THE IMPACT OF CANCER ON THE EVERYDAY LIFE OF WOMEN IN THEIR FAMILY NUCLEUS¹

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ABSTRACT

Cancer has a major impact on a woman's life and on the family, which has her as responsible for affection and nurture ties. For this reason, this research aimed to understand the impact of cancer on the everyday life of a woman within her family nucleus. The qualitative study was conducted by means of life stories told through an open-ended question asked to 18 women undergoing cancer treatment. Data analysis used ALCESTE®, which provided the category called "Health, job, family and leisure of women with cancer", with information about changes in their lifestyle and in their families, caused by the need to treat their disease. Such category allowed identifying that cancer and therapy caused undesirable reactions that, in their turn, resulted in an altered perception of the women's self-image and affected their marital life. Though sensitized by physical reactions, they sought to keep caring for their families and doing housework. However, they neglected leisure activities by reacting through isolation for fearing social reaction. It is concluded that changes occur in the daily routine of women undergoing cancer treatment, affecting their family dynamics, and that support from health teams is of vital importance.

Keywords: Women's health. Oncology nursing. Life-changing events. Family relationship.

INTRODUCTION

Cancer comprehends a set of more than 100 diseases characterized by an uncontrolled growth of cells that invade organs and tissues, which may spread to other body parts and cause metastasis. The most frequent types of cancer in women are breast, intestine, lung and cervix cancer, with the latter being the second most common among women, falling behind breast cancer only. According to the Brazilian National Cancer Institute estimates, around 526,000 new cases of cancer in women are expected for 2016⁽¹⁾.

This chronic disease, feared by the common sense and associated with death, brings important consequences to the patient's life after the diagnosis. When it happens to a woman, it affects her routine and the family that has her as responsible for affection and nurture ties. She spends most of her time on housework and raising her children, in addition to being part of the job market⁽²⁾. Simone de Beauvoir states that one is not born a woman but rather becomes one⁽³⁾, ratifying that in her several roles she builds up the conception of the female being as a subject of

duties, nurture, attention and family support.

Face this social legitimation, some women find themselves in the middle of a crisis for not being capable of fully handling their daily functions. This conflict is identified when cancer is diagnosed, when the female subject perceives the fragility of her health and needs to withdraw for treatment. There is a break in her physical, psychological and social balance, which causes her to interrupt her routine and face the unexpected reality of having cancer.

However, the increasing incidence of cancer among women, added to the fact that the latter are important members in their families, promoting relations of support, care and family subsistence, becomes a problem with the existence of cancer and, consequently, its treatment as a predisposing factor for changes in a woman's everyday life and family dynamics. With that said, this research aimed to understand the impact of cancer on the routine of a woman within her family nucleus.

METHODOLOGY

This research has a qualitative approach of

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descriptive and exploratory type. Studies of this nature enable the analysis of particular and subjective matters, in addition to greater understanding of the meanings of human relations⁽⁴⁾. Thus, it favored a better comprehension about the experiences of women undergoing cancer treatment within the domestic environment.

This investigation was conducted in the city of Viçosa, Minas Gerais, with 18 women older than 18 years, who were undergoing cancer treatment between July and September of 2014 and accepted to participate in the research by signing an informed consent form. The participants were chosen from a list of women undergoing oncological treatment through the Treatment Away From Home Health Program and, after their stories were known, a meeting at their homes was scheduled. An open-ended question was asked to allow the social actors to speak freely: "So, I would like you to tell me about how you found out about the cancer and how the routine of your family and yours is going since then."

The form of approach was based on the life story data collection method, which is focused on Daniel Bertaux's precepts. In it, the subject is the owner of knowledge and seeks to tell his story with the aid of remembrances, reflections, retrospective evaluations, memory, moral judgement, ideology and worldview⁽⁵⁾. Through this method it was possible to see in those women their tensions, processes of permanent reproduction and their transformation dynamics face changes in their families.

The interviews were audio recorded and transcribed, composing the corpus for analysis of the text that was processed beforehand to be subjected to software reading. Data were by analyzed a computer program lexicographical quantitative analysis of textual material, called Analyse Lexicale por Contexte Ensemble de Segments de (ALCESTE®). The latter is supported on calculations done about the co-occurrence of words extracted from text segments, seeking to distinguish word classes that represent distinct forms of speech about the investigation's topic of interest⁽⁶⁾. That is, depending on the frame of reference, there will be a different way of talking about a theme and, thus, there will be

opportunity to identify different ways of thinking about a social object or world.

This research received positive legal opinion No 717.902 from the Federal University of Viçosa Ethics and Research Committee, complying with all precepts for research involving humans, in accordance with Resolution 466/2012⁽⁷⁾. The participants were requested to sign an informed consent form and given pseudonyms with the letter W (Woman) followed by Arabic numerals (1-18) in order to have their identities preserved.

RESULTS AND DISCUSSIO

The mechanized lexical content analysis, through descending hierarchical analysis of textual content, identified pieces of information that were essential in the text for the statistical significance of words measured by frequency of appearance, which guided the selection of the most significant text segments. The latter were organized into five classes, which were analyzed and titled according to the meanings that such lexica, when grouped, had according to the researcher's qualitative interpretation.

Class 3, titled "Health, job, family and leisure of women with cancer", presented 168 Elementary Context Units (ECU), which corresponded to segments of the text composed by the sequence of main words, in a total of 136, and accounted for 24% of the corpus. It is given highlight in this article. The other Classes that portrayed therapeutic itinerary, spirituality, financial impact and quality of women's healthcare accounted for, respectively, 26%, 15%, 20% and 15% of the analyzed corpus. There was balanced distribution between ECU and their Classes.

Class 3 elucidates how the new process of female activity in households took place, when full dedication to their microsystems was no longer possible. Thus, ALCESTE® drew the Class that referred to the health, domestic job and leisure domains that affected their family dynamics and roles as women.

Changes in their bodies and in the way they perceive themselves

Physical changes caused by cancer and its treatment lead to physiological, emotional and behavioral fragilities, making women vulnerable to facing conflicts. Women with cancer report their lives as orderly and ordinary before the onset of the disease but, face the diagnosis, there was a break in their inner balance, causing them to feel vulnerable and emotionally unstable in the acceptance process⁽⁸⁾. In addition to these reactions, they complain about pain, changes in their vision, taste, and veins, besides nausea, feebleness and anemia:

The treatment, it affects the patient's blood, because the patient's blood decreases, the veins get weaker, the arm hurts a bit. Health changes because it affects a lot the patient's body, chemotherapy affects patients from head to toe... you feel weak, even salted foods, and you can eat right... (W07).

Cancer slows you down a lot, chemotherapy too. The other day my stomach was not good, then another day the problem was my blood, because the medicine is strong. You do not really feel like eating, you have to choose things because your stomach does not accept them (W13).

Adaptation to their new routine may be tough for women and intertwined with peculiarities that demand perseverance in the search for wellbeing. Cancer is still considered by some as a disease endowed with negative meanings that can significantly change the routine of women in the job market, as well as their role as the one who takes care of their houses, children and partners. It can limit the continuity of such roles, causing suffering face their loss of self-esteem and the need for changes in their professional careers⁽⁹⁾. The treatment routine changes not only a woman's physiology but also her lifestyle, priorities and plans.

Thus, when health is affected it reflects on the way of being of female subjects. When it affects their body and shape, it also changes the way women perceive and feel themselves. Consequently, their understanding of self-image becomes negative, followed by reactions of emotional nature that make them react with shame and social withdrawal.

Participant W10 reported changes in her body and showed a negative self-image. W18 saw changes too and began to feel embarrassed by the extravasation of urine through the fistula and scars in their abdominal area. These women changed how they perceived themselves and

began to feel imperfect, as it is exemplified below:

I felt a lot of pain, discomfort, and a fistula appeared so the piss would leak all the time so I was getting more nervous... I had to take antidepressants, use a tube... What affected the most was this scar in my belly; it is very ugly and big... I had adhesion too, which was only found when the fistula was extracted (W18).

I did not feel it much, the second time I got really swollen, seeing a picture makes me sad, wow, terrible! (W10).

Moreover, cancer brings the stigma of death, which has a major emotional impact. It was possible to identify feelings of fear, anxiety, distress, suffering, doubt and anger. The fragilities come along with the consequences of therapy such as inhibited psychosocial interactions at work and with family, mood swings and emotional instability, changes in body image, sexual satisfaction⁽¹⁰⁾. For feeling physically unattractive, losing hair, going through body changes, feeling pain and knowing they have a disease that can be fatal, women react with sadness, shame and fear:

I used to feel a lot of pain and now it hurts all the time, I do not feel happy anymore (W11).

You are not ready to deal with this disease, you are not ready to deal with anything and they think that this disease has no cure. Therefore, I do not even know how to talk about how hard it was in the beginning, now it is more balanced, but in the beginning, it was sad. Where there was hair it fell all out, I felt a huge pain, lost my hair (W14).

Although women have conquered a big space in society, their representation is still linked to body image; consequently, feeling they do not meet beauty standards due to therapy can change their self-image, which triggers feelings of inferiority and fear of rejection from their partners⁽¹¹⁾. In addition, having a chronic disease and needing care also interferes with a subject's perception about autonomy and independence, that is, it brings about feelings of fear and anxiety for not being capable of performing daily tasks, which could lead them to withdraw and spare their families worries⁽¹²⁾.

During and after treatment, women find themselves in the middle of limiting situations that prevent them from handling routine activities. Face such difficulties, there is an evident need for support from family and friends for the provision of direct and indirect care that promotes emotional comfort, in addition to help with daily activities⁽¹³⁾. Faced with such a situation, spouses feel a need to make changes in the marital relationship, emotionally helpless and overburdened in relation to chores and raising kids, as well as dissatisfied with their sexual life, which is affected too⁽¹⁴⁾.

Thus, cancer affects a variety of roles played by women, including that of sexual partner. These experiences are addressed by W07 and W03 and ratified by Santos et al. (2014), which identified that cancer involves a radical compromise of a woman's sexuality for inducing to early menopause, vaginal dryness and lower libido, which interfere with her marital relationship⁽¹⁵⁾.

This treatment affects your whole body, vagina, intestines, it affects a lot of things... sometimes I think that women don't say it hurts because when they don't show that in bed is one thing but when they can't it's another thing (W07).

During chemotherapy, I had no feeling of pleasure, I grew colder... My husband changed completely, he even got a lover (W03).

The signs and symptoms of cancer, as well as the side effects of chemotherapy and radiotherapy contribute to women feeling weaker and powerless to perform routine activities. Pain, feebleness, hair loss, body changes and low libido affect their self-determination to the point of making them feel they are not capable of doing something for their self-esteem, which reinforces the vital importance of families helping them cope with such conflicts.

Situation of discomfort about the impossibility of doing chores

When it comes to chores, that is, tasks involving cleaning, cooking, washing and ironing clothes, and other actions, it was possible to identify big changes between diagnosis and treatment. When those women became incapable of taking on housework due to their condition of physical fragility, somebody else needed to do that instead or an adaptation had to be made so

they could keep up with household chores without the aid of another person.

Interview W03 reported the absence of physical strength to perform their activities, which led her to fractionate her actions so she could take care of her house. These difficulties with household chores were reported by W04 and W06 as well:

...you no longer have that strength to clean your house, you need someone else. Because there it needs heavy cleaning, it affects your body and I cannot do it anymore. I feel dizzy and have to stop all the time because I do not have saliva and feel like fainting (W03).

The chores, I do it a little, and then stop for a while. I can never do many things properly, I stop when I cannot anymore, and my daughter does it for me (W04).

About chores, washing clothes mainly, it is harder now, because everything hurts... Doing the dishes is ok, the problem is washing clothes. I keep doing the same things, I still wash my clothes, do the dishes, sweep my little house, I rest a bit and then go back (W06).

Interviewee W06, incapable of doing heavy physical exertion, adapted to her new condition and, in order to continue doing the chores, began to perform the activities with breaks for rest. The participants attributed this incapacity to symptoms such as pain in the limbs, decreased physical resistance, dizziness and xerostomia. However, despite all difficulties, they did not stop taking care of their homes.

Changes in their way of being, caused by the disease, make women restrain themselves from routine activities such as working, taking care of their husband, children and homes, and this causes them to feel dependent, especially for needing help to do housework, which used to be performed with ease⁽¹⁶⁾. Such women, despite feeling less fit for daily tasks, sought to act according to their previous routine; if they felt incapable after persisting, they would appeal to their children or another family member.

Another example of search for balance and adaptation face the new living condition of women due to loss of strength and physical resistance to perform ordinary activities in their houses was reported by W05, when she emphasized the use of technologies and

electronic innovations as a support to domestic tasks:

About chores, I had to forget about the house, let it go, this changed a bit indeed. I began to use some things I was not used to like electric pan, electric coffeemakers, these little things I wasn't used to (W05).

The inclusion of other subjects to be in charge of domestic work was identified in the reports by W09, W14 and W15. In these cases, the ones taking responsibility was a sister, daughter and, or, husband. Family stands out as the main source of support to women during oncological treatment. Family members offer direct care or indirect support, that is, not only emotional comfort but also help with their domestic tasks.

With the participation of spouses in household activities, it is possible to see that new social adjustments are happening in society and chores are no longer a woman's duty exclusively. Men, then, began to do housework and be responsible for raising their children too. The example given by W14 shows the case of a husband that took on the domestic role when his wife was diagnosed with cancer so she could devote her time to treatment and health recovery.

It impacted housework because I don't do anything, when I do something it's something lighter, things I can do, that's all that changed, all the rest is normal. My husband does it, he and my daughter, my daughter helps too (W14).

However, the other cases still evidence a traditional view of sexual division of labor, in which it is a woman's duty to stay confined in the private environment of her home. If the patient is unable to do household chores, another woman does it. Thus, a sister or daughter took on this role, as exemplified by W09 and W15.

I can no longer do the things I enjoyed doing, like sweeping, mopping, cleaning the floor, I cannot do this anymore. I really want to do things and always really enjoyed doing my things and, all of a sudden, I had to teach my daughter to do it instead (W09).

My sister is the one who's always there for me, she's doing all the cleaning because the doctor told me not to move this side here too much until this chemo phase ends, she comes and cleans it all and stays with me (W15)

Although the roles prescribed to women within the family have changed, they try to reorganize their lives in order to keep up with their functions within the domestic context and, when were not able to, showed their suffering for an unfulfilled action, as expressed by W13 while telling her life story face the cancer diagnosis. That woman manifested pleasure in taking care of her children and home, was pride of cooking and being praised for the meals she cooked and enjoyed the impeccable way she kept her house clean.

My routine before finding out about the cancer was hectic, working. I would do this and that all day long, always ready for everything, I would wash my clothes, work, go out, come back. My house was super tidy, my children, my things, I was always doing something. I controlled everything, but then, when I found out about the cancer they made me quit my job, would not let me work (W13).

The frequency of care was built up throughout generations and now, for women, caring is natural. Becoming the recipient of care, prevented from performing social activities, contributes to the development of feelings like loneliness and depression⁽¹⁶⁾. For this reason, it was possible to understand that the women in this research did not abandon their role of caregiver and were concerned about acting as such with family members, despite their limitations.

Changes in leisure for women undergoing cancer treatment

Leisure is the life domain in which individuals use their free time for pleasure, fun, amusement and relaxation. Women enjoy leisure in moments of altruism, during which they spend this time of tranquility thinking and doing their activities alone or, in other situations, do leisure activities with their families.

In this research, it was possible to identify leisure experiences in different ways. Interviewees W01, W11 and W14, due to the cancer diagnosis, waived leisure moments and isolated themselves socially. Was the life stories of these women showed their fear of social reaction, of going out and revealing an abnormality or change in their beauty standard and even triggering a reaction of sorrow:

I would hide myself, I would not expose myself, and they would say I never showed up, but everyone behaves a certain way (W01).

I enjoy going out, traveling, I loved to go to the countryside. Now I don't like it anymore, since I found out about it, because when I get there they keep asking if I'm better, how I am, I said I'll stop going to the countryside because they keep asking me those questions, reminding me of things (W11).

You just cannot do anything; you fear that something will happen to you. I stopped doing things, but now I am resuming some activities because of them. About two weeks ago I felt sick and got to stay home more because I'm afraid of falling ill, of doing this, doing that, people out there can talk about it too (W14).

In addition to fear of social repercussion regarding cancer, there is the fear of acquiring a new pathology, since their bodies have been weakened, are fragile and vulnerable to diseases. W15's speech refers to this fear as well, to the fear of environmental adversities:

I'm afraid of going out, of dancing because of that, I enjoy going to dance clubs but not to dance, you sweat a lot, then you expose yourself to the cold and have a relapse. Life after the diagnosis has been normal, I just feel I could do more, I feel useless, I want to do many things that I like and have always liked but that I cannot, that I am not doing. Meanwhile I feel useless (W15).

As it could be observed in that interviewee's speech, she felt weak for no longer doing activities that used to give her pleasure, for going through the fear of having cancer and for no longer being able to contribute to chores and to work; all this comes along with other emotions and a sensation of uselessness. The growth of the tumor and effects of the treatment can cause weight loss and fatigue, which is perceived as the absence of strength and incapacity to perform tasks. However, women, in their daily functions, act as daughters, wives and workers, but without strength, they cannot see themselves as an active part of their own lives.

For depriving themselves of leisure moments after the cancer diagnosis, those women also failed to provide fun moments to the family. W03's children had planned weekends to play and enjoy a fun time with their families but had

to adapt to other forms of leisure, since their mother was unable to engage in that. That woman feels that her absence brings negative reactions to her family's life.

Since I started this treatment, I became very nervous so I do not even have a fun time. About leisure, it has not been part of my routine lately, it is rare. It was not like that before, for example, I would go out on weekends, sunbathe, I would go to the uni with the girls, played football, shuttlecock, but now I do not do it anymore (W03).

Cancer treatment demands dedication and time, which used to be reserved to family, job and leisure. In the case of women with this disease, there is the risk of frustration about time control because it is necessary for healthcare instead of other activities.

Though faced with the tough consequences brought by cancer, the female subjects of this research showed their empowerment as to their representativeness within their family nucleus. The pathology brought not only fears, fragilities, reactions to the social world but also new significations.

FINAL CONSIDERATIONS

Faced with cancer, the women in this study began to realize changes caused by the disease. They had their personal balance, family routine and domestic and leisure activities affected by therapy. Their marital life was impacted by lower libido or incapacity to play the sexual role of "woman". The physical changes also caused changes in their self-image and self-esteem, besides preventing them from doing a heavier housework.

Unable to do chores, they came up with a strategy to keep their homes tidy, fractioning their actions or asking someone to do them. They isolated themselves when they could participate in fun activities with their families for fearing how people would react to their cancer. They went through changes in how they perceived themselves, acted and cared, with consequences to different domains of their lives and family dynamics. There was a change in how they played their roles, without, however, neglecting any of them.

This research aimed to understand the

experiences of women undergoing oncological treatment in order to fill gaps of knowledge with respect to family relationship and supported nursing knowledge in order to bring about a holistic and singular view of the care to be provided to these women. Nevertheless, it also

presented limitations for not specifying treatment phases, as well as when cancer was diagnoses, which could provide information on how women perceive their bodies, housework and leisure, in addition to familial behavior.

REPERCUSSÕES DO CÂNCER SOBRE O COTIDIANO DA MULHER NO NÚCLEO FAMILIAR

RESUMO

O câncer é uma doença que traz importantes repercussões na vida da mulher e de sua família que a tem como responsável pelos laços de afeto e cuidado. Para tanto, esta pesquisa teve como objetivo compreender as repercussões do câncer sobre o cotidiano da mulher no núcleo familiar. O estudo qualitativo foi realizado pelo método história de vida, realizada através de pergunta aberta com 18 mulheres em tratamento contra o câncer. Para a análise dos dados utilizouse o software ALCESTE® que traçou a Classe nominada como "Saúde, trabalho, família e lazer da mulher com câncer", que trazia informações sobre as alterações no seu modo de vida diante da família, pela necessidade de se tratar do câncer. Nesta, identificou-se que o câncer e a terapêutica provocam reações indesejadas que, por sua vez, implicam na percepção modificada da autoimagem da mulher e afetam a vida conjugal. Mesmo sensibilizadas pelas reações físicas, procuraram manter o cuidado da família e do trabalho doméstico. Mas se tornam ausentes na prática do lazer, pois reagem através de isolamento por medo da reação social. Conclui-se que ocorrem mudanças no cotidiano da mulher em tratamento oncológico que repercutem na vida da família, sendo importante o apoio a estes pela equipe de saúde.

Palavras-chave: Saúde da mulher. Enfermagem oncológica. Acontecimentos que mudam a vida. Relação familiar.

REPERCUSIONES DEL CÁNCER EN COTIDIANO DE LA MULHER EN EL NÚCLEO FAMILIAR

RESUMEN

El cáncer es una enfermedad que trae repercuciones importantes en la vida de la mujer y de su família, la cual es responsable por los lazos de afecto y cuidado. Por lo tanto, esta investigación tuvo como objetivo comprender las repercuciones del cáncer en la rutina diária de la mujer dentro del núcleo familiar. Este es um estúdio cualitativo, ejecutado por el método: história de vida. Fué realizado por médio de preguntas abiertas com 18 mujeres em tratamiento contra el cáncer. Para el análisis de los datos se utilizó el programa ALCESTE® que trazó la clase denominada como "salud, trabajo, família e esparcimiento, de la mujer con câncer. Lo que trajo informaciones sobre las alteraciones en su estilo de vida en relación a la família, por la necesidad de tratar el câncer. Se identifico que el câncer y su tratamiento provocan reacciones indeseadas que, a su vez, repercuten en la percepción modificada de la autoimagen de la mujer y afectan la vida del matrimonio. Apesar de sensibilizadas por las reacciones físicas, procuran mantener el cuidado de la família y del trabajo doméstico. Pero se toman ausentes en la práctica de esparcimiento. Porque la reacción principal es el aislamiento por miedo de la reacción social. Se concluye que ocurren câmbios em la rutina diária de la mujer en tratamiento oncológico que repercuten em la vida familiar. Siendo importante el apoyo del equipo de salud.

Palabras clave: Salud de la mujer. Enfermería oncológica. Acontecimientos que cambian la vida. Relación familiar.

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