in front of the assisted person with an attitude of genuine interest, with an attitude of respect, empathy and understanding, without prejudice, encouraging the suffering person to express himself, asking a question stimulus "what do you feel the need at this moment?"

With a prior written consent, the audio recording of each interview with the NCCM was literally transcribed by the research team. The qualitative data were then subjected to the a research tool used to determine the presence of certain words, themes, or concepts within some given qualitative data. Using content analysis, researchers can quantify and analyze the presence, meanings and relationships useful to identify the needs of the woman.

Results

Participants

12 women aged between 40 and 60 took part to the study, as required by the pre-established inclusion criteria. Unfortunately, the current situation linked to the Covid-19 emergency has caused a reduction in the number of participants compared to the predetermined amount (20 women). In particular, 6 patients did not feel comfortable staying in hospital beyond the necessary time for therapy and / or medical visits and 2 women refused to participate in the study when they were informed that the interview would be recorded. The average age of the participants is 52.58 years. If we divide participants into age groups, 25% of women belong to the age group between 40 and 50 years and the remaining 75% to the age group ranging from 51 to 60 years. 8.33% of the interviewees are unmarried or do not have a partner.

Furthermore, 8.33% of the women examined still have no children. 83.33% of the participants have a stable job and the remaining 16.67% are in early retirement.

1. Needs of psycho-emotional-spiritual support

The first area of content concerned the needs for psycho-emotional-spiritual support. This category includes four three dimensions that have helped to define a picture of emotions that accompany women from the moment of diagnosis along their journey within the Breast Unit: 1) the need for psychological support; 2) the spiritual need; 3) the need for comparison with people who have had the same experience; 4) the need to feel less pitied by others.

1.1 Need for psychological support

3 out of 12 interviewees refer they felt need for psychological support. In absence of a specialist, some women have relied on the NCCM. "Yes, at the beginning. At first I thought that... I was told that I would have psychological support. Then I was always told: "later, later, later", I have had psychological support from the NCCM! (cit. interview 1). "So I thought about it at the beginning of my illness: "why did it happen to me? with moments of despair. Because then I had metastases to the bones, and I think they can also reach the lungs so when I

think about this I feel overwhelmed by these thoughts and I need to share these things with a specialist” (cit. interview 6). “There it is, in that moment I found myself alone, that’s why I decided to go to the psychologist, because that is to say, I found myself alone in the midst of everything ...” (cit. interview 9).

1.2 Need for spirituality

Only one woman spoke of spiritual need, while the other women do not seem to have expressed this need. *“No honestly. I somewhat envy those who have faith. Because I have nothing. Everyone is made in their own way. You cling to something else ... That is, if I get well it will certainly not thanks to the candle lit” (cit. interview 7).*

1.3 Need to deal with people who have had the same experience

6 patients refer the need for women to relate and dialogue with women who in turn are facing or have already faced their own treatment path. *“Not with those who are experiencing it but with those who have won it! And then you know, to let those who have experienced these things, speak to those who also understand how they have faced them. I know very well that we are different, each of us faces it in a different way, but I would like it” (cit. interview 3).*

“I would like to compare myself” (cit. interview 4).

“Yes, it’s good, because then you realize that there are those who are actually worse, so it’s not that bad ... then there are those who are obviously better, who have had smaller, lighter things, here, I’m not going to subscribe to a Facebook group. I found out, I did the pre-admission, I was talking to a lady, or you know, when you are in the waiting room it’s nice!” (cit. interview 12).

1.4 The need to feel less pitied by others

5 out of 12 interviewees expressed the need to feel less pitied by others *“Instead of continuing to say poor girl, poor girl ... and then do nothing ...” (cit. interview 2). “That is, even when they tell me, my cousins send me messages who are all very worried and they say to me – you are very strong – how do you do it? And I answer: I mean, guys, I have to, that is, I don’t have an alternative” (cit. interview 3). “... This feeling of being pitied! and I don’t like it! “ (cit. interview 4). “I have a disease, I keep it and*

I don’t like that you tell me poor thing” (cit. interview 9). “Don’t worry! I have always reassured everyone, my husband, my son when they came to visit me in the hospital “ (cit. interview 10).

2. Information needs

With reference to this need, 4 sub-dimensions have emerged: 1) the need to have more information on the diagnosis; 2) the need to receive more information on the future conditions; 3) the need to receive more information on the exams they are subjected to; 4) the need for more explanations on treatments.

2.1 Need to receive more information about the diagnosis

5 out of 12 women show the need for information on the diagnosis of cancer that has affected them. *“You find yourself in this situation as an ignorant because I do a completely different job ..., you stay at home and try to reassure yourself but you always have this ignorance on the subject, that you ... that is, it is never enough in our opinion. That’s why I need more information, but for me, to be calm! “ (cit. interview 7). “To know everything in this way at least my family too, so at least I can explain everything to them. Everything that concerns my illness ...” (cit. interview 11). “Okay, they explained to you well, well, well, well. Yes, they tell you: it is this, it is not this, positive lymph nodes, the third degree one, words that one... too many technicalities! Why then does a thing do? He goes on the Internet, to look, and then in reality he doesn’t. On the other hand, if the doctor explains it to you a little easier, maybe you don’t need to go and search on Google what the third level is” (cit. interview 12).*

2.2 Need to receive more information on the future conditions

8 out of 12 interviewees expressed the need to have more information about their future conditions: *“I would have liked that the first visits with the doctor, the oncologist ... had explained me better what I was going through, not ... I was told” (cit. interview 1). “You must tell me what percentage I have of being able to have a recidivism” (cit. interview 2). “I have a question mark about the intervention in the sense that I know that there will be an intervention and that based on how the therapy will go, they will evaluate what type of intervention to do. Here is this stuff, here I have it a bit nebulous” (cit. inter-*

view 3) *“More than anything else on the resolution, on the evolution of the therapy, the effectiveness of the therapy, at what point I am and the resolution ...”* (cit. interview 8).

2.3 Need to receive more information about the exams

From the interviews it emerges that 5 out of 12 women feel the need to receive more information about the exams they were doing *“I told her: tell me what you see in the plate at this point, that I am no longer understanding a damn thing! I told him, actually. He tells me: I can't tell you anything”* (cit. interview 4). *“Actually, precisely on medicines, here ... before I was a P, but they tell you that it is a drug that tends to block ... But then it ends here, even with chemo, doctors tend to say who keep the disease under control... then maybe I want to know more, but it is normal”* (cit. interview 6).

2.4. Need to have more explanations on treatments

4 out of 12 interviewees declared that they needed more explanations on the treatments carried out *“That is, I got upset immediately and he said to me: now don't worry, now we do this that absolutely does not affect the type of path we have decided to do with you, so now you don't worry and then we'll talk about it. So that is, he didn't explain it to me because most likely it wasn't even the right time ...”* (cit. interview 3). *“So, there, I always relied on doctors and I always did what they said, however, no one actually explained what we were going to do. In the sense, then maybe I was wrong not to ask what it is for.”* (cit. interview 12).

3. Financial needs

The diagnosis of the disease has a heavy impact on women's lives, including from an economic point of view. This need emerged in 5 out of 12 women. *“Finish paying the mortgage, so the house isn't totally mine yet, so if I was thinking about death, no, so when I, if I die, will I have time before my death to sort out all my things? From this point of view I have no financial problems but I am a woman who, in any case... I am the head of the family, and so incomes are only mine.”* (cit. interview 3).

Women express the need to be guided in fulfilling the bureaucracy necessary to obtain the benefits provided for by Law 104/92 which protects sick people and their caregivers, they would also need to know with certainty what benefits they are entitled to and how to

benefit from them; they also need indications on how to obtain exemptions from health insurance tickets *“I just don't even know where to start with these things.”* (cit. interview 3). *“At the beginning I paid for the exams because they had not given me the exemption yet. Then I inquired about the invalidity through a patronage, then I heard the general practitioner.”* (cit. interview 6). *“Without talking about accompaniments or sensational things or salary, however, even a small contribution could help... Yes, then it's such a complicated speech. ... More than anything else because asking for permission to accompany me to visits a few times (the family member) cannot do them even if he wants to. Because he asked for permission so he can't work overtime, there are hours left on his paycheck at the end of the month.”* (cit. interview 7). *“I had to make the appointment myself here in the hospital, I can't afford it!”* (cit. interview 5). *“I chose this wig, and I spent 400 euros!”* (cit. interview 3).

4. Socio-relational needs in family

For the interviewees it is important to maintain an active role in their family, feeling reassured and not being left to themselves makes women feel less “sick”. The sub-categories that emerge in this area are: 1) need to be more reassured by family members; 2) need to feel more useful in the family; 3) need to feel less abandoned to themselves.

4.1 Need to be more reassured by family members

Only 2 out of 12 interviewees reveal the lack of family support they would have desired and that some family members do not show *“No because she never asked me anything... Maybe I would have expected a question from her... that is: why do you wear a wig?”* (cit. interview 4). *“No, because anyway listen to me, you don't understand how these teenagers are so selfish about their situation that they see you lying down and therefore you are always lying down, what do you want from our life? Always lie down! So this makes me suffer!”* (cit. interview 5).

4.2 Need to feel more useful in the family

4 out of 12 women expressed the need to feel more useful in the family *“I am very tired. I am physically tired, more than I have never been and consequently when I come back from the hospital or when I come home I am no longer able to do what I usually did, I am so tired that I only lay down on the sofa”* (cit. interview 5). *“I'm*

getting crazy! Yes, because I live days that are useless! Of course, I spend the whole day vacuuming. What I did before...waking up my daughter, before feeding the dog, getting dressed and going to work, taking my daughter to school, that is, my life is really on a break..." (cit. interview 7). *"Basically...my son took me on Saturday and did my jobs, last night he put the washing machine, he hung my clothes..."* (cit. interview 11).

4.3 Need to feel less alone

3 out of 12 women, in fact, expressed the need to feel less abandoned to themselves *"I find it hard to support myself, because sometimes I start crying and I never finish..."* (cited interview 2). *"There are moments when you are particularly in crisis, when you feel alone!"* (cit. interview 4). *"Precisely that is, I found myself alone in the midst of everything... yes, (the family member) was close, the only thing is that I was supporting him!"* (cit. interview 9).

5. Needs for assistance and care

The needs affecting this area are those related to the need to control symptoms (eg. pain, nausea, insomnia), to be helped in the main activities (eating, dressing, going to the bathroom). A major topic in oncology is coping with symptoms due to the side effects of therapies in addition to those related to the neoplasms.

It is difficult for a woman to accept the diagnosis of breast cancer and suffer the consequences, but it gets even more difficult to live with the symptoms of the disease and the therapies.

4 out of 12 women have expressed this need *"So all this work of things that you always doubt what are they introducing to me? Definitely for my good because in any case the national protocol provides this... In this case I have always, always, always said that after the therapy I had burning in my eyes, a tiredness that took over my ocular part, all of it, a burning sensation, general burning. I've always been told it wasn't related to therapy but I don't know."* (cit. interview 5). *"My main sickness is mouth problems and I also told the doctor about it. And then these swellings that come to my stomach, even there, I feel swollen. Okay, they gave me medicines for nausea but I have never took them. I take omeprazole and also paracetamol"* (cit. interview 6). *"The nausea, yes, I take what they prescribed to me to control the nausea, but they only manage to stop it for a few hours"* (cit. interview 8).

6. Communication needs

The needs of women in this area are relevant so that patients can feel an active part of the care process, be reassured and considered as people and not as objects to be treated. The following sub-categories emerged: 1) need to be more involved in therapeutic choices; 2) need for the information provided to be more understandable; 3) need for doctors to be more sincere 4) need to have a greater dialogue with doctors. 5) need for reassurance from doctors.

6.1 Need to be more involved in therapeutic choices

3 out of 12 interviewees showed this type of need, highlighting poor education and involvement with respect to treatment, side effects and possible advice and interventions to prevent them *"I also hope in the future if someone could listen to me a little more carefully, because I will also explain the pain in the arm that I have now, I manifested this pain more than three months ago saying that at night I cannot close my hand and it was a bit unheard. Then as I repeat I was tired of complaining. This is because if I expose you a problem and you belittle everything I said, I don't even tell you anything anymore, and then I decide to pay for a talking about my problems with a psychologist"* (cit. interview 5). *"I still don't understand what I'm doing, in fact I'll have to tell the doctor too. I feel very swollen, I wanted to ask if anything could be done in the meantime about this swelling. I drink and I pee, but I really feel like a ball"* (cit. interview 8). *"Same thing as before, if you had known, you know, ask some questions, ask something ..."* (cit. interview 12).

6.2 Needs of having more understandable information

4 out of 12 interviewed ask medical and health personnel for more understandable information *"Difficult difficult words...that is, I'm not a doctor!"* (cit. interview 2). *"For example, I noticed one thing, when I have chemo I see all those little bottles, I would like to know what they inject me before that medicine but I don't ask because I don't want to be bothering. I understand it a little in what nurses say: we are putting this, this, that other in the mood ..."* (cit. interview 6). *"It is a bit linked to the organizational problem, which are always in a hurry, very in a hurry."* (cit. interview 8).

6.3 Need of more honesty from doctors

At this juncture, the need to have a sincere relationship with the doctor is expressed, be it the oncologist, the general practitioner or the surgeon. In the interviews it emerged that 2 out of 12 women expressed the need for doctors to be more honest with them *“you have to be honest though! I’m 40, I’m not 15!”* (cit. interview 2). *“But I would always prefer that they are sincere”* (cit. interview 11).

6.4 Need to have a greater dialogue with doctors

6 out of 12 respondents feel this need as unsatisfied. The main reasons and shortcomings that emerge from this modest dialogue with doctors are mainly linked to two aspects. The first concerns the excessive frankness and coldness in the communication of information *“I felt disrespect more than once on the part of a doctor. Why do you have to get them! You have to! You have to! You have to! Well explain to me!”* (cit. interview 2). *“To make you understand that sometimes it is not so much the disease itself, it is as you say that maybe, the same sentence said with a different tone or with a smile or with a hand on the shoulder”* (cit. interview 5).

The second aspect refers instead to the need to receive the richest and most complete information. *“So I write to myself all my doubts every time, but often doubts or pains are not taken into consideration, it depends on the doctor. Because... those who care for me know me and I feel they pay more attention. The moment of replacement has happened several times that I was replied: this is not my competence... Yes, sometimes then I felt, I was even ashamed to say my pains and my feelings”* (cit. interview 5). *“Maybe they told you something more. I don’t know if it’s because maybe they are unbalanced on something that maybe doesn’t come true, I don’t know. But maybe something more”* (cit. interview 6).

6.5 Need for reassurance from doctors

From the moment of diagnosis, 5 out of 12 women have expressed the need for reassurance from medical staff, as a figure that more than any other is seen as a reference to mitigate the anxieties and feelings of loss that pervade them. They feel a sense of abandonment when they feel neglected by the care team *“I always talk about the beginning of the blow, which was given to me, who told me: You have a tumor, you must do this! I was*

not reassured by the oncologist” (cit. interview 1). *“I have an anxiety ... afraid, I’m afraid!”* (cit. interview 2). *“I had that phase of... loss... because then I didn’t feel like... talk maybe ask... I’m afraid of the answer! And so I was left like this ... in the uncertainty of ... of a situation that would end badly!”* (cit. interview 4). *“I would like them to tell me what I was told at the beginning, that the result will be certain”* (cit. interview 8).

Discussion

As far as the literature, needs related to the psychological or emotional health sphere (1, 6, 8-13), those relating to information (19, 20-22, 30) and those of communication (24) are the needs most manifested in the active treatment phase. As stated in literature, needs related to the sphere of relationships (16) and social support (17) are also found in the research carried out. In particular, it emerged that patients who are in the active treatment phase, in an age group from 45 to 55 years, develop greater needs related to the adverse effects related to the pathology and related treatments followed by the spheres of emotional health’s needs., the social the economic-financial support’s needs (18).

Academic literature documents that these needs do not all emerge at the same time, but manifest themselves at different times according to the phase of the disease in which the patient is (23) and in relation to the related interventions that aim to prevent the onset of further problems and new pathologies (24). Initially, the woman manifests physical, information needs related to emotional health and continuity of care; then, needs of a social support, financial worries, relationships and the need for educational plans linked to correct lifestyles are adopted to prevent relapses or the onset of new pathologies arise. The narrative interview highlighted the poor quality and quantity of information, the lack of clarity and the superficial way they were given. In some cases information is too direct, or women felt as they were not taken into consideration. Thus generates a sense of loss and fear. Some patients underlined the lack of coherence between the information received from the clinicians who followed them along the treatment path as well as the lack of explanations when the timing of the therapy cycles changed

compared to what was planned at the beginning of the treatment.

In particular, 8 out of 12 women further strengthened the concept of wanting to receive information mainly related to a future life perspective, highlighting how the sense of uncertainty is one of the major sources of concern that characterize this phase of the disease. The need for information is therefore very important, as it provides the patient, through knowledge, with the tool to take an active role in the management of her own state of health. From the analysis of the needs regarding the emotional sphere, it is clear that women have expressed the need to deal with people who have lived the same experience.

Half of the women have expressed the desire to be able to freely express their fears and anxieties, and to confront themselves with people in the same situation to find relief in the words of those like them who are facing the same path and are felt emotionally close. Furthermore, the interview confirmed the need to receive psychological support from specialized and trained personnel. At the same time, the assisted patients stated that this need was then satisfied along the therapeutic process, sometimes by the figure of the NCCM, as a trusted figure who accompanies them along the way. In other stories it has emerged how women have found in themselves the resources and strength necessary to react and fight to take their lives back. In 5 other situations, the patients expressed the discomfort of having to face mechanisms of commiseration and overprotection towards them, on the part of those around them, who, albeit unconsciously, tend to assume attitudes and words of compassion.

The doctor - patient relationship was fundamental in the treatment process. Women want to be more informed about the disease that has affected them and about the possible therapeutic choices that are presented to them, with the expected results and possible side effects, asking the doctor for coherent and understandable explanations. In this situation, the patient acquires the knowledge and the tools necessary to take an active role in the management of her own health, leading to an improvement in terms of her quality of life and satisfaction. Half of the patients involved therefore request the possibility of having a better dialogue with their caregivers. In this circumstance, the need arises

to seek support from the healthcare staff, which at that moment represents a concrete help in terms of listening and reassurance. Breast cancer and the resulting treatments, whether surgical or therapeutic, involve enormous physical and psychological levels.

In the narrative interview for 5 women doubts and uncertainties are highlighted more than what they are experiencing, followed by 4 women who complain of inadequate education in the management of side effects and on how to prevent them, also regretting the lack of attention from medical staff as far as their problems are concerned. Hence the need for women that their needs are taken into consideration and not diminished. The person who undertakes this path needs explanations and truths, as well as reassurance, which he consciously knows cannot be absolute certainties, but which serve to reach a level of inner tranquility such as to give him the necessary strength to continue to continue the path of illness. These answers are expected by the doctor, the one who at that moment represents the figure who more than others can fill insecurities.

Women affected by breast cancer live in situations of profound crisis due to the breakdown of the equilibrium achieved in their lives, also with regard to the family sphere. 4 of them focus on the discomfort of feeling of little use in the family context, starting with the performance of normal daily activities, to which they can devote less time and energy, to the insecurities in being able to take care of their children and to the difficulties in relating to their husbands affectively and sexually due to the bodily changes undergone. 3 interviewees then confessed to experiencing a sense of abandonment and loneliness in facing their emotional suffering and 2 of them expressed the need to receive reassurance from their relatives. Very often it happens that a family member is not emotionally able to support and reassure the patient, but on the contrary, he himself manifests the need for psychological support because he is unprepared to cope with the dynamics that the disease generates in the context of daily life. It can therefore be said that breast cancer is destabilizing for women who are affected by it, with repercussions in the family context, from which patients would expect encouragement but which is often caught unprepared.

As regards the relational aspects aimed at the needs of social support, what emerged in the litera-

ture is therefore confirmed, with fear of social isolation and the need for emotional support (17). Concerns regarding the diagnosis of the disease were also raised through the narrative interview, which took over the lives of women, especially aimed at family members who accompany them along the therapeutic process and who are also forced to take time off from work. From their stories it was possible to deduce how the impact of the diagnosis and treatment of breast cancer is very relevant in terms of workplace. Some of them, being very active women from a working point of view, are forced to devote a large amount of time required to care, followed by physical and psychological discomfort that forces them to prolonged absences. At this juncture there is the need among the patients to receive economic - insurance information related to their disease. Women and their families feel the need to be made aware of their rights and to be oriented in the simplest way in the paths of bureaucracy, in order to make the most of the facilities provided for by the regulations. The need to receive financial support has also emerged and this need may also be linked to the uncertainties related to a future condition and to the costs associated with the disease.

The unwillingness to receive help with regard to the performance of daily living activities is confirmed, probably due to the fact that the age and the phase of active treatment in which they are, did not compromise the residual autonomy of the patients who is still able to fulfill their daily lives independently. In fact, the need of these women to come back to a normal existence as soon as possible, to get the possession of their lives and to achieve a new balance has emerged.

They declare the desire to maintain an active life, which means moving, carrying out household chores, playing sports, compatibly with health conditions, but also returning to a working and social life. They aspire to share the days and future planning with family and friends. Finally, a very important aspect is inherent in the physical changes that the disease has brought about. The more or less demolishing surgical treatment and the side effects of adjuvant therapies, in addition to involving transformations of the body image, also affect aspects related to physical perception, to which the body requires time and energy before returning to face daily activities. The experience of surgical treat-

ment of breast cancer is a test for women and difficult to deal with because it always involves, even when conservative, a change in their physical perception that can also have a psychological impact. It can be presented with the embarrassment of showing themselves to the point of having a hard impact on the dimension of the couple's intimacy. The stories of the women revealed that body image is an important factor in the context of breast disease. The pathology and its treatments can change the image of a woman in a more or less permanent way, from the loss of a part of their body, to the presence of scars, to hair loss, to changes in body weight, all elements that can create situations of discomfort towards themselves and those around them.

Conclusions

Breast cancer, with 53.000 new cases in 2019, is the most diagnosed cancer in the female population, accompanied however by a reduction in mortality and a constant increase in relative survival 5 years from diagnosis, thanks to advances in medical science, which have led to an exponential increase in available therapies with proven efficacy. Research has confirmed that the increase in life expectancy has brought with it a series of needs that sometimes remain unsatisfied.

In this initial framework and on the basis of these premises, we wanted to investigate which of the main needs of women suffering from breast cancer were still unsatisfied.

To achieve our goal we started from the literature, from which it emerged that women with breast cancer have different needs, some of which, despite the progress made in the medical field, remain unsatisfied. During the interviews it was clear how much the NCCM has been a support in overcoming the inconveniences that have arisen in the treatment process, whether they were psychological or informative, proving to be a resource that the women of the Breast Unit know they can draw on in meeting their needs.

In addition, the interviews conducted underlined the importance of the role of the Nurse Case/Care Manager as a facilitator of the disease path that patients are experiencing, both in terms of the clinical and psychological component. The NCCM seems

to be the health figure who has best been able to respond to the unmet needs of its patients, filling gaps that have arisen throughout the entire therapeutic process. The interview highlighted that understanding the needs and factors that influence the lives of women with breast cancer can help them prevent the onset of unmet needs. Thanks to the listening time dedicated to women, the NCCM has understood the unmet needs, demonstrating that it possesses not only clinical-care skills, but also communication and relational skills.

At this point it would be appropriate, with further research, to investigate the role, preparation and skills that the Nurse Case/Care Manager must have in order to respond to the problems of women with breast cancer.

The research has the limit of having involved a limited number of women selected with a sampling of convenience and therefore arises as purely exploratory research. Expanding the number of participants would allow to broaden the range of needs and requirements that did not emerge from this research.

The active treatment phase chosen for this research could also be compared to the needs of women in the newly diagnosed or follow-up phase.

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