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Original Article

# Experience of rural families when having a father/husband with prostate cancer

## Experiência da família rural ao ter o pai/esposo com câncer de próstata

## Experiencia de la familia rural al tener padre/cónyuge con cáncer de próstata

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**Objective**: to report the experience of rural families when having a father/husband with prostate cancer illness. **Methods**: qualitative research, conducted at the residence of four rural families with nine subjects. A semi-structured interview was used, and thematic categories were established by the data analysis. **Results**: men with cancer were between 66 and 68 years old, knowing the diagnosis at least four years ago. Respondents family members were wives or children, aged between 30 and 69 years old. Families worked on agriculture and livestock. The nominated category A prostate cancer in our life is formed by the sub-categories: discovery of the diagnosis; family support; changes resulting from illness and difficulties faced during treatment. **Conclusion**: the rural family experience is full of constant division of tasks between the care for the father/husband and work activities, changes in marital life, sadness, distress and hopes about an uncertain future.
**Descriptors:** Family; Prostatic Neoplasms; Rural Population; Nursing.

**Objetivo:** relatar a experiência da família rural ao ter o pai/esposo frente ao adoecimento por câncer de próstata. **Métodos:** pesquisa qualitativa, realizada na residência de quatro famílias rurais com nove sujeitos. Utilizou-se a entrevista semiestruturada, e pela análise dos dados, foram estabelecidas categorias temáticas. **Resultados:** os homens com câncer tinham idades entre 66 e 68 anos, conheciam o diagnóstico no máximo há quatro anos. Os familiares respondentes foram esposas ou filhos, com idades entre 30 e 69 anos. As famílias se dedicavam à agricultura e pecuária. A categoria nominada A neoplasia de próstata na nossa vida é formada pelas subcategorias: descoberta do diagnóstico; apoio familiar; mudanças decorrentes do adoecimento e dificuldades enfrentadas durante o tratamento. **Conclusão:** a experiência da família rural é permeada pela constante divisão de tarefas entre os cuidados ao pai/esposo e as atividades laborais, mudanças na vida conjugal, tristezas, angústias e esperanças sobre um futuro incerto.
**Descritores:** Família; Neoplasias da Próstata; População Rural; Enfermagem.

**Objetivo**: relatar la experiencia de la familia rural al tener padre/cónyuge delante de la enfermedad por cáncer de próstata. **Métodos**: investigación cualitativa, en la residencia de cuatro familias rurales con nueve sujetos. Se utilizaron entrevista semiestructurada y análisis de datos, categorías temáticas se establecieron. **Resultados**: hombres con cáncer entre 66 y 68 años, con conocimiento del diagnóstico hasta en el máximo cuatro años. Encuestados familiares eran mujeres o hijos, entre 30 y 69 años. Las familias se dedicaban a la agricultura y ganadería. La categoría A neoplasia de próstata en nuestra vida está formada por las subcategorías: descubrimiento del diagnóstico; apoyo familiar; cambios resultantes de la enfermedad; y dificultades enfrentadas durante el tratamiento. **Conclusión**: la experiencia de la familia rural está permeada por la constante división de tareas entre los cuidados al padre/cónyuge y actividades laborales, cambios en la vida conyugal, dolores, angustias y esperanzas sobre un futuro incierto.
**Descriptores:** Familia; Neoplasias de la Próstata; Población Rural; Enfermería.

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## Introduction

Depending on the severity, individuals´ illness can cause major changes in their daily lives in physical, psychological, economic and social aspects. These modifications can also be extended to the family sphere this individual belongs, since usually there are ties between him and his family, keeping them connected so the events happening to one family member can somehow compromise the operation of their routine and emotional stability of the others[1].

The family has a significant impact on health and well-being of each of its members, influencing on their illnesses[1]. In this sense, family is a group of people united by emotional and/or biological bonds, committed to each other and usually participating in each other´s lives, reinforcing the idea that the family "is whom its members say they are"[1-2].

Some diseases cause greater social, physical and emotional reflection, such as prostate cancer[3]. Being with prostate cancer may have important consequences in the life of the man and his family, at any stage of the disease, from the emotional upheaval at diagnosis; fear of surgery; the uncertainty of the prognosis and recurrence; the effects of radiotherapy and chemotherapy, particularly, referring to sexuality in its broader aspects; the fear of pain and facing an undignified death.

Prostate cancer is the sixth most common cancer worldwide, accounting for about 10% of all cancer cases. Its incidence rate is about six times higher in developed countries compared to developing ones, and in Brazil is the second most common cause of death in men[4-5]. In this context, the Ministry of Health created in Brazil in 2009, the attention of Integral Care National Policy to Men´s Health, in order to facilitate and expand equitable access of the male population to health services in response to the observation that male diseases are a public health problem, considering their differences, including the place of urban or rural housing[5].

For rural context, the family living in this environment normally uses the body as a working tool for survival, and the care of this body are often considered secondary[6].

The search for health services, to carry out measures to promote health and prevention of prostate cancer occurs less frequently by men who live in rural areas, depending on the work activities, the difficulties of access to health services and socio-cultural concepts on health and disease, which can increase the risk of impairment and harm an early diagnosi [7].

Cancer can contribute significantly to be a disruption of family-based due to the suffering of all those involved[8]. This is because the family appears as a hierarchical group of people who practice mutual commitment ties and affective relationships[9].

Confirmation of the diagnosis of prostate cancer can lead to the man and his family a time of difficult decisions and confrontations, especially when he plays family roles of father and/or husband. The family unit needs to define behaviors and strategies that promote balance in situations considered as problems, revealing that the family needs to identify possible conflicts, so that they will not emerge in the future in irreparable discord[10].

Men in rural family often has the main financial provider function and also family protector. Knowing about the experience of rural families with prostate cancer illness can contribute to the knowledge of the repercussions and ways of coping used by rural families and qualify nursing care. The question of the research study is: How do rural family experience the illness of the father/husband for prostate cancer? I aims to describe the experience of rural families to have the father/husband with prostate cancer illness.

## Method

It is a qualitative research. Participants were four rural families, with nine subjects.

Inclusion criteria were: be a spouse and/or children and/or sons and daughters in law of patients

with prostate cancer undergoing oncology treatment in a teaching hospital in the interior of Rio Grande do Sul, be up to 18 years old; with knowledge of the disease and able to communicate verbally; whose father/husband resided in the rural area. More than one family member should be present at the interview, including the patient.

Study participants were selected intentionally and for convenience, considering the accessibility to the place of residence. After identifying in the hospital medical records the patients of interest for the study, there was a contact with the families to invite them to participate in the research, with home visits mediated by Health Community Agents of three Health Strategies of Rural Family. The time of the interview was agreed with the availability of the families. The interviews lasted an average of 40 minutes, took place in the homes of families in January and February 2014, being conducted by the same researcher, recorded and transcribed in full.

The interview followed a semi-structured script with the following guiding principles: characteristics of participants (gender, age, marital status, income, occupation and phase of treatment) and guiding questions (organization of family life facing the disease; family organization after involvement by the disease and todays family life).

The process of analysis, discussion and interpretation of data was guided by the thematic analysis technique, following the steges: pre-analysis, material exploration, treatment of obtained results and interpretation[11]. In the pre-analysis stage, there was a contact with the material elaborated from the interview transcript, proceeding to exhaustive reading, aiming to immersion in the contained information; in the exploration stage, there was the categorization of data, organizing the text from cuttings that enabled the formation and registration of units that were grouped considering its thematic affinities. In the interpretation stage, the understanding and interpretation of data was sought, linking them to the anchor literature and read-back[11].

The project was approved by the Ethics Committee in Research of the Federal University of Santa Maria, in the opinion number 245,217. To ensure confidentiality and anonymity of participants, the letter "P" (patient), followed by numbers: P1, P2; and "F" (Family): F1, F2, were used.

## Results

Study participants were nine people members of four families, where four were father/husband and five were family members. Men (patients) were from 66 to 68 years old. The discovery of the cancer diagnostic occurred between one and four years. All were married, from a rural area with two or more children, religion Catholicism and incomplete primary school education. About family work, all were dedicated to agriculture and livestock. Family income was three or more national minimum wage, which corresponded to R$ 724.00 (seven hundred and twenty-four reais) equivalent to US$ 329.00 (three hundred twenty-nine US dollars). As for the age group of family members, two were from 30 to 49 years old and three from 50 to 69 years old. Regarding their bond, three are spouses and two are children.

From the analysis of interviews a thematic category, the cancer of the prostate in our life has emerged, having four sub-categories: discovery of the diagnosis; family support; changes resulting from the disease and difficulties faced during treatment.

### The cancer of the prostate in our life

The discovery of the diagnosis of prostate cancer often occurs unexpectedly or casually, as can be identified in the following lines: *I never felt nothing, no pain, nothing. I discovered it by chance. In fact, the food made me ill and I went to see, I asked some tests because he had never taken cholesterol. Then the doctor wanted to do an examination of the liver and I said I did not need just so does the prostate. The test showed this issue, 8,5 of Prostate Specific Antigen* (P1). *It was a cardiologist consultation, and he asked me the Prostate-Specific Antigen examination* (F2).

T*he Prostate Specific Antigen had alterations, but he did not tell me anything. After I did it by myself, it was already quite changed, Prostate Specific Antigen 21, so I tried the specialist* (P2).

The diagnosis of cancer among the study participants occurred because men did, incidentally, the screening test, the Prostate Specific Antigen, or from tests performed for other purposes. In addition, the incentive to carry out the examination for early screening of cancer of the prostate is often made because the constant encouragement and even the insistence of family members, as outlined in the following statement: *I saw that my father felt very tired. I invited him saying, Father, you are already sixty-three, we'll do some tests. He never did an exam, never needed a doctor, never consulted. It was hard to get him to a doctor. When I showed the test to the doctor, he said: Let pray to be benign and not malignant, because it is well advanced* (F4).

As the above statement, the diagnosis was the perception of signs and symptoms indicative of the disease, identified by a family member. From this perspective, family support constitutes an important feature also for dealing with changes caused by prostate cancer, whether in routine household, access to local treatment, being highlighted as a major source of support for men. This issue is explained in the following lines: *The woman (wife) has to double her service* (P1). *I had a guaxo (calf) to create. The son took milk and gave breast morning to the calf, then took care of the rest during the day* (F1). *All of them, both the sons, the daughters, sons in law helped. I do not know how to thank them for this care* (P4).

According to the testimonies, the family support is about help of his wife and children to carry out the tasks of the house that before the disease, they were developed by the husband/father. Thus, some family members are divided between private activities (care of the house, children, profession) and the routines imposed by the therapeutic process of family member´s disease, as seen in the statements below: *So, when my father was hospitalized I was delegated to this situation care* (F3). *I can divide the space between them (work, kids, husband and father). If I cannot come to him (father), I call, I see if he took the medicine, if the doctor went to visit him, if he did not forget. So, I adapted to this way of life, thus dividing tasks* (F4).

Another family support situation is the help when accessing to the treatment site, as the rural areas has restricted places for means of transport that circulate in these places, as can be seen in the following quote: *My brothers in-laws carry me to the highway and from there I go by bus (to the hospital)* (P2).

On the statements of the study participants, it is clear that the union for the division of tasks and the activities of reassignment during treatment, either in hospital or at home, are usually consequences of family support. However, there are changes due to the disease and the limitations imposed by cancer of the prostate are contrary to the role assigned to man in our culture, providing a transformation in the life of the father/husband and family. This was pointed out in the following statements: *The greatest difficulties are to maintain the work of the people (agriculture). He worked, the guy did all the service. This has changed because we are always at home just doing nothing, so my wife knows more than me, because she has to work harder. For her, it has changed more* (P1). *I did not like to stop the service. But then, I started thinking that I have to take care of my health first* (P4). Working *in the field has changed a lot, now he (father) wants, but he knows it's not like it was before. It is now all more slowly. Now, when he was doing radiation therapy, he had a stage that was difficult for even grilling meat. He followed, but others were grilling the meat* (F4).

According to the testimonies, with the onset of neoplasia, changes in the work performed by the men in agriculture occurred, resulting in the wives´ workload as a compensatory strategy in family income. Another change pointed out by the participants of the study is related to the practice of the family leisure activities. *Before the disease, we went out on foot from here and went there to the river to fish, now not anymore* (F1). *The hardest thing was to see his change. It was sad for us to see that he did not participate in the ride because we know him in the middle of this problem* (F4).

For family members, the absence of leisure activities by the father/husband was difficult, since they used to hang out with the family, fishing and participating in horseback riding. Sadness in speaking of families was observed when they reported on modifying some habits, including the leisure.

In the same perspective, it is about change caused by the disease in the emotional life of man and his spouse. *I stopped working. No, I never had an erection again. We have to accept it, right* (P2). *The sex has changed very radically. At the first visit when we went to the doctor, twelve years ago, he said: The erection will change dramatically* (P3). *No (after surgery had no erection). Four years ago, I go round the house with her (wife), but it's the same as two ladies. And I do not even care, because neither I have provision for it* (P4).

It was found that, due to the disease, affective conjugal love of man has undergone changes in aspects related to sexual activity, such as decreased libido, difficulty or impossibility of penile erection. In addition, urinary problems were described as a change occurred for prostate cancer. *I had a very serious problem. I urinated every ten minutes and I felt a burning sensation in the bladder. It hurt so much that I wanted to twist the wooden wheel* (P4).

The urinary elimination have become more frequent and painful after the onset of the disease. When addressing the memories of the difficulties relating to cancer, some men expressed pain phases, denoting as striking and such negative experience may have represented.

About the difficulties faced during treatment, they reported: *The difficulty I had was after the surgery to do my needs (urine and feces) it was kind of hard. I had to straighten me because it forced where the sewing was done, the itches, and I was afraid, it hurt a lot and I thought he could even open it* (P4). *I had already harmed (erection). But now, with radiotherapy and hormone therapy, it ended. But, there is love and coexistence, nothing to do* (F6).

The difficulties faced by the treatment of neoplasia, that is surgery, radiotherapy and hormone therapy, the decrease or absence of penile erectile function and dysfunction in the urinary and intestinal physiological eliminations, participants also reported difficult access to the treatment place. *I did radiotherapy in Z city because the examination of Prostate Specific Antigen was high and they (doctors) failed to remove all (tumor) because it has spread. Sometimes I took the bus here, went to another city, got there just in time. I had trouble in that part* (P1). *It was an easy treatment. The hard part was the means of transportation. Most of the time, I go by bus. I go in the morning there (hospital). Up the road, my brother in law takes me there, then, I go by bus. Getting there, I take the municipal transport. When it is early, examination has to go by the town hall transportation* (P2).

As places that offer treatment for prostate cancer are located in cities far from home municipalities, and therefore they must leave soon from their houses to be displaced by means of private transportation or municipal. However, despite many difficulties experienced by rural families to have the father/husband with prostate cancer, solidarity situations were highlighted, such as those cited below. *They helped me a lot in the pension, giving me medicine, sunscreen and gel. I opened the door (of a room) and I had a big table with candle cake, a birthday cake and they sang happy birthday* (P1).

The friendship established in the places where men passed, the trust and gratitude to those who contributed to brighten the life before the disease. Such situations were striking for these rural families, when leaving their means of living for treatment for cancer they were lonely, but they found affection of strangers who had empathy for their situation.

## Discussion

Living with cancer of the prostate means to experience a saga that begins with the receipt of diagnosis and continues throughout life, configuring a dynamic care process that goes beyond the limits of time and space, and is independent of biology or result of tests, reflected in quality of life of man and

his family[12].

The performance of tests for screening and early detection of prostate cancer are also some self-care practices followed by the male population. Compared to men, both rural and urban areas, it is worth considering that the literature indicates that they do not seek regular way of health care, going only when in emergency case [6].

Such behavior was identified through the data collected, since families in rural areas highlight their daily work, place from which derive their livelihood, and the removal of these activities to conduct screening tests in health care can mean decreasing their work production, hence impede the promotion and protection of health related to prostate cancer.

Given these unique characteristics of this group of men, educational activities in health are necessary, for the resistance presented by them in seeking the health service, related to cultural and emotional contexts, such as the hegemonic masculinity model that combines the need of health service as a weakness, "because from an early age they are conditioned by society to the ideology that men do not cry, do not feel pain and that is strong"[13:18].

However, to experience the diagnosis of cancer, rural families faced with situations of suffering, and thereby seeking to protect their values, beliefs and habits to care for the sick person and deal with the disease[14]. Although the diagnosis of prostate cancer through early screening is an emerging practice in the reality of Brazilian health services, there is evidence of the leading role of the family as supportive in the process of finding and treating the disease.

The families of the study showed attention and care to the father/husband, since they observed and concerned with the onset of signs and symptoms by the disease. In some cases, the family were women who realized the change in men´s health and looked for the diagnosis.

The female population seeks care more often in health services compared with male. This situation can be explained by the gender issue, in which the male and female cultural elements develop patterns of different behaviors related to self-care of their health[15].

While having a confirmed diagnosis of prostate cancer, families indicate they were surprised by the result of the diagnosis, but it did not elicit feelings of fear. On the other hand, they urged to seek optimism, strength and courage within each family member to face and fight disease by treatment to achieve cure.

Father/husband investigated report that the disease left them vulnerable when it comes to performing daily work activities, but they were overwhelmed by the support of their families that fit their routine to continue the service in agriculture, animal care, in frequent visits and monitoring during treatment.

Such attitudes were perceived as a form of the family stimulate the father/husband to fight the disease, demonstrating his importance as a male reference and signaling the union, dedication, love and family commitment. An investigation with rural families, which had one of its members undergoing chemotherapy, showed the supporter bond represented by family members, neighbors and others in the community[14].

"The affection, love, protection, unity, faith, being together describe the care and are constituted as care practices of rural families to the person with cancer"[14: 1376]. Experience cancer implies the need for care of family members and health professionals. Such disease causes some limiting consequences that often are overcome by the help of the people who live or have close ties with the patient[4].

In addition, as stated in the words of one participant, the wife often is who is in charge of supplying needs and perform activities that were once performed by the patient husband. "The woman caregiver stands out in practice to care, since this practice arises in the home environment where the family is recognized as the source of care for the dependent members"[16: 293].

The readjustment of the activities of family

members investigated to assist the father/husband was showed as easy to perform because they felt prepared for it and the act of contributing in some way in the health recovery led to satisfaction and contentment. Thus, it is believed that the prostate cancer situation can generate a transformation process that implies reorganization and adoption of coping strategies of family members, to assist the man in daily activities, the rehabilitation of routine and facilitating access to the treatment place.

The rural family, as part of a larger system, performs care practices to the person with cancer in the through healthy relationships, when support bonds are important. In this way, they depart from what happens in the immediate family environment (microsystem) for mesosystem (interactions between family members) and the exosystem (connection between the family and social), maintaining the reciprocal realization process care practices[14].

Support for moving the man from home to the place where there is access to the transportation taking him to the hospital, as well as the reference health facility for treating cancer of the prostate used by the men in the study, is located in another municipality and its access is often through intercity bus, with little time available and roads, often in poor conditions. The difficulty of displacement, small periodicity and lack of public transportation and long distances in rural areas to reach health centers is a reality that becomes a limiting factor for the population´s access to health services[17].

Some men stressed that the involvement by neoplasia left them more vulnerable, with powerlessness because they are limited to the performance of activities previously performed, and the family improved their self-esteem. Changes in daily life to help that man assumes a new social position/condition, that is, sick, vulnerable, with limitations and frailties exposed and requiring third-party care[18].

The families of Brazilian society still maintains its organization with predominant model in the patriarchal system, where man is the central figure[18]. When this figure is removed, either by disease or death, and the redefinition of roles in the family is needed, feelings of distress for both the man in illness situation, as for the other family members emerged, having a disorder in their organization[18].

Depending on the disease, there are cases where the man is isolated from society or give up to participate in leisure and recreation activities, and this kind of attitude can compromise their quality of life, lower their closeness and intimacy with family members resulting in the feeling of not belonging to the group[19].

It is also noteworthy the understanding attitude by wives on the absence or diminution of sexual intercourse quality. They claim that after becoming ill by cancer, they did not judgments or charges relating to sex, showing love, affection and, above all, companionship. When answering about the changes after the disease, men reported discomfort and shame to talk about the lack of erection, but expressed gratitude for being alive.

Sexual life permeates gender relationships, since it is one of the pillars in the construction of masculinity, expressing hegemonic values, such as virility, power and domination. When there is a decrease or not erection, there is an impact on the meanings of masculinity, because the power and sexual activity (with penetration) are seen as symbols of virility[19].

Analysis of the consensus of international urologic entities found that 19.4% of men sought the health service only after feeling pain and 19.4% when they have a urinary problem, particularly the difficulty of eliminating the urine[20]. The establishment of cancer clinical picture does not appear significant symptoms, however, with the evolution of the disease there are "voiding dysfunction (urinary frequency, dysuria, reduced strength and caliber of urinary stream, nocturia)"[20:94].

In the context of rural families, the changes caused by the disease from prostate cancer are

reflected in the limitation to work in agriculture, reversal role with the spouse to maintain the family income, the abandonment of leisure activities, the loss in marriage affective life of man (decreased libido, difficulty or impossibility of penile erection) and in urinary dysfunction. There was a perceived need to reconfigure the marital relationship between husband and spouse, and the creation of a new social identity in the figure of the father/husband on the family and society.

The difficulties pointed out during treatment are related to the side effects caused by surgery, radiotherapy or hormone therapy, due to the decrease or absence of penile erectile function and dysfunction in the physiological deletions, as well as access to places where they perform the treatment. Friendships made during the illness process were resources that encouraged self-esteem and motivated to follow the treatment and life.

## Conclusion

The family is configured as a caregiver unit of the rural man with prostate cancer, involved in all phases of the health-disease, from diagnosis to treatment. The experience is permeated by the constant division of labor between the care for the father/husband and work activities, changes in marital life, sadness, distress and hopes about an uncertain future.

The study reveals that rural families are strengthened through the experience, expressing much more potential than weaknesses in the care performed by providing the necessary support to the father/husband. Although they were experiencing a situation of suffering, families mobilized to identify viable strategies that would enable the family functioning. For this, they undertook changes in their daily lives that allowed facing the difficulties and challenges of cancer, contributing directly or indirectly in the sense of belonging to the father/husband to the family unit.

It should be noted that this research has limitations, such as: the number of study participants and restricted representation, because it is a specific context that reflects the reality of where the study was conducted. At the same time, it is believed to be necessary to carry out further research investigating the family´s experience on the father/husband with prostate cancer disease, using populations with another housing profile (urban area), education and income, in order to verify congruencies/differences with this research.

In nursing care to the family in the disease process of the man, father/husband who has prostate cancer, the recognition of the uniqueness of lived experience can contribute to well accommodate actions and guide/inform the family, considering the context of life and care practices, beliefs, values and culture.

## Collaborations

Mathias CV contributed to study design, collection, analysis, data interpretation, article writing and final approval of the version to be published. Beuter M helped in interpreting the data, article writing, critical review and final approval of the version to be published. Girardon-Perlini NMO contributed to study design, analysis, data interpretation, article writing, critical review and final approval of the version to be published.

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