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RESEARCH

CHANGES IN THE DAILY LIFE OF MEN WITH CANCER: INTRODUCING ONE OF THE INTERFACES OF GETTING SICK

*MUDANÇAS NO COTIDIANO DE HOMENS COM CÂNCER: APRESENTANDO UMA DAS INTERFACES DO ADOECER

LOS CAMBIOS EN LA VIDA COTIDIANA DE HOMBRES CON CÁNCER: MOSTRANDO UNA DE LAS INTERFACES DE LA ENFERMEDAD

Andréia Burille¹, Eda Schwartz², Juliana Graciela Vestena Zillmer³

ABSTRACT

Objective: To present the changes occurred in the daily life of men with cancer. **Method:** It is a qualitative research, accomplished from March 2006 to December 2007. The semi-structured interview was used as instrument and the data were organized starting from the thematic analysis. **Results:** It has verified that several modifications in the daily life of the men have been modified, especially, in aspects related to sexuality, corporal image, and social life, financial and labor aspects, in which they had to introduce strategies to face them. **Conclusion:** The study made possible to understand how the daily life of the individual with cancer has suffered modifications and it provided a greater sensibility about the health topic of men. **Descriptors:** Nursing, Neoplasms, Chronic Disease, Men, Men's Health.

RESUMO

Objetivo: Apresentar as mudanças ocorridas no cotidiano de homens com câncer. **Método:** Trata-se de uma pesquisa qualitativa, realizada no período de março de 2006 a dezembro de 2007. Utilizou-se como instrumento a entrevista semi-estruturada e os dados foram organizados a partir da análise temática. **Resultados:** Constatou-se que ocorreram diversas modificações no cotidiano dos homens, sobretudo, em aspectos relacionados à sexualidade, imagem corporal, vida social, aspectos financeiros e laborais, fazendo com que eles lançassem mão de estratégias para enfrentá-las. **Conclusão:** O estudo possibilitou compreender o quanto o cotidiano do indivíduo com câncer sofre modificações e proporcionou maior sensibilização acerca do tema saúde do homem. **Descritores:** Enfermagem, Neoplasias, Doença Crônica, Homens, Saúde do Homem.

RESUMEN

Objetivo: Presentar los cambios ocurridos en la vida cotidiana de los hombres con cáncer. **Métodos:** Se trata de una investigación cualitativa, realizada entre marzo de 2006 a diciembre de 2007. Se utilizó como herramienta la entrevista semi-estructurada y los datos fueron organizados a partir del análisis temático. **Resultados:** Se comprobó que hubo varios cambios en la vida cotidiana de los hombres, especialmente en los aspectos relacionados con la sexualidad, la imagen corporal, vida social, financiero y laboral, haciendo con que llegase a las estrategias para hacerles frente. **Conclusión:** El estudio permitió comprender cómo la vida cotidiana de la persona con cáncer sufre modificaciones y proporcionó una mayor conciencia sobre el tema de la salud del hombre. **Descriptores:** Enfermería, Neoplasias, Enfermedad Crónica, Hombres, Salud del Hombre.

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INTRODUCTION

The current context marked by the aging population and the growing number of individuals affected by chronic non-communicable diseases, has required that health professionals take ownership of different strategies to perform strategies oriented to health needs. In this new scenario, it becomes important that professionals consider beyond the biological, cultural, social, and in particular gender issues when providing care, considering that these significantly influence ways of living healthy or not.

Cancer is considered a metaphorical harm, since it brings different meanings. Some authors even associate the disorder, punishment, and ultimately relate to fatality¹⁻². Along the same line of thinking, other scholars of this subject refer to the diagnosis of cancer is seen in society as an unwanted and unexpected situation, which is not part of the plans of life.³⁻⁵

Chronic non-communicable diseases, such as cancer and hypertension, affect men more than women, generating an increase in mortality rates of male population.⁶ In this sense, becomes relevant that this issue be included in discussions about planning and implementation of public health policies, when they are aimed at promoting healthy communities.

The World Health Organization (WHO) estimates that more than 11 million people are diagnosed with cancer every year, and it is estimated that there will be 16 million new cases annually before 2020.⁷ In our country, cancers correspond to the third question of male mortality, behind only the circulatory system diseases and external causes. Regarding morbidity this profile also repeats.⁸

The individual with cancer confronts predetermined roles and constraints that dictate which social roles and behaviors need to be exercised on the basis of gender. Besides the

difficulty of coping with the disease, goes to live with numerous changes caused by it. Thus, the encounter with the illness creates stress and anxiety, because in many situations, brings fear of death, abandonment of plans for the future, changes physical, psychological and social as well as financial and legal concerns.⁹

Points out that the motivation which led this study to be focused on the male figure emerged due to the knowledge gap the human health issue. It is noteworthy that the Brazilian production of books on the topic is relatively new and not very extensive. But the same cannot be said with respect to the published articles, however, these approaches do not allow a full view of maleness as just addressing the man as a variable in epidemiological profiles of sex, an agent transmitter diseases, a factor that generates violence, as well as an actor missing in health services.¹⁰

In this production, we seek to know the reality of man facing cancer and its consequences, which overcomes barriers and social norms for support and a new meaning to live. Thus, this study aimed to understand the changes occurring in the everyday men with cancer undergoing radiotherapy.

METHODOLOGY

This is a descriptive, exploratory, qualitative approach. Survey participants were men diagnosed with cancer undergoing radiotherapy. Data collection occurred from March 2006 to December 2007, the Radiotherapy Clinic of the Federal University of Pelotas. As a tool for generating data was used to semi-structured interview, proposed by Minayo.¹¹ All interviews were recorded and soon after, transcribed and analyzed.

Data analysis followed three steps:

Sorting Data, which includes exhaustive reading of the reports, the moment of transcribing the interviews, rereading the material, and the organization of the stories in order of ranking research theme; Rate Data: time in which were grouped the subjects of the research, according to the objectives; Final Data Analysis: deep reflection on the empirical data, the interpretation of the researchers.¹¹

The project was submitted and approved by the Ethics Committee of the Faculty of Medicine, Federal University of Pelotas, under number 028/06, following the principles of the Resolution of the National Health Council No. 196/96. By agreeing to participate in the study, subjects signed a consent form. To maintain anonymity, the men were identified by fictitious names, plus the age.

RESULTS AND DISCUSSION

Initially, individuals are presented in the study. They are: Helium, 65, farmer, skin cancer, Marcio, 63, farmer, lung cancer, William, 56, farmer, prostate cancer, Peter, 79, farmer, skin cancer, Ivo, 61, autonomous, Lymphoma, John, 76, farmer, esophageal cancer, Felipe, 48, an office assistant, lung cancer.

The following will discuss the themes that emerged in the analysis of the interviews, which are: The encounter with the sick: the fear of death to the hope of better days; Changes in body image and sexuality; Changes in eating habits and beliefs; Changes in social life: from public to private space.

The encounter with the sickness: the fear of death to the hope of better days

Since the beginning, mankind has faced health problems as part of their daily lives, developing, therefore, several strategies for

dealing with them. Damage related to health always symbolized much of the anxieties and fears of the people and society.² This fact was also observed in the speeches of men in this study. For them, the cancer diagnosis was received so overpowering, and many reported that they were in shock and even death in thought. From this, it became clear that cancer is a damage wrapped in mystification, beliefs and meanings, and some of the interviewees were seen as a punishment, a death sentence.

The thud is great time [...] It was horrible, first sensation of death, I thought, I'll die [...] the feeling was that I had two bodies, understand? My body was divided, the good and the bad [...] (Felipe, 48);

[...] Right from the moment we get a little shocked, can be fatal [...] (Guilherme, 56);

In daily life, talk is talk of cancer death and suffering. Having the disease and, or, being in treatment means constantly living with uncertainty and very close to finitude, and these were attributed symbolizations being built by people who have experienced the disease throughout their lives.²

One has to consider here that coping with this diagnosis may have been more difficult to overcome by respondents due to illness is considered a sign of weakness for men who do not recognize this as a process inherent to their own biological condition. Moreover, the cultivation of magical thinking that they would never get sick makes men feel invulnerable then encounter face to face with a situation of illness, especially with a chronic injury can trigger negative feelings.

It is noteworthy that there are feelings of indignation and revolt, a fact that is reflected in the speech below, when the interviewee says "could not have happened", which reinforces the idea that cancer is still seen as punishment.

We get a little nervous, thinks it's a fact that could not have happened, but it happened [...] I always thought it could be such a case, but I have been emphasizing [...] (Helio, 65);

The person receiving the diagnosis of cancer often feel trapped, seeking an answer to this ordeal of life sometime in the past. Others, for personal religious training, project their fears, anxieties, expectations and responses in God.¹³

It was also observed that with each passing day, subjects were gradually accepting the chronic damage that assailed, going to see it not as a punishment, and, yes, as an ordeal that has come to strengthen. In speeches are statements such as "I was accepting," which denotes the gradual acceptance of such damage, as if it was part of his mission in life here.

Oh! Lots of crazy [...] for a couple of months I got crazy! Crazy, so to speak, so ... I did not want to see anyone, did not want to talk to anyone. Then later, I got used to [...] was accepting until I accepted (Felipe, 48);

Over time, the individual can be reintegrated and seeks the support of family, friends and the other people with whom they live, strength to start the "battle against cancer." At this moment of encounter with the disease this can give new meanings to the illness process, becoming to see it as a time that is part of life, from glimpsing addition, new possibilities.¹⁴

For men interviewed, the treatment was significantly more than the opportunity to prolong life, was a new chance at life and realize dreams unfulfilled until then, a new time to rediscover. In this new "start", hope and faith to overcome "obstacles cancer" were present. Just as certain aspects of everyday life, not previously appreciated, now have a greater appreciation. Material gave way to immaterial, as the company of friends, family support, a conversation, a walk, a moment with their children.

R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3539-48

Changes in the body image and sexuality. It is known that individuals with cancer, and incorporate changes to their daily social and psychological experiences of a number of physical changes such as weight loss, alopecia, fatigue, weakness.¹⁵ These changes generate several transformations in daily life, which required the development of coping strategies. In the reports of respondents, one can visualize the physical changes that occurred in the course of treatment:

[...] I lost almost 10 kg [...] was 62 kg and now I'm 52 kg. After I recovered again, here before this treatment (radiotherapy) [...], but it seems like I'm losing again [...] (Marcio, 63);

I lost a lot of weight, I lost 12 kg [...] I have no disposition to leave, to walk [...] (John, 76);

The speeches above express how physical changes affect the welfare and psychological. Both reported weight loss as the main change occurred after the diagnosis of cancer. In the story further, it becomes clear how physical changes triggered social isolation:

[...] Today I'm not going to a party with a crutch, I'll be feeling bad before my class, and I am embarrassed. Not that it's ugly, even I, with a cane, keep taking, smoking and talking. It means a portion left for me is not cool [wept quietly] (Felipe, 48);

This account allows you to reflect on the image of man in society, as linked to the masculine image characteristics such as strength, virility and beauty.¹⁰ Thus, the fact that it does not correspond to the image presented by society as masculine may negatively influence the man with cancer, causing, well, social isolation and often depression.

Thus, one can say that the physical changes, or rather "marks on the body" triggered by cancer and its treatment trigger many

unpleasant effects in daily life because they start to live with an identity of patient, the carrier cancer in society.

The man with cancer, in addition to dealing with the symbolizations about the damage, has to live with the ghosts involving sexuality at that time. It is evident in the speech following the fear of transmitting the disease. This shows that, even with all the knowledge that is disseminated about the chronic condition, in the imagination of many people it is still seen as a contagious damage.

[...] I am separated, but had a few people. Not that I, today, I live just me and my son, I did not want more people to live with me [...] I put aside, for now, I walked away [...] I will not feel well, I know it will not be a cool thing [...] for more protection, as much as [...] I know that contagion has not, has nothing to do one thing with another, but is the head [...]] (Felipe, 48);

Complementing this finding, it is noted that this myth about cancer is related to insecurity, fear and also the social representation of the damage, because the vast majority of the population knows that the disease is not contagious.⁵ Accordingly, points up how necessary it is that health professionals, especially nurses, to perform a clear dialogue with individuals, taking out from them doubts and providing information to reassure them about the process they are experiencing.

Still in relation to sexuality, the report below evidences changes after the discovery of cancer. In this situation, for example, the sex scene came on the day of the couple, but the kindness and remained filled the place occupied by sex in marriage.

The affection is always normal, nothing has changed, only about sex [...] because now no good sex more [...] more tired, must be because of the illness (John, 76);

Individuals who suffer from cancer are experiencing changes in self-esteem and self-image, and thus initially tend to feel unwanted and unattractive, which consequently alters the expression of their sexuality and sexual performance.¹⁶ Also the side effects of cancer therapy are act upon sexuality, as it became clear in the reports of some men interviewed for this study.

Sexuality is one of the primary sources of masculine identity, therefore cannot perform it as they wish is one of the most common fears found among men. These concerns come sometimes characterize an area where navigates the desperation of some men as sexually fail is to fail as a man.¹⁷

Please note that different meanings were assigned to the word "sexuality", and the fact that describes the changes after diagnosis triggered shyness interviewed. Changes in sexuality of men in this study often generated negative feelings were overcome with the passage of time and with the care and understanding of companions.

Changes in eating habits and beliefs

In this issue, we considered factors such as diet, drug use (cigarettes, alcohol, etc.), search for faith / religion / spirituality, as well as complementary practices to radiotherapy: use of medicinal herbs, ointments, teas.

The chronic damage pose a challenge for affected individuals, because in most cases it is necessary to change habits, medication use continuously, depend on other people and devices, and in general, undergo adaptations to the new reality of life. In this regard, we note that individuals undergo profound changes in lifestyle after diagnosis, and some restrictions are present, as evidenced by the speeches below: *I smoked [...] now and again on Saturday or Sunday, I smoke a cigarette (Helium, 65);*

Especially in the food [...] a BBQ I cannot eat, is now more vegetables, bland foods. Already, I cannot chew before could now everything is food paste (John, 76);

In general, men report greater difficulties in dealing with the limitations imposed by the situation of illness. Among the complaints present in male discourse is the difficulty of following the diet and the need to adapt the routine closest to home.¹⁸

From this perspective, also notes that new practices were incorporated into daily life, such as use of medicinal teas and salves. Some individuals reported that, in addition to conducting radiation treatment, resorted to herbal teas and ointments, as a complementary therapy.

[...] Is my natural treatment with herbs [...] I take horsetail, cacao, ipe and purple crushed walnut shell also [...] it is indicated for it there, says cancer cure [...] I do not know if it is a result of tea, or if by nature, the disease stabilized [...] (Guilherme, 56);

[...] Sometimes the guy gets there, a tea known, there are people out there who goes from house to house to sell, and then the guy buying some tea here and there (Marcio, 63);

Ointment I always wore [...] but I washed with tea, aloe vera, marcela tea, chamomile [...] I believe what they said was good and used [...] (Helio, 65);

Note that the above reports of men residing in rural context in which beliefs about the use of medicinal plants are still very strong and are rooted in the customs and practices of care of families. Above all, it shows up in a meaningful faith discourses about the use of teas and ointments as a strategy to seek a cure for cancer, because many of them sought an explanation for these treatments, a cause or solution to the problem faced consistent with their perceptions. It also highlights that the use of such practices

before starting radiotherapy, as in the case of helium, may represent an attempt to delay seeking care professional, because this would imply recognizing that he was sick and need help. It is noted that women are more aware of the changes they consider normal and more willing to check their doubts with the health professional. For them, the idea of submitting to the medicalization even more invasive is fairly quiet, while most men are resistant to this medication. In some cases, a trip to the doctor is considered a display of weakness and vulnerability, questioning the masculinity of those seeking help, and this action should be avoided at all costs.¹⁹

The faith / spirituality / religiosity also gained emphasis in the speeches of men, to be seen as a contribution, a support that promotes aid in the process of meeting with the cancer and the course of treatment. It is observed that, for individuals, believe in "something more" was an important support, plus there is a strong connection between faith and healing because many deposit their expectations of cure in a "Higher Being" (God).

I sought God [...] the blessings is the prayer that we can do. Or we can do to ourselves or anyone else can do for us, my gullible [...] I was taught that there is [...] my strength came from God to follow [...] but if God's get there again [...] but so far as I'm taking is going with confidence. And, thank God, is getting better [...] Hope is large (Helium, 65);

Now I'm fine, I'm fine thank God [...] (Felipe, 48);

Reported by the respondents, it is observed that faith in God was accentuated after the diagnosis of cancer, even for those who were already fans of religious beliefs, revealing that all men and women, need spiritual support in times of distress. In this sense, it is understood that spirituality gives meaning and support for those who are experiencing the disease, as it enables

empowerment and serenity to accept and face the obstacles in the course of the search for a better state of health.

Changes in social life: from public to private space

Cancer and radiotherapy impose conditions that affect the life of the individual, i.e. cause interference in social roles, such as work, activities of daily living and even the relationship with the family. Furthermore, this condition affects the socioeconomic issues, especially among members of the working class, in which the salary of each, are not always sufficient, composes the family income.

The work has structuring function in society, therefore, conforms individuals in its various aspects, among these "genres", which also are structured from the social and sexual division of labor. When moments of rupture are experienced in everyday life of individuals, as in the case of illness, you can see how these distinctions are socially constructed, so the man who does not work, he fell ill, is seen as weak and less value that which endures and wins the job, hard, dangerous, unhealthy and risky.²⁰

When the worker man falls ill, faced with a situation of inability to exercise this labor, which often destroys the possibility of returning to their usual activity, and therefore the disease, to remove it from public space and male 's work, refers to the private space of the feminine. At that point the worker faces a break identification, i.e., becomes by in check the constituents of what is socially defined as being a man and being a worker.²⁰

In the reports of men with cancer is explicit that the chronic condition caused profound changes in working life. The removal of the work changed the daily lives of these individuals, generating unpleasant feelings, as evidenced in the speech below:

R. pesq.: cuid. fundam. online 2013. abr./jun. 5(2):3539-48

[...] Now no activity, totally stopped [...] I would like my service, taking care of the lawn Brazil [football team] [...] I stopped when I heard of the disease (Ivo, 61);

The association between being a provider and being a man is still very present in the social imaginary. This design makes the concerns of man are directed to work and to keep the home and family.^{8;12} Thus, points out that the work is an important support tool for individuals who are experiencing cancer, since it provides recognition of his social group as an active person in context, despite its limitations.

It is noteworthy that most of men in this study lived in rural areas; and the fact of having to stop, even temporarily, to work in the field, generated a feeling of dissatisfaction, which can be evidenced in the statements:

[...] I was brought up on the farm, working in the fields, and finally gave no further [...] I feel pretty [...] (Marcio, 63);

[...] I've always lived on the farm working [...] and so we get halfway ... (Helio, 65);

Working in the field, do not do anything now. I want to plant my corn in the field, raise my pigs (João, 76);

For farmers the work is seen as a source of renewal and health, although they considered that such activities are tiring in farming and require sacrifices. The man generally fit the work in the fields, as well as the purchase and sale of material connected to work and family. In this context, even men with older age are still doing some kind of work because they work for health means the possibility of not getting sick. Thus, working up to be healthy, but one gets sick to work, implying the job as a limit situation, both health, as disease.²¹

It is observed that in speeches, in addition to changes related to work activities are present in everyday financial difficulties. With a

chronic condition, the costs increase, it depends up transportation to travel to the health service, is to use drugs and require continuous medical monitoring, besides conducting examinations.

[...] I depend on me to survive, now who helps me is my mother [...] many tests I paid because I was in a hurry, was taking too long to treat me, I felt a lot of pain. So much I paid, but only that there came a time that no longer had the reserves ended all [...] (Felipe, 48);

[...] Come from there to here by bus, by myself [...] joining each small changes [money] holding. There, enough to pay for the bus to come back and forth [...] now has more difficulty to live [...] you spend much money has nowhere to go [...] (Marcio, 63);

The diagnosis and treatment of cancer involve not only a decrease in salary, but a loss of economic reserves the search for treatments that do not always increase survival.¹⁶ In this context, the individual besides facing the impact of living with a serious illness, such as cancer, starts to experience financial difficulties.

Moreover, the removal of social activities is also added to the changes generated by cancer. This situation meant that individuals made the friends away, family and leisure. This fact can be evidenced in the following discourses:

[...] I attended the service [...] I really liked "bunch" [horse racing], but I was sick and then lost the fair [...] Now the business is staying at home lying , sleeping and stuff [...] (Marcio, 63);

[...] No one turned away from me, is that I pulled myself away from people [...] I stopped after diagnosis with everything [...] today I'm going to do the treatment, my mother and I visit someone but party, I stopped going out and partying total [...] (Felipe, 48);

Social relationships tend to change by the presence of cancer, and most of the time, issues such as loss of purchasing power, social isolation,

family tension, maintaining friendships, ability to maintain employment or studies are involved in this process. Thus, it becomes a challenge for the individual to live with the damage.

In this sense, it is believed that men often feel pressured by the social construction of masculinity on which reinforces the stereotype that men have to be strong, manly, brave, and in turn they end up adopting posture of isolation society for failing to meet the expectations and roles assigned to be "masculine".

CONCLUSION

In developing this study, it was noticed that there were several changes in the daily lives of men with cancer radiotherapy and these were not limited only to the physical aspects, and yes, interfered in the social and emotional aspects of these subjects.

Because of that, we emphasize the need for greater awareness of health professionals on the issue of human health, as they have, yes, their singularities and need to be welcomed by health professionals. Furthermore, it is emphasized that gender issues influence ways of living healthy or not, and the way to deal with the changes caused by a chronic condition such as cancer and its treatment.

To finish, points up the need to develop more studies with a focus on health, as well as mobilize efforts towards encouraging men to seek health services to prevent further harm and promote them to be healthy and live.

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Burille A, Schwartz E, Zillmer JGV

Changes in the daily life of...

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