### FAMILY PERCEPTIONS ABOUT CARE FOR MEN WITH CHRONIC CONDITIONS

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### **ABSTRACT**

The objective of this study wasto know the family's perceptions about care for men with chronic conditions and dependent on home care. This is a qualitative study carried out with 17 relatives of men with chronic illnesses which adopted the references Family and Gender Centered Care. Data were collected in 2014, through open interviews conducted in the households of the relatives, and submitted to Content Analysis, in the thematic modality. The results showed that most of family caregivers were female, were between 49 and 83 years old and who also had chronic conditions. Most men had hypertension, diabetes mellitus and sequelae of stroke. The care measures mentioned included from bathing to handling more complex devices - tracheostomy and gastrotomy. The relatives pointed out different behavioral motives due to which, they believe, the men became ill; they reported that they performed the necessary care, although the men were reluctant to accept this help. The study leads to the conclusion that it isimportant to consider gender differences in relation to chronic illness and dependence on family care at home, as a basis for planning and providing care focused on the needs of men and their families.

Keywords: Men's Health. Family. Chronic disease.

### INTRODUCTION

The National Health Survey conducted in 2013 in Brazil showed that the self-reported prevalence of Chronic Non-communicable Diseases (CNCDs) was lower among men. This is supposedly due to the lower use of health services by men, causing, consequently, less opportunities for medical diagnosis<sup>(1)</sup>. External causes, diseases of the respiratory system and diseases of the circulatory system are the main causes of hospitalizations of males in Brazil<sup>(2)</sup>. Causes linked to behavior such as poor physical activity, failure to perform routine exams, inadequate diet and abusive alcohol consumption also have a high prevalence among men<sup>(3)</sup>.

These aspects of male behavior may interfere with health care<sup>(4)</sup> and, sometimes, they are associated with health problems that can negatively impact the quality of life, not only of the individual but also of his family, and predispose to the occurrence of chronic conditions<sup>(5)</sup>. Given these circumstances, in 2009 the Ministry of Health launched the National

Policy on Integral Care to Men's Health (NPICMH), which has been implemented mainly through Family Health Strategy (FHS) teams that are part of the Primary Health Care (PHC)<sup>(6)</sup>. At the heart of this policy, male resistance to seeking PHC is believed to overburden society and increase the physical and emotional distress of families<sup>(6)</sup>.

When men are in a situation of chronic illness, they begin to face certain threats to their condition as men. That is, their socially and culturally constituted masculinity is put to the test by the need to think and talk about health. The fact of falling ill, the need to seek care and the dependence on others, the limitations in carrying out their daily tasks, the barriers to performing routine examinations or screening, and aging itself are elements that may represent indicatives of fragility<sup>(7)</sup>.

The illness of a family member brings important changes to the family because people usually do not know how to deal with the difficulties and complexity of the illness. Thus, when a diagnosis of a disease comes up, it is understood that not only the patient needs to be treated, but also his entire family<sup>(8)</sup>.

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The family caregiver who provides the care for the relative with a chronic illness, sometimes, ends up giving up his/her personal life. This causes family relations to change, and the roles undergo a process of resignification. In short, the chronic illness, in its various dimensions, strongly influences the daily life of the family<sup>(9)</sup>. Moreover, depending on sociodemographic characteristics - sex - and cultural aspects - gender constructions - even when the family is the main source of support, it may face difficulties to provided this care the men.

In this sense, a study carried out with 32 men aged 20-59 seeking care in emergency services in the Northwest region of Paraná, Brazil, found that men reveal their perceptions about the support network, with a centrality in the family and in the corresponding emotional support and sharing of guidelines for health care<sup>(10)</sup>. On the other hand, a study carried out with female caregivers of men with chronic kidney disease advanced the knowledge in the health area as it points out gender representations implied in the care of men and the resignification that women themselves give to in their social environment in function of the care exercised<sup>(9)</sup>. However, there is still space for the advancement of the understanding of this phenomenon, using as starting point the many questions and reflections in the literature<sup>(11)</sup>.

Therefore, the question raised here is: how does care provision by families to men with chronic conditions and who depend on home care take place? Are there specificities to be considered in the care for men who have diseases? It is understood that, in order to respond to such questions, subsidies need to be obtained for a personalized professional care, based on subjective and cultural aspects of family care for men, as well as a deeper knowledge in the area of family and public health nursing. In view of the above, the objective was to know the family's perceptions about care provided for men with chronic conditions and who depend on home care.

### **METHODOLOGY**

An exploratory descriptive study of a qualitative nature was carried out within the framework of FHS teams of three Basic Health Units (BHUs) in the municipality of Maringá, in the northwestern part of the state of Paraná.

The contacted BHUs were defined for convenience - geographical ease to access - and FHS

nurses that indicated possible study participants, according to the predefined inclusion criteria: being a relative and primary caregiver of a man with a chronic condition and dependent on home care (need for food aid, hydration, hygiene, medication use and/or complex care). Family members who after three attempts and presentation of different options continued to have difficulty scheduling the interview were excluded.

The first contact with the families was carried out in home visits, which were made along with CHAs. On that occasion, the purpose of the study and the type of participation desired were explained. In case of agreement, the day and time for the interviews would be scheduled, without the presence of the CHA.

The data were collected by the second author of this study from May through July 2014, through open interviews and aid of a script with questions about sociodemographic and clinical characteristics related to the men and their primary caregivers, with the following guiding question: "Tell me how you take care of your relative, recalling moments since the beginning when the need for home care arose to the present day".

The interviews were recorded and transcribed verbatim as a way to gain access to the senses attributed to the participants' experience and to the interpretations about the reality of daily life. Data were submitted to Content Analysis, in the thematic modality<sup>(12)</sup>, which involves the quick reading and subsequent immersion in detailed readings of the participants' reports in which generic components and inferences are generated, allowing for codification and subsequent interpretations. With this, it was possible to create thematic categories that grouped the results in the form of similar messages.

The central ideas that formed the nuclei of meaning were identified in the analytical course, which composed the themes, and they were later grouped into thematic categories, as shown in Box 1.

Also in relation to the analysis, the theoretical assumptions of Family Centered Care (FCC) and gender were used to support the interpretations and understanding. The FCC is an approach that recognizes the importance of the family as the source of care, identifying its needs and ensuring itsparticipation in the planning of actions. Its central assumptions are based on four concepts: dignity and respect; shared information; participation and collaboration, mediated by the continuous negotiation

between family and health professionals, which aim to meet the health needs and well-being of the sick person and her family<sup>(13)</sup>.

### **CENTRAL IDEAS**

A - Feelings; B - Disabilities and dependencies; C - Family abandonment; D - The process; E - Role reversal; F - Feeling of being trapped; G - Social isolation; H - The feminine role of caring; I - Neglect with self-care; J - Surveillance in the role of caring; K - Particularities of the male sex; L - Changes in the daily dynamics; M - Empathy; N - Determinant factors; O - Behavior in health; P - Work; Q - Resignification; R - The figure of man; s - Resistance to ask for help; T - There is no turning back; U - Do not accept; V - The before and the after; X - Support.

### **NUCLEI OF MEANING (CENTRAL IDEAS)**

Nucleus 1: The dimensions of the social network: support and abandonment (C, X)

Nucleus 2: Men's attitude and feelings involved (A, G)

Nucleus 3: Disabilities, dependency and needs (B)

Nucleus 4: Determinants of chronic illness and consequent dependence (N)

Nucleus 5: Sex/gender as determinant of illness and the caring process (I, K, O)

Nucleus 6: Gender/masculinity model (P, Q, R, S, T, U)

Nucleus 7: The process, the before and after (D, V, L)

Nucleus 8: Caring as a female role (E, F, H, J, M)

## THEMES (NUCLEI OF MEANING)

Theme 1: Attitudes and feelings of men (2, 3)

Topic 2: Determining factors (4)

Theme 3: Sex, gender and masculinity (5, 6)

Theme 4: The female role of caring (8)

Theme 5: Sickness/dependence and social networks (1, 7)

## THEMATIC CATEGORIES (THEMES)

TC 1: Determinants of the chronic condition and coping with the dependence on care (1, 2)

TC 2: Care and dependence surrounded by sex and gender aspects (3, 4)

TC 3: The process of illness/dependence and the dimensions of the social support network (5)

Box 1. Components of the thematic content analysis process. Source: Prepared by the authors

Regarding gender, it refers to the way in which people act, think and feel, based on culturally established models of masculinity and femininity and that allow them to be recognized as men or women. It also refers to the ways in which roles and models of behavior are socially incorporated and reproduced.14 Thus, the meanings that permeate masculinity and femininity are composed of ideas and attributes created in social relations to classify subjects according to their sexual, anatomical and psychological characteristics<sup>(14)</sup>.

The project that gave rise to this study followed the ethical precepts established in Resolution 466/2012 of the National Health Council on research involving human beings and it was approved (Opinion 623.541) by the Permanent Human research ethics committees of the State University of Maringá and had its realization authorized by the Municipal Health Department of Maringá. Family members who participated in the study signed two copies with

equal content of the Informed Consent Form. To ensure their anonymity, the letter I (interviewee) was used in the text to present their excerpts, accompanied by a number corresponding to the sequence of interviews by the degree of kinship with the man, and the age.

# RESULTS

We interviewed 17 family caregivers of men suffering from chronic illness and depending on home care. Most of the caregivers were female (n=15) - wives (n=12) or daughters (n=3) - aged 49-83 years, with complete primary education (n=10), with varied chronic conditions (n=11) including arterial hypertension (n=3), diabetes mellitus (n=3) and depression (n=1). On the other hand, the men had hypertension (n=12), diabetes mellitus (n=9), Alzheimer's disease (n=4), depression (n=2), multiple sclerosis (n=1) or Spondylitis (n=1) and/or

stroke sequelae (n = 8).

The thematic categories are presented and discussed separately, but then articulated together. Intrinsic to each thematic category, the nuclei of meaning obtained from the analytical process are also articulated in order to allow greater fluidity to the interpretations.

# Determinants of the chronic condition and coping with dependence on care

The participants pointed out the incapacitation, dependence and needs of men with chronic illnesses. In some cases, their a total dependence on care, from basic needs - food and body hygiene - to those involving complex care and the handling of technologies: gastrotomy and tracheostomy.

He is totally dependent. Bathing, oral hygiene, bearding, hair cutting, getting dressed, bedding, standing up, feeding (I2, wife, 49).

His bowel doesn't, his bladder doesn't work... I have to give him laxative drugs once a week, to pee he has to take a pill every day, otherwise he does not pee [...] it is something that everything stops working, all his organs are gradually stopping [...](15, wife, 73)

Before he started with this disease, he knew how to take the medicine, but now he even remembers the medicine, but if are not monitoring him, he takes the medicine all the time, then I myself separate the medicine and save it, but he does not trust someone else (I8, wife, 74).

You need to bathe him in bed, feed by a tube in the belly, he has "tracheo" to breathe. The medicine is through the probe, everything smashed to avoid clogging (E11, wife, 63).

In general, the participants pointed some factors that would have acted as determinants for the onset of the chronic condition or for the occurrence of some events that limited the man's ability to perform self-care, triggering their dependence on other. Among the factors identified are behaviors that are harmful to health, once practiced by men, but also the management of work-related stress, mental disorders, such as depression, and even the situation of abandonment.

Because he drank too much, smoked too much [...](I1, mother, 67).

[...] he declined overnight after his family abandoned him (I2, wife, 49).

Then he was getting nervous and then he had the "stroke" [...](13, wife, 53).

Oh, it was diabetes [...](I4, wife, 64).

[...] it was stress in the trade bussiness. I believe it was a depression, stress [...](I6, wife, 71).

He is a person who, after his mother died, he stayed in the shop, he had no right life, no right food... all he got was to drink (I9, wife, 61 years).

He never liked greenery. He used to eat sausage, canned beans [...](I12, brother, 44)

It is noteworthy that, faced with the various disabilities, needs and dependencies, the caregivers perceive different postures and feelings sketched by men: fear, panic, social isolation, aggression and revolt. The difficulty that men have to face not only the chronic condition, but also the situation of dependence, is clear in the speech of the caregivers. These findings, expressed by the family members themselves, seem to stress even further the care.

Every time he comments on his things it seems that he is even sadder [...] I do not know, he got very scared, in panic (I1, mother, 67).

He cries, she gets sad, he says he does not like to depend on people (I1, mother, 67 years).

[...] if the medicine runs out, he becomes angry, you have no idea, and he is aggressive (I3, wife, 53).

He felt yes, that he is depending on others and this I try to make him take it out of his head, because it is bad, instead of helping him [...] the end of the table there is his, we motivate him to that. But I believe, that he feels this "loss" in the day by day by his own attitudes of not being able to follow the development of others (I6, wife, 71).

This was death for him. Even today, what he can do, he does, he does not ask anyone for anything. My father always worked all his life, and when he retired, two years later, this happened, he lost sight, it was terrible. He does not leave home [...] I call him to go to my sister's house but he won't go [...] (17, son, 34).

He already cried a lot, he already had depression, he already asked to leave him in the hospital (I9, wife, 61).

Therefore, besides the aspects of causality and reaction to the situation that is presented to men, in the view of the caregivers, sex and gender aspects are perceived, those that are imbricated in the care process and in the position of dependence on care, as seen in the following thematic category.

# Care and dependence surrounded by sex and gender aspects

Based on the perception of family caregivers, it was observed that gender and the cultural representation of gender generate some particularities in the care provided to men, influence the genesis of male illnesses, and the way men behave toward the chronic condition and dependence on care. Caregivers themselves draw comparisons between men and women to explain the neglect with self-care and the negative consequences of maintaining male roles, such as the family provider. Regarding sex-related biological specificities, the participants perceive difficulties in providing care due to, for example, the body size and weight of these men, in addition to describing their strategies.

First, men care less than women, that's a trend. Men start to worry with care when he is already sick, right? Because men are like that, I think they have that need to be the man of the family, strong! If he feels anything, he will not seek help, he thinks: if I go to the doctor, I may be sick, I have to stop, and what about my family? (I2, wife, 49).

I have to lift him alone from the bed, I hug him and sit him in the wheelchair... to bathe him, I have to lift him all up like this {gesture} [...] Dou you have idea of what is to be sick and unable to move?! Then I hug him like this and I raise him and my grandson lowers his clothes and I sit him in the chair and take him to the shower, then I dry him, all very carefully, and then I dress the clothes up to a certain height and I put him back in my arms and my grandson raises his clothes... I suffer my dear. No one knows what I'm going through (I5, wife, 73).

I think that men are not the same as the women; women is more careful, always going to doctors. Men are like "machos" that do not need doctors, you know? (I5, wife, 73)

I think it was because of carelessness really. [...] his leg was amputated quickly (I14, daughter, 49).

Other gender-related aspects were presented by the interviewees in their perceptions, but anchored in actions practiced by men. I3, for example, points to cessation of work as a contributing factor to the decline of her husband's health status. On the one hand, one can also see the lack of acceptance of the condition of illness and dependence on men and, on the other, the motivation to continue to face the disease and even to make future plans, such as having a child.

Before that, he used to play soccer, but after he left the bank, he began to decay (I3, wife, 53).

He does not accept that. He thinks that as he was always a live person, very agitated, did not stop... and when he felt that there is no return (I10, wife, 65).

He likes his nephews, when he's with them he doesn't even remember what happened. He wants to get well soon because he wants to get a girlfriend and get married and have children. That's what he says. (I12, brother, 44)

In addition to permeating the male attitude before chronic illnesses and dependence on care, it was observed that, in the perception of family caregivers, gender constructs also condition the inclination for care, especially because there are elements that reinforce the attribution of care as a feminine trait.

He is a man full of prejudice, he always depended on me, from the sock to be put up to the clothes. But I must have contributed to the habit too... but I like to give myself and this donation makes him feel dependent on me, do you understand? But I think men are a little bit spoiled too (I4, wife, 64).

When he is going to take the medicine, he says: "- for what?". And I say: "I also take it!". When he had a lot of pain in his leg, I would say, "I have it too!". "My arm hurts". I say, "mine hurts too". Then everything he feels, what he said he had, I would say I had it too. All the medicines, I said: "I'm taking it!" By doing this, he slowly started to "recover" (I12, brother, 44).

It is evident in I4's speech an allusion to cultural influence over how men understand their role and that of women. I fact, even the woman's speech, who proved care, it seems to be in harmony with the "habits" and the "prejudices" of men, since she believes that she has contributed to the reproduction of this dynamic. Furthermore, there is a strong affective involvement in the care of men, translated in the need to "donate" of oneself, which may also predispose to greater emotional overload.

# The process of illness/dependence and the dimensions of the social support network

Each man and family experienced different processes of illness/dependence. In cases where the degree of dependence of men was present in basic needs, it was perceived that the involvement, the coping and the suffering experienced were more shared between man and family. Thus, an evident interdependence arose: a dependence of man on his family due to dependence on care; and of the family on the man by conducting activities based on the needs of men and resulting from the limitations that changed daily life.

At first I had meetings just to learn how I was going to "move" him (I3, wife, 53).

At first we said, what are we going to do? How are we going to adapt? (I2, wife, 49)

I left the driving school that I was going to get my lincense, because I have a car, he had the car right, but that's how its is, I let it go to take care of him, I left my job as a saleswoman, I gave up a lot of things and now I even stopped going out (I8, wife, 74).

The nurse stayed 24 hours a day, he and I, I took my leave, plus a few medical declarations[...] 24 hours, day and night, without sleep. Because he would rip everything, he did not speak... it was difficult (I12, brother, 44).

[...] first he had time to leave, now he does not have any more, he stays alone inside the house all the time, it's difficult [...] only when the boys take us for a walk (I13, daughter, 59).

The statements of the caregivers show that the professional care is responsible for the follow-up of the sick man and for the supply of necessary material for the maintenance of health, although the family realizes that these material is not enough. On the other hand, the church and informal supporters offer religious, material and emotional support.

So I seek a lot of guidance with the priest (I1, mother, 67). They are always here giving advice, measuring his pressure, you know? They do not give that assistance that we need, no, I think a bedridden person deserved more, you know? I think a bedridden person needed more (I5, wife, 73).

The guys from the "little unit" come home so that he does not have to go there, it's always the same people, the doctor, the nurse [...] when the medicine is over, they come too (17, son, 34).

There are a couple of friends who help us a lot. And the Catholic Church, since they heard about the case and everything, I went to ask for help, to this day the church provides me with a market basket, I am very thankful for that! This is what has supported us (I9, wife, 61).

In vaccines they come home. At least once or twice a month they come here, they measure the pressure, and in some days, they even called (I9, wife, 61).

#### DISCUSSION

The narratives presented here allowed us to highlight the peculiarities of family care for men with chronic conditions, especially those surrounded by sociocultural signs. These signs and peculiarities influence both the path of men in the situation of chronic illness and their experience of dependence on care, and the perceptions of the caregivers, who are mostly females.

In this sense, the finding that the majority of the caregivers was female corroborates the findings of a study carried out in a municipality in the Northwest of Paraná<sup>(15)</sup>. Besides the observation that most caregivers are women, it is relevant in the present study to observe the perceptions of these caregivers on the care provided to men with chronic conditions and the eminent unfoldings for the family and the social support network.

A study carried out in Chiapas, Mexico, with men who had hypertension and/or type 2 diabetes (DM2), family members and health professionals, revealed factors that are both determining for the chronic conditions presented by men and barriers to their participation in self-management of care - the time, the age, the perception about the chronic condition, the work and the relations with the health services (16). Gender appears to complement these factors, materialized in the role and behavior of men and women in family relations of care to chronic conditions. In the speech of the men interviewed in the study, they themselves, as a result of gender models, have difficulty recognizing and accepting the chronic condition and dependence on care (16).

Aspects related to gender, expressed by the participants of the present study, are imbricated in a model of masculinity considered hegemonic. Mention is made of hegemonic masculinity when there are predominant positions and behaviors among men: the idea of invulnerability, the resistance to recognize fragilities or need for care, persistence in sustaining the role of family provider and the valuation of work, to the detriment self-care<sup>(7)</sup>. Such factors, throughout men's life, can predispose them to injuries and determine the occurrence of chronic conditions that compromise the quality of life not only theirs, but of the family environment as well.

In chronic conditions, as illness, the needs considerably exceed the biological dimension and begin to embrace psychosocial, economic and cultural aspects<sup>(17)</sup>. Furthermore, the complexity of the family caring phenomenon is reiterated based on the observation of the frequent rearrangements necessary for the realization of the family's care potential, understood as the set of movements performed by the family members to be able to meet the demands and needs of the sick person<sup>(18)</sup>. These efforts include the search for professional care, which, as a rule, needs to be family-centered so as to enable a

partnership in identifying problems and planning care<sup>(19)</sup>.

In fact, the act of caring is turned to women. Thus, during their routine, caregivers perform several tasks: bathing, helping dressing, preparing and providing food, transporting, not to mention household chores. These activities can physically and emotionally wear out the female caregivers, leading them eventually to poor health<sup>(15)</sup> It is therefore necessary to know the socio-cultural aspects that are imbricated in this family care provision to men and this dynamics of attribution of care to women. Thus, as recommended by core assumptions of FCC, especially those of dignity and respect, it is imperative that health professionals offer qualified listening, consider the choices and perspectives of the person and his family, and incorporate, in the planning and provision of care, how much listening brings knowledge<sup>(13)</sup>. In this way, these professionals have the opportunity to open up to the needs of the family and rethink a practice capable of meeting their needs.

The presence of the relational perspective of gender was identified in the participants' speech, configuring a line of thought in which male and female roles and models are identified based on the comparative and relational exercise of the cultural aspects related to men and women, allowing a mutual understanding of these socio-cultural constructions. The concept of comprehensive health care is part of this perspective, which presupposes that, in order to plan and implement actions directed at men or women and their families, it is important to think about the specificities of the health/disease process.

Understanding family care for men from the perspective of socially constructed traditional roles allows both family and health professionals to seek coping and transformation strategies that are more coherent and effective than simply reproducing cultural trends or even provoking confrontation with and/or disregarding male health needs.

Although the thematic approach always refers to the masculine linguistic term: caregiver, in most cases the role of the main caregiver, within the family context, is assumed by women, who provide shelter, food and support for maintenance and prolongation of the life of the group. This role has historically been constructed, as women who experience the care of the family appoint their daughters to assume such responsibility.<sup>(19)</sup>.

These women are mainly in the role of spouses or daughters of the sick person, often in precarious

economic situations, with a low level of schooling, who dedicate full-time care and experience an overload, besides in some cases also presenting illnesses<sup>(19)</sup>, as it was seen in this study.- It is observed that family caregivers of these men resort to a support network, in order to facilitate care, to obtain guidelines and the resources needed to cope with the chronic condition and the dependence. This search crosses different possibilities, among them the religious aid, the sources of informal and formal support, mainly from the FHS teams.

The study shows that health professionals, in turn, also prefer to teach women to teach men what to do with their health, because they consider that men are difficult, less able to perform care than women and do not take their health seriously<sup>(20)</sup>. Such attitudes, which are very common in professional health practice, and sets a further distance between men and care and health services, also increase the overload of women. Hence the need to know more deeply what families observe and think about care and the relationship of closer interdependence before the fragility of men, in order to qualify the care and strengthen the support network.

With a focus on FCC, the demands of these families exceed the sporadic visits and the supply of material, since they involve emotional aspects resulting from the home care process. Furthermore, the socio-cultural characteristics of men are imbricated in this care, in which families end up having to face difficulties and barriers imposed by the model of masculinity, obstacles that health professionals also face due to the existing limitations in the deeper issues related to care - gender relations and health<sup>(11)</sup>. These limitations are mainly associated with inherent cultural aspects, masculine identity, knowledge gaps about the health of men and the distance associated with the lack of knowledge on the importance of their presence in health production scenarios<sup>(21)</sup>.

During the interviews it was possible to note that caregivers are more focused in providing care than on caring for themselves, and they claim not to have time to take care of their own health. This can generate a physical and emotional wear and tear that contribute to the onset of stress and even depression. The overload of family members is evident, as they change their routines to assume their role, especially in cases where they can not count on the help of other people<sup>(9)</sup>.

The findings of the present study are considered to corroborate those of another study carried out with 11

relatives of people with chronic conditions (both sexes) in the Northwest of Paraná, who pointed out a minor or even non-existent support network, when the primary caregiver was a woman<sup>(15)</sup>. This fact makes caregivers and the cared person even more vulnerable.

Therefore, thinking about interventions based on FCC in the context of care for men with chronic conditions does not mean disregarding the importance of these men in caring relationships and relegating all responsibility to the family, but rather integrating these actors, together with health professionals, as co-responsible for care. Stabilizing chronic conditions requires people to become proactive; they need to leave their place as merely patients to become agents of their health, with the support of the health team and its social protection network, in order to produce collaborative interactions<sup>(22)</sup>.

Regarding the difficulties of adopting the family as the focus of the present study, it is considered that, from the family members, it is possible to obtain a perspective that does not always exactly match that of the family member who is ill, because each individual experiences his chronic condition in a very peculiar way. However, in the case of men, there may be resistance in socializing issues related to their health, and the act of accessing family members may allow the professional to obtain more subsidies to improve care, or otherwise generate discomfort in men who may not wish have perceptions about them revealed by the family.

Addressing the family is a challenge for researchers and health professionals because, although it is a tool to expand the possibilities of obtaining information and a wider perspective of care, more and more demands arise, extrapolating, in some moments, the spectrum of action and professional support. Among the challenges, more specifically, is the need to deal with gender issues related to care. These are historical constructs rooted in the social imaginary. Caution is also important

regarding the need to approach the family, in the sense of not disqualifying the autonomy and self-efficacy of the sick individual, which denotes the importance of working with the family to be extremely dynamic.

It is necessary to persist in the search for the understanding of the socio-cultural dimensions that involve the care of the family, since it is within the family that a great part of the cultural content of individuals is formed, including attitudes towards health. Focusing the care on the family can substantially contribute to the design of health care projects and policies for men, health care evaluation for this population, and the way in which daily interaction occurs between PHC service users, family members and health professionals<sup>(11)</sup>.

### **CONCLUSION**

The findings of the present study highlight the lack of zeal on the part of men in maintaining their health, besides the non-acceptance of the chronic condition and vulnerability. Family care in the home context to men with a chronic conditions and depending on others for their basic needs is centered on the female figure.

It is observed that these caregivers have to face issues involved in socio-cultural relations and constructions - gender models - that end up making both men and families vulnerable. It is therefore reiterated the urgent need to provide family members with a moment to narrate their experiences in the care process and to socialize their needs in the care of the man, including their perceptions about the support they have or not.

Thus, it is important that nursing and health professionals take gender differences in chronic illnesses and dependence on home care provided by the family as a basis for planning and providing effective care focused on the needs of men and their families.

# PERCEPÇÕES DA FAMÍLIA ACERCA DO CUIDADO AO HOMEM COM ALGUMA CONDIÇÃO CRÔNICA

### **RESUMO**

O objetivo deste estudo foi conhecer as percepções da família acerca do cuidado a homens com condições crônicas e dependentes de cuidados domiciliares. Estudo de natureza qualitativa, realizado junto a 17 familiares de homens em adoecimento crônico, que adotou os referenciais do Cuidado Centrado na Família e Gênero. Os dados foram coletados em 2014, por meio de entrevistas abertas, realizadas nos domicílios dos familiares, e submetidos à Análise de Conteúdo, modalidade temática. Os resultados mostram que a maior parte dos familiares cuidadores era do sexo feminino, tinha idade entre 49 e 83 anos e também apresentava alguma condição crônica. Os homens cuidados tinham, em sua maioria,

hipertensão arterial, diabetes mellitus e conseqüências de acidente vascular cerebral. Os cuidados referidos foram desde o auxílio no banho até o manejo de dispositivos mais complexos — traqueostomia e gastrotomia. Os familiares apontaram diferentes motivos comportamentais pelos quais, acreditam eles, os homens adoeceram; relataram que realizavam os cuidados necessários, embora os homens manifestassem resistência em recebê-los. Conclui-se ser importante considerar diferenças de gênero em relação ao adoecimento crônico e à dependência de cuidado familiar no domicílio, como subsídio para fundamentar o planejamento e a prestação de um cuidado centrado nas necessidades do homem e sua família.

Palavras-chave: Saúde do homem. Família. Doença crônica.

# PERCEPCIONES DE LA FAMILIA ACERCA DEL CUIDADO AL HOMBRE CON ALGUNA CONDICIÓN CRÓNICA

#### **RESUMEN**

El objetivo de este estudio fue conocer las percepciones de la familia acerca del cuidado a hombres con condiciones crónicas y dependientes de cuidados domiciliarios. Estudio de naturaleza cualitativa, realizado junto a 17 familiares de hombres con enfermedad crónica, que adoptó los referenciales del Cuidado Centrado en la Familia y Género. Los datos fueron recolectados en 2014, por medio de entrevistas abiertas, realizadas en los hogares de los familiares, y sometidos al Análisis de Contenido, modalidad temática. Los resultados muestran que la mayor parte de los familiares cuidadores era del sexo femenino, tenía edad entre 49 y 83 años y también presentaba alguna condición crónica. Los hombres cuidados tenían, en gran parte, hipertensión arterial, diabetes mellitus y consecuencias de accidente cerebrovascular. Los cuidados referidos fueron desde la ayuda a la hora de ducharse hasta el manejo de dispositivos más complejos — traqueostomía y gastrostomía. Los familiares señalaron diferentes motivos conductuales por los cuales, creen ellos, los hombres se enfermaron; relataron que realizaban los cuidados necesarios, aunque los hombres manifestaran resistencia en recibirlos. Se concluye ser importante considerar las diferencias de género en relación a la enfermedad crónica y a la dependencia de cuidado familiar en el hogar, como base para fundamentar la planificación y la prestación de un cuidado centrado en las necesidades del hombre y su familia.

Palabras clave: Salud del hombre. Familia. Enfermedad crónica.

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