

Experience of young women with breast cancer and mastectomized

Vivência da mulher jovem com câncer de mama e mastectomizada *La experiencia de la mujer joven con cáncer de mama y mastectomizada*

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ABSTRACT

Objective: The aim of this study was to understand the experience of young women diagnosed with breast cancer and mastectomized. **Methods:** This is a qualitative study with a phenomenological approach, grounded in Heideggerian framework. After being approved by a Research Ethics Committee, open interviews were conducted, guided by the following question: What was it like for you to have breast cancer and undergo mastectomy? A total of seven women aged between 18 and 35 years participated in this study. **Results:** Three thematic categories were obtained: The experience of being diagnosed with cancer; The experience of undergoing treatment in search of a cure for cancer; The experience of overcoming cancer. **Conclusion:** This phenomenon appears to be fraught with anguish and bewilderment of being-in-the-world with breast cancer, ignoring the fact that such a grim diagnosis may belong to the world of the young.

Keywords: Oncology Nursing; Qualitative Research; Women; Breast Neoplasms; Mastectomy.

RESUMO

Objetivo: O objetivo deste estudo foi compreender a vivência da mulher jovem diagnosticada com câncer de mama e mastectomizada. **Métodos:** Trata-se de uma pesquisa qualitativa com abordagem fenomenológica, fundamentada no referencial heideggeriano. Após a aprovação do projeto pelo Comitê de Ética, foram realizadas entrevistas livres, guiadas pela seguinte pergunta norteadora: Como foi pra você ter câncer de mama e ser submetida à mastectomia? Participaram da pesquisa sete mulheres com idade entre 18 e 35 anos. **Resultados:** Foram obtidas três categorias temáticas: Vivência da descoberta do câncer; Vivência do tratamento em busca da cura do câncer; Vivência da superação do câncer. **Conclusão:** O fenômeno revela-se permeado de angústia e perplexidade diante do estar-no-mundo com câncer de mama, por desconhecer que um diagnóstico tão sombrio pode pertencer ao mundo do jovem.

Palavras-chave: Enfermagem Oncológica; Pesquisa Qualitativa; Mulheres; Neoplasias da Mama; Mastectomia.

RESUMEN

Objetivo: Comprender la experiencia de la mujer joven con diagnóstico de cáncer de mama y mastectomizada. **Métodos:** Estudio cualitativo con enfoque fenomenológico, fundamentado en el referencial de Heidegger. Después de la aprobación del proyecto por el Comité de Ética, fueron realizadas entrevistas abiertas, guiadas por la pregunta orientadora: ¿Cómo fue para ti la descubierta del cáncer de mama y la realización de la mastectomía? Participaron de la encuesta siete mujeres con edades entre 18 y 35 años. **Resultados:** Emergieron tres categorías temáticas: Experiencia del descubrimiento de la enfermedad; Experiencia del tratamiento en busca de una cura para el cáncer; Experiencia de superación del cáncer. **Conclusión:** El fenómeno revelase lleno de angustia y perplejidad frente al estar-en-el-mundo con cáncer de mama, por ignorar que tal diagnóstico sombrio pueda pertenecer también al mundo de los jóvenes.

Palabras clave: Enfermería Oncológica; Investigación Cualitativa; Mujeres; Neoplasias de la Mama; Mastectomia.

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INTRODUCTION

The word cancer carries much stigma. There is greater fear when it comes to breast cancer as this is a part of the body valued by women, meaningful for their sexuality and identity in many cultures¹.

Breast cancer continues to be one of the main causes of death in women worldwide². In Brazil, mortality rates remain high, most probably because this disease is still diagnosed in advanced stages³. In 2014, 57,120 new cases of breast cancer were expected, with an estimated risk of 56.09 cases per 100,000 women⁴.

This is considered to be a complex disease that requires painful treatments and its cure is surrounded by uncertainties, thus having an impact on women's lives. This type of cancer is the most common among women, frequently affecting those aged more than 40 years, although an increase in incidence among younger ones has been observed⁵.

Breast cancer more frequently occurs in menopausal women when compared to younger ones. As it is considered to be infrequent, breast cancer in young women should be emphasized. Systemic metastases occur in 55.3% of cases among young women with breast cancer and in 39.2% of cases among elderly women, while the mortality rate is 38% in the former group and 33% in the latter⁶.

Many young women suffer the psychosocial impact of being diagnosed and they have more depression and worse quality of life than those who are middle-aged, due to the treatment effects, as breast removal causes negative feelings, especially in younger ones⁷.

The most frequent treatment used for breast cancer is mastectomy, which causes a number of changes experienced by patients who undergo this, as it is an aggressive surgical procedure followed by traumatic consequences for women's health and life⁸.

Breast cancer involves the taboo of being a "cursed disease", possibly causing disfigurement of body parts and suffering during treatment, as it affects the body/mind and spirit unit. Additionally, it is viewed as a potential stressor as it causes a number of changes in the life of both the women with cancer and their family. Aiming to improve their quality of life, these women need special nursing care that can see them through the changes occurring in terms of psychosocial aspects, so they can readapt to their living conditions.

In view of what has been described, the present study had the purpose of answering the following guiding question: What is the experience of young women undergoing mastectomy?

This study is justified by the need to give theoretical support to the development of adequate nursing care for mastectomized young women as this enables better conditions to cope with the situations experienced, while emphasizing the importance of providing humane care to these women and their family members in the process of adaptation to their new image through the active participation of nursing professionals.

Only women aged between 18 and 35 years were included in this study as they were not considered to be in population groups at high risk for breast cancer, assuming a hidden phenomenon could be observed.

The construction of knowledge about this theme becomes relevant as understanding the experience of young women diagnosed with breast cancer and mastectomized allows the phenomenon experienced by them to be observed, enabling an understanding of the experience and challenges encountered. By observing this phenomenon, researchers can also know the consequences of this experience and the possible existential conflicts faced by these women in their daily routine.

Thus, the present study aimed to understand the experience of young women diagnosed with breast cancer and mastectomized.

THEORETICAL-METHODOLOGICAL APPROACH

In view of the nature of the object of investigation, which focuses on the phenomenon experienced by young women with breast cancer, qualitative research was selected for this study, using Heideggerian phenomenology as theoretical framework.

Phenomenology has been an approach frequently used in studies performed in the area of Nursing, showing its restless nature as it attempts to understand the phenomena experienced by individuals in their daily life, including their complexity as well as each individual's particularities⁹.

Martin Heidegger's philosophical and theoretical framework was considered to be relevant to reveal the phenomenon experienced by young women who have been mastectomized. According to this framework, human beings are constituted under three perspectives in their routine: facticity, existentialism and decadence¹⁰.

The authorization to perform the present study was granted by the Professor Alberto Antunes University Hospital Department of Teaching. The research project was submitted to the *Plataforma Brasil* database and approved by the Alagoas Federal University Research Ethics Committee (CEP-UFAL) in accordance with the ethical and legal principles of National Council of Health Resolution N^o 466, from December 12th 2012. Data collection was subsequently conducted between October 2013 and January 2014. Firstly, the Nurse and Coordinator of the High-Complexity Oncology Center of the Professor Alberto Antunes University Hospital was contacted. She collaborated with the selection of participants among women cared for in this institution, indicating exclusively the young women aged between 18 and 35 years, diagnosed with breast cancer and submitted to mastectomy.

Women who met the inclusion criteria were approached and researchers explained the study objectives to them and invited them to participate in the research project to be performed. All of them accepted, totaling seven participants. Next, an individual meeting was scheduled for each, taking into consideration the

most convenient day, time and location for participants, when one of the High-Complexity Oncology Center's rooms was chosen for this purpose.

Prior to the interviews, in accordance with the ethical precepts recommended by the Human Research Ethics Committee, an Informed Consent Form was read and signed by all participants, thus confirming their agreement to participate freely and voluntarily after being guaranteed non-disclosure, anonymity, dignity, respect and equality of rights. Subsequently, the interviews began, aiming to understand the phenomenon and grasp its essence. The approach used enabled participants to answer the following question spontaneously and freely: What was it like to have breast cancer and undergo a mastectomy?

The interviews were fully recorded and transcribed. Josgrilberg's phenomenological framework¹¹ was used to analyze participants' speeches. Initially, each speech was read and re-read attentively to identify units of meaning and gather similar units. Finally, the units of meaning included in each speech were grouped together and compared to each other, indicating specific moments in the narration and connecting the meanings that were revealed. At this stage, the thematic categories emerged.

Aiming to maintain their anonymity, the first letter of pseudonym flower was adopted to identify each participant.

RESULTS AND DISCUSSION

Through the path followed to achieve the meaning of each participant's Being, the units of meaning of speeches showed the structure of the phenomenon studied, so that the results were grouped into the following thematic categories: the experience of being diagnosed with cancer; the experience of undergoing treatment in search of a cure for cancer; and the experience of overcoming cancer.

Therefore, the impact of being diagnosed with breast cancer as experienced by these young women represents the category that reveals the first findings of this study.

The experience of being diagnosed with breast cancer

In this thematic category, it was possible to reveal the way of *being-there* of young women submitted to mastectomy upon the diagnosis of breast cancer.

Through participants' speeches, it could be understood that, when finding out about the diagnosis of breast cancer, their existential universe began to be permeated by feelings that ranged from indifference to deep fear.

The condition of being young women did not enable them to awaken to the possibility of *being-in-the-world* as someone who has breast cancer. The majority reported having been taken by surprise because they were not aware that such a serious diagnosis could be made at such a young age:

[...] I was 23 and it took me a long time to get the diagnosis, I think almost a year, because at my age I thought it could never be malignant. (R.)

Thus, it can be observed that human existence is constituted of possibilities on which all its transcendence is based¹⁰. When transcending, young women with breast cancer are faced with the insurmountable fact of being diagnosed with cancer, thus experiencing a moment in which they suffer and consequently the denial of reality, which will hinder the beginning of treatment:

[...] but when I found out I began to cry, right at the beginning I said I wouldn't go through the treatment. (S.)

At that time I panicked, I said that the test was wrong, that the doctors were crazy. (R.)

Among the psychological stages of coping with cancer, denial of this disease represents the time when individuals do not believe the news they are receiving. This is a temporary stage that will soon be replaced by partial acceptance. At this stage, the transition from speaking about the reality of this matter at one moment to completely denying this the next moment is still frequent. When women reach the acceptance stage, facts begin to be dealt with according to these women's awareness of their possibilities and limitations¹².

Based on the reports, it could be observed that young women with breast cancer deny the reality which was forced upon them, they experience this denial permeated by feelings of despair and sadness as previously described.

Likewise, it could also be noticed that the meaning of young women being diagnosed with breast cancer is probably not associated with the meaning of this disease that older women usually have. Participants' speeches clearly show that this meaning is never fully achieved, as young women do not feel that they have cancer when discovering their condition.

I felt a tiny lump, but I thought it was because of the breast reduction I'd had. I didn't think that a disease like this could affect me. (O.)

When finding out they are a *being-in-the-world* with cancer, young women understand that having a disease like this is a fact that can cause disappointment, despair, deep sadness and fear. As a result, they experience anguish as reported below:

[...] then, when she (the physician) said, "it was what I expected!", to me it was like everything had just collapsed. (L.)

At that moment, I panicked. (R.)

When the doctor said to me that it was cancer, I didn't believe it, I burst into tears. I kept asking, "My God, why me?" (D.)

This different experience can cause the *being-there* to abandon herself in the face of the diagnosis of cancer:

Honestly, to me, this news was terrible, I saw it and I said I was going to do nothing. (S.)

These statements reveal distinct experiences. However, they clearly show that the young women with breast cancer who participated in this study felt the impact of being diagnosed with this disease, not only because of its severity, but mainly because this age group is not considered to be high risk for the onset of breast cancer.

It could be observed that the confirmation of a serious diagnosis with a strong stigma such as cancer is the initial stage experienced by women. Up to that moment, the Being who did not believe to be the victim of a disease shrouded by the "stigma of death" is taken by surprise with such confirmation. Consequently, this fact causes women to experience conflicting feelings.

Breast cancer represents a threat to their life and physical and emotional integrity. Therefore, being diagnosed with breast cancer causes women to experience the expectation of an uncertain future and a path full of obstacles, including the fear of death and mutilation¹³. In addition, they deal with intense and conflicting feelings that become part of their routine, such as fear, anger, uncertainty, denial and even acceptance.

As a result of the confirmation of the diagnosis of breast cancer, young women begin to experience negative and frightening thoughts, which exacerbate feelings of guilt and failure:

My mistake was that I didn't have a mammogram in the following year. Because they say we have to do it when we turn 40. That was my mistake! (crying) (L.)

The reports of these young women clearly show that the experience they had from the moment they were diagnosed to the beginning of the treatment included feelings of anguish, fear, uncertainty and mistrust.

In Heideggerian phenomenology, the feeling of anguish with death is the anguish "with" the most appropriate and invincible way, considering the fact that anguish is innate to human nature, part of the structure of the being and of the *pre-sence* that is put before oneself.

Certain feelings can be observed in women with breast cancer, as a result of the social imaginary of a disease that causes pain and suffering and that may be fatal. In this sense, cancer is among the diseases that cause the most fear and concern in the population, creating a stigmatized image of suffering, aversion and death¹⁴.

Still under the impact of the discovery, women experience doubt and uncertainty regarding the future. For the *being-there*, being diagnosed with cancer is an indication of death at first, as observed in the following speeches:

I often asked myself "My God, what now? What about the future?" (L.)

It's something you never want to hear about, because cancer [...] sometimes I thought "I'm gonna die, I'm gonna die!" (crying) (D.)

In this sense, women somehow transform themselves into a *being-for-death*, showing the emotional weakness experienced with the possibility of dying from a disease that carries stigma, as is the case of cancer. This weakness is very intense, especially because it is breast cancer, characterized as a mutilator that causes changes in body image, which often lead to feelings of depression and fear when facing the possible end of their life.

At this moment, it is essential to understand the feeling of living with breast cancer, as experiencing future uncertainties is a constant reality in the life of this Being, which often results from the fear of not being cured from this disease.

Feelings of hopelessness cause young women with breast cancer to experience future uncertainties, as they catch a glimpse of the long path of treatment against cancer, as discussed in the following thematic category.

Experiencing the treatment in search of a cure for cancer

Being aware that their condition of young women with breast cancer means facing the factuality of existence and being thrown into the world among other existing beings. In Heideggerian phenomenology, care is inherent in the existence of being human; as a result, young women with breast cancer require care in the quality of *being-in-the-world*.

The reports in this category indicate that, after being diagnosed with breast cancer, the *being-there* see themselves before a new reality and, in addition to reacting to the actions of others, they also define these actions while being afraid of how they will receive care to treat this disease and overcome it.

The search for care is sometimes permeated by the difficulties found in the service of health institutions, which includes excessive bureaucracy and a level of demand which is frequently higher than the resources available in the public health system.

It's not good to get there and she (the physician) says that you have cancer, then you bring a lot of documents and wait for 60, 90 days to begin chemotherapy? This time is terrible for us! (D.)

The meaning that young women with breast cancer attribute to this question is one of the difficulties encountered, because they realize they depend on public health services and feel helpless due to their need for care.

Once the search for access to treatment ends, they can focus on overcoming the difficulties they will have to face based on their possibilities.

The speeches reveal relevant observations about chemotherapy, where the possibilities found while dealing with different chemotherapeutic protocols stood out:

[...] I suffered at every session. My reaction to chemo was a lot of vomiting, body pain, headaches, and I'd lie in bed for seven days, no eating, nothing. (O.)

[...] I had a normal life, I exercised and went to a gym. I'd go for my chemo on Thursdays and on Mondays I'd already be back at the gym. (R.)

Feeling sick from chemotherapy was reported by participants. Oncological treatment through the administration of chemotherapeutic agents is characterized by the occurrence of adverse effects caused by changes made by these agents not only in tumor cells, but also healthy cells in the organism. Additionally, the severity of these effects depend directly on both patient and disease characteristics¹⁵.

It is believed that chemotherapy is feared as much by the majority of women, due to its power to have effects such as systemic toxicity, which can be manifested as alopecia, causing significant changes in their self-image.

Losing hair due to chemotherapy was an event experienced by all of them. The difficulty to go through this new stage of treatment could be observed:

But this moment was like the second most difficult, because seeing them cutting my hair... Look, it'd been a month since I had my hair highlighted, I was so vain, always fixing my hair. Then, a month later, I go back to this hairdresser to have this done to my hair. (crying) (L.)

When I saw my hair falling, it was very painful, at that moment I didn't even think about the disease, the only thing in my mind was the hair I was losing. (O.)

According to women's reports about hair loss, it could be observed that each Being experiences this process through a close relationship with their existence and peculiar way of *being-in-the-world-with-the-others*.

For young women undergoing cancer treatment, hair loss is a difficult stage to be overcome, including feelings that were more intense than those observed in reports about mastectomy:

[...] I wasn't afraid of losing a breast, I was afraid of going bald, go out on the streets like that and everyone staring at me and thinking I'm weird. Because I knew there was a breast reconstruction surgery! (R.)

The impact resulting from hair loss was due to its sudden occurrence and the fact that baldness is visible, which can expose the disease and affect women's self-esteem¹⁶.

Culturally speaking, hair is considered to be a feminine characteristic and women flaunt their long and beautiful hair¹. Therefore, the majority of them found it difficult to experience alopecia due to chemotherapy.

Throughout the treatment, young women experience the surgical procedure stage known as mastectomy. In the present study, all participants had undergone radical mastectomy.

The physical aspect of breasts has a direct relationship with the sensuality and vanity of a beautiful body, in addition to playing an important role in maternity, considered as relevant by women in modern society. Mastectomy is one of the therapeutic approaches experienced by the *being-there* with its resulting mutilation of the breasts. This mutilation has strong repercussion in their femininity, causing them to experience different emotional, physical and social consequences associated with body image¹.

The following reports reveal the difficulties encountered while experiencing breast cancer treatment:

[...] I need to look, I need to touch my body to know what happened, to be aware, because I need to live with this [...]. (L.)

He (the physician) said that I needed to have my breast removed, the one that had cancer, if I wanted to get well. This was awful for me! (S.)

After this moment, the body becomes somewhat strange to young women and, as a result, time is required for them to accept their new image.

Women submitted to mastectomy feel ashamed before society, as their body image is an essential factor to develop their self-image and to value them before others. Breasts are seen as a symbol of beauty, femininity and sensuality and mastectomized women show great concern for their body image. Breasts play a key role in their image and identity¹.

There are women who accept the loss of their breasts. However, this acceptance comes as a result of inevitability, the only way for the long-expected cure, i.e. believing that surgery is a possible cure, as described below:

I didn't think about surgery or what was going to happen, I only thought about getting rid of the tumor and taking it out, taking it out soon! (L.)

Despite the difficulty encountered due to the loss of a breast, young women have the misconception that it will no longer be necessary to worry about cancer, believing that the loss of this organ took the whole disease away with it and, as a result, all questions related to cancer would be under control. At moments like this, women require care from their family and health professionals to help them towards accepting and continuing the treatment, considering the fact that they are facing physical and social limitations, in addition to psychological changes.

With the onset of this disease, there is a shift in roles and women are often forced to let go of routine activities such as working and caring for their husband, children and home. Affective relationships are sometimes impacted, causing women to be socially isolated:

I was always studying and working, I was about to start working for a school of a friend of mine, so to stop my routine and see that I couldn't do the things I used to like doing the laundry, cleaning my home, cooking, because I was very nauseous [...] (L.)

While experiencing breast cancer, women become dependent, especially during the treatment and postoperative period due to adverse effects, requiring help to perform house chores that they could easily perform before¹².

This new phase requires re-adaptation to routine activities, because initially women tend to feel vulnerable and useless when dealing with both simple and more complex activities, something they used to do naturally on a daily basis.

The life transformation experienced by women with breast cancer is greater because it involves restrictions to social life, as in a shift of roles. That being who cared for everyone around her is the one who needs to be cared for at this moment. As a result of this disease, they have to quit their jobs and their home and social activities are restricted, contributing to the development of feelings of loneliness and depression.

The support provided by family and friends is essential to overcome conflicting feelings such as fear, anxiety and depression and it can provide women with optional ways of living, even with limitations. Additionally, family affection can help them fight against this disease, meet their needs and achieve greater acceptance and behavioral stability, as will be discussed in the following thematic category¹⁴.

The experience of overcoming cancer

After being diagnosed with cancer and, consequently, experiencing denial, women undergo the treatment, which is not regarded as simple. Although fear is always latent throughout the development of the disease, during treatment, young women seek to overcome their obstacles, accept breast cancer and mastectomy in its several stages and thus succeed in their search for rehabilitation:

And, above all, you have to do it like this, fight because, at moments like this, we understand that there is something greater, we can't just say, 'I'm surviving everything through my own efforts only!'. At moments like this, we find greater strength, when my body ached a lot, I thought I was not going to make it, but I did it! (L.)

At the end of the process, young women seek something to hold onto, an inner trust that they will overcome this difficult time in their life. In view of the reports, it can be inferred that these women with cancer experience very complex feelings, in an attempt to understand the reason for their disease and with the purpose of adapting to this situation and coping with this problem.

However, some of these women find out that they are strong, adopting strategies such as faith and hope. Despite the impact of being diagnosed with cancer at such an early age, they seek new purposes in life, supported by new expectations.

Religiosity is considered to be a source of support to cope with the experience of cancer, as faith brings one close to subjectivity, which can help one to understand and positively deal with this disease¹⁷.

It is believed that religious faith or belief enables women with breast cancer to feel at peace with their condition, so they can live with great optimism. In this way, the reports revealed that spirituality significantly influenced the life of the *being-there*, so as to encourage women to face the obstacles and continue their life in a more peaceful and eager way.

Holding onto faith and religiosity allows hope to be a resource that provides support for young women to deal with the facticity of being thrown into the world of cancer, enabling the being to temporarily avoid the anguish of a possible early demise.

I'm Catholic and I'm a devout follower of Our Lady, mother of Jesus. So I pray, 'Our Lady, everything is temporary, so please help me, may this moment pass, and it passed!' (L.)

I hold onto this name, God! He is the one helping me go through this. (D.)

Religion is found to be an important source of social and psychological support. Women view religion as a foundation of support, associating the disease with some higher and divine power, believing that they can be healed¹⁴.

Apart from spirituality, another strategy adopted by these women at this moment is to seek strength in their family:

I found support in my two small children in our home, they were the ones who didn't let me feel sad. Did I cry? Yes, I cried! But then my little boy would come close to me and that was all it took! (crying) (O.)

Women find in their children, in God and even in themselves the courage required to become a warrior and seek treatment and, consequently, a cure, thus becoming stronger and more certain about their decisions.

Family appears as the main source of support for women during oncological treatment. Family members provide direct care or indirect support to these women, i.e. not only emotional comfort, but also help with their routine activities, assisting them with daily tasks, taking on house chores and caring for their children while they are physically and psychologically vulnerable¹⁸.

It could be perceived that family support significantly helps women to cope with the circumstances experienced

and provides the means for the *being-there* to develop skills to prevent stress and to positively and safely adapt to and accept their new condition.

FINAL CONSIDERATIONS

The present study enabled researchers to observe the phenomenon experienced by women who experience breast cancer at an early age. Being diagnosed with a devastating disease such as cancer can change the feelings and emotions experienced by these young women. This diagnosis causes them to experience its harshness and surprise, as they do not associate the detection of a nodule with a disease as serious as cancer. This is because they do not believe or they are not aware of a possible onset of breast cancer at such an early age.

Upon receiving the diagnosis, women experience the perspective of an uncertain future and an unknown path with great difficulties that include emotions such as anguish, sadness and fear of death and mutilation, which are found to be much more intense when felt at such an early age.

Despite all the difficulties experienced during cancer, young women find out that they are strong and search for reasons for fighting against this disease. In the majority of times, they find this emotional support in their spiritual faith and family.

Based on the phenomenon revealed here, nursing professionals can significantly contribute to the prevention and promotion of health among these young Beings who are unaware of the possibility that can be achieved through cancer, using simple strategies such as health education. Moreover, emotional support and care are key factors that must be present in nursing care for young women diagnosed with breast cancer and mastectomized.

The following must be a part of nursing care: listening, touching, expressing feelings and being willing to care for this being in its totality, observing the relationship between body and mind.

Some limitations should be emphasized here, such as the fact that results cannot be generalized. This study had a phenomenological approach, in which only seven women participated. However, researchers believe they have found answers to questions about this complex and endless phenomenon experienced by young women aged between 18 and 35 years, who were diagnosed with breast cancer and submitted to mastectomy.

In conclusion, it is hoped that this discussion can effectively contribute to changes in health and nursing practices, as there is room for comprehensive and humanized care aimed at young women as well.

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