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## KNOWING THE FAMILY FUNCTIONALITY UNDER THE VIEW OF A CHRONICALLY ILL PATIENT

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**ABSTRACT:** The objective of the study was to identify the perception of the chronic patient on the functionality of his own family and know the way he perceives this context. It is a descriptive study of qualitative nature, accomplished with 12 chronically ill individuals. Data was collected from April to November 2010, through semi-structured interview, based on the instrument APGAR of family evaluation. The results showed four functional families, five moderately dysfunctional and three severely dysfunctional. It was observed, throughout the patient's statements, feelings of autonomy loss, decrease on the participation of family decisions, changes of roles, loss of freedom of choice to accomplish new tasks, isolation desire and the fact of considering themselves a burden for the family. It is concluded that the chronic diseases, which require family care, are followed by the need of family readjustment and reorganization. These factors can trigger conflicts and dissatisfaction by the patient and hinder the family relationships.

**DESCRIPTORS:** Chronic disease. Family relations. Family. Nursing.

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## CONHECENDO A FUNCIONALIDADE FAMILIAR SOB A ÓTICA DO DOENTE CRÔNICO

**RESUMO:** O objetivo do estudo foi identificar a percepção do doente crônico sobre a funcionalidade de sua família e conhecer como ele se percebe neste contexto. Estudo descritivo de natureza qualitativa, realizado com 12 doentes crônicos. Os dados foram coletados no período de abril a novembro de 2010, utilizando entrevista semiestruturada, baseada no instrumento APGAR de avaliação familiar. Os resultados mostram quatro como famílias funcionais, cinco moderadamente disfuncionais e três severamente disfuncionais. Nos depoimentos dos doentes crônicos foram observados sentimentos de perda de autonomia, redução da participação nas decisões familiares, troca de papéis, perda da liberdade de escolha para realizar novas tarefas, desejo de isolamento e o fato de sentirem-se um peso para a família. Conclui-se que as doenças crônicas que necessitam de cuidados familiares são acompanhadas da necessidade de reestruturação e readequação familiar, fatores estes que podem desencadear conflitos e insatisfação por parte do doente, dificultando as relações familiares.

**DESCRIPTORIOS:** Doença crônica. Relações familiares. Família. Enfermagem.

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## CONOCIENDO LA FUNCIONALIDAD FAMILIAR BAJO LA ÓPTICA DEL ENFERMO CRÓNICO

**RESUMEN:** El objetivo del estudio fue identificar la percepción del enfermo crónico sobre la funcionalidad de su familia y conocer cómo él se percibe en este contexto. Estudio descriptivo de naturaleza cualitativa, realizado con 12 enfermos crónicos. Los datos fueron recogidos en el período de abril a noviembre de 2010, por medio de entrevista semiestructurada, basada en el instrumento APGAR de evaluación de la Familia. Los resultados muestran que cuatro familias fueron funcionales, cinco moderadamente disfuncionales y tres severamente disfuncionales. En las declaraciones de los pacientes fueron observados sentimientos de pérdida de autonomía, reducción de la participación en las decisiones familiares, cambio de papeles, pérdida de la libertad de elección para realizar nuevas tareas, deseo de aislamiento y el hecho de sentirse un peso para la familia. Se concluye que las enfermedades crónicas que necesitan cuidados familiares son acompañadas de la necesidad de reestructuración y readecuación familiar, factores que pueden desencadenar conflictos e insatisfacción por parte del enfermo, dificultando las relaciones familiares.

**DESCRIPTORIOS:** Enfermedad crónica. Relaciones familiares. Familia. Enfermería.

## INTRODUCTION

The family is a complex and dynamic system influenced by the experiences of historical, social and cultural environments. The family relationships, to some extent, interfere in the process of health and illness from its members, as well as the experience interpretation of each person of the family, before this process.<sup>1</sup> Also, it is known every family has specific characteristics that make it unique in the way of being, and because of this, it presents different behaviors in relation to the need for adaptation when a member becomes chronically ill. However, over time, there is a family restructuring and the person responsible for the exclusive care will appear automatically, so, there will be changes in the family dynamics and a possible exchange of roles and functions in order to assist the individual, in the process of falling ill.<sup>2</sup>

But, even being considered the primary care unit of the subject, in a state of illness, the family may find difficulties and hesitation in the face of stressful factors related to the chronic disease care. Therefore, the chronic illness might act as a force driving the family members to focus intensively on the sick person care, and reformulate the biopsychosocial aspects of the family life.

In this scenario, it is possible to understand that illness experience, especially when related to chronic diseases, means to suffer changes in all aspects of the individual and family life. Besides, it is noteworthy that requires facilitative attitudes in order to cope with the situation posed, promoting the search for the reconstruction of a new reality and identity of the patient and his family.<sup>2</sup>

The process of coping with illness, in the family, depends on factors such as the stage of life where the family is, role within the family of the sick member, implications that the impact of the disease causes on each member, and how the family gets organized during the disease period.<sup>4</sup> In this context, it is necessary a family readjustment in which all members start to perform tasks and assume roles in order to allow the family system operation, demonstrating a good adaptation to the situation. The way in which these relations and adaptations happens, will determine the family system classification in functional or dysfunctional.<sup>5</sup>

The functional family system is the group that responds to the conflicts and critical situations in order to get emotional stability, seeking appropriate solutions through its own resources. The family members are able to harmonize their own

duties toward the others in an integrated, functional and affective form, protecting the integrity of the system as a whole and functional autonomy of its parts.<sup>5</sup> On the other hand, dysfunctional family systems are those in which there is no commitment to the dynamics and system maintenance by its members, prioritizing private interests at the expense of the group, without assuming their roles within the system.<sup>5</sup>

In situations of chronic disease, it was observed that depending on the seriousness degree people assign to these conditions, some adjustments may occur or not within the family.<sup>6</sup> If the condition is asymptomatic, as occurs in some chronic diseases like hypertension, changes are often considered as unnecessary. But, if the sickness gets worse, especially when there is some kind of dependency related to these diseases, the situation will require the restructuring of all family members roles.<sup>6</sup>

The importance given by empirical researchers in learning the dynamics and functionality of the family, in this study, took place from the experience in the extension project "Identifying the permeability between family caregiver and professional at different times of family life", linked to the Nucleus of Studies, Research, Assistance and Family Support (NEPAAF), at the State University of Maringá. Thus, it was considered the family importance to the satisfaction and integration of the chronically ill patient with the family environment, and the consequent influence in the adaptation and coexistence with the disease.

Thereby, the present study is justified by the need to know the dynamics on family functioning in relation to the chronically ill patients care, and also identify how they perceive themselves and realize the family dynamics in order to enable the identification of dysfunctions and early intervention, in the search for the restoration of this structure of relationships. This is an important step for health professionals in order to promote care quality improvement provided to the patient, family and caregiver.<sup>2</sup> Thereby, the objective of the present study is to identify the chronically ill patient's perception about the functionality of his family and know the way he perceives himself, in its context.

## METHODOLOGY

This is a descriptive, exploratory and qualitative study conducted with 12 chronic patients receiving family care and who are assisted, along with their families, by the extension project "As-

sistance and support to the families of chronic patients at home", linked to the NEPAAF.

Data were collected from April to November 2010, through semi-structured interviews conducted in the households and only those patients who were able to verbalize their perceptions and experiences. It was requested a reserved place only for the participation of the researcher and interviewee in order to ensure greater accuracy on the information and freedom of expression, considering that the questions were related to the family functioning and dynamics. To facilitate this privacy, the visit was conducted by two researchers, so that one of them performed the interview with the patient, and the other one talked about other care aspects to the relative who were at home.

The interview was guided by a questionnaire consisting of seven semi-open questions about family functioning, based on the tool APGAR of the family, which was proposed by Smilkstein in 1978.<sup>7</sup> The purpose of this instrument is to identify the satisfaction of one or more members on the family functioning. It has a small number of items, it is easy to apply and the cultural level of the respondents does not influence the results.<sup>8</sup>

The acronym APGAR, from the English language, means<sup>9</sup> Adaptation (satisfaction degree according to the received attention), Participation (satisfaction with communication and participation in the solution of problems), Growth (member satisfaction with the freedom to change roles and start new activities), Affection (member satisfaction with the emotional interaction in the family), and Resolution (the way time is shared).

The answers are presented in a Likert type scale of three points: almost always, sometimes and rarely, and it is worth from two to zero points consecutively. When the sum of the scores obtained is between seven and 10, indicates highly functional family; from four to six, moderately dysfunctional family and from zero to three, severely dysfunctional family.<sup>9</sup>

The instrument extension was performed because the intention was not only to measure the family functioning, but also to identify the perception of the chronic patient before this functioning, and then, to learn how he perceives himself in the family context. This way, the participant was requested to justify his answers to each item, and answer two more questions: is there anything you would like to be different in your family relationships? How do you feel when you need to be cared by your relatives?

For data analysis, the interviews were transcribed in full and subsequently subjected to a process of content analysis<sup>10</sup> consisting of a pre-analysis and data exploration, followed by the systematic organization of data into thematic units with detailed description of relevant characteristics. So, the results were grouped into thematic categories, according to the similarity in the statements.

The development of the study occurred in accordance with the established by the Resolution 196/96 of the National Health Council, and its design was approved by the Ethics Permanent Committee with Human Beings Research of the University of Maringá (Opinion number 084/2006). The participants of the study or their legal guardians signed a term of Consent in two copies. For the subjects differentiation and preservation of their identities, it was used the following codes: the letter P, related to the patient, followed by the reference number of the interview, and with the letter M or F to indicate the sex of the person.

## RESULTS AND DISCUSSION

### Study participants characterization

The studied patients were between 50 and 89 years, and predominantly between 70 and 79 years. More than half (seven) were female and the most frequent health problems cited were: hypertension and Diabetes Mellitus, with associations to other diseases such as stroke, heart failure, dyslipidemia and rheumatic diseases. The progression of chronic diseases causes extensive repercussions on the affected people lives, especially the elderly. This is because diseases are often multiple and if they were not properly monitored they could lead to difficulties in performing daily activities and having social relationships.<sup>11</sup>

Regarding family income, nine participants reported incomes ranging between one and three minimum wages, two of them received on average four minimum wages and only one reported above five minimum wages. Low income, in this study, is an important fact because minimum wages may limit the access for food and social care, significantly compromising people's life quality,<sup>4</sup> especially when it is related to chronic patients and/or elderly, due to the need for spending on medicines and health services.<sup>12</sup>

The type of family varied; it was six complete nuclear type families (formed by biological parents

and unmarried children), four extended families (it has more than one generation in the same environment), and two single parent families (consisting of unmarried children and one parent.)<sup>4</sup> It is worth noting that extended and complete families offer greater support and financial resources to care for the chronically ill person,<sup>4</sup> especially when it comes to the elderly, as it was the case of some participants in the study.

When this type of family constitution is present, it is observed a decrease in the family members' workload, reducing the overload and improving care quality through the alternation among its members. In these cases, it is important to characterize the emotional and instrumental support, because its members act as facilitators of care.<sup>12</sup>

### Family functionality

In relation to the family functionality, it was found through the score obtained with the application of the APGAR scale, that only four individuals consider their families as functional, and the others consider them dysfunctional, either in the moderate way (five) or the severe form (three).

Regarding the first component of the APGAR on family, which is adaptation, seven respondents stated that when looking for family help almost always are satisfied with the attention they receive, four of them are sometimes satisfied and only one affirmed he is rarely satisfied.

In relation to the second component, which is participation, five subjects confirmed they are sometimes satisfied with the way their family speaks and shares the resolution of problems with them, four of them are almost always satisfied and the other three are rarely satisfied.

The third component is related to growth, that is, it assesses how the family accepts and supports the desire of the individual to initiate or pursue new activities, and make changes in their lives. This item presented the highest number of rarely satisfied respondents (six), the other five reported they are almost always satisfied, and only one is sometimes satisfied.

Affection refers to the way family shows affection and reacts to emotions such as grief, sadness, anger and love. It was noted that three chronic patients reported being almost always satisfied with the emotional interactions within the family context, six of them were sometimes satisfied and the other three were rarely satisfied.

The fifth component refers to the problem-solving capacity, then, five respondents reported to be sometimes satisfied with the manner the family and the individual share time together; four declared to be rarely satisfied, and three to be almost always satisfied.

Finally, it is observed the elements that contributed a lot to the identification of dysfunctionality; in the studied families were affection, participation and resolution, while adaptation was the largest contributor to the identification of a positive functionality.

The family is the main source of support and assistance that members appeal to solve problems, especially when they are associated with health or lack of it.<sup>1</sup> When there is a health problem along with limitations due to old age, the family is still more necessary because its involvement in simple and complex activities. Some examples of activities are meal preparation, perform direct care, provide leisure activities, medication administration of continuous use and monitor consultations to assess the health status.<sup>13</sup>

This way, families assume a significant part of responsibility in the provision of health care for their members. In cases of chronic condition, their participation is critical to the disease, health maintenance and prevention of possible complications associated with it.<sup>7</sup> Therefore, the assistance implemented by the family is designed to preserve the patient's life, according to its own possibilities, cultural patterns, particular needs of each individual and conditions of the environment they live in.<sup>14</sup>

Before the need for family adaptation to the assistance and the patient himself to receive care, it is possible to highlight the importance of knowing the family functionality, because the relationship among family, care quality, satisfaction of the patient and the caregiver is directly proportional.<sup>8</sup>

It is noted, with this study, that the need for family adaptation brings discomfort and dissatisfaction to the patients:

*[...] I feel very bad because they [referring to the daughters] have to take turns to look after me and they do not leave me alone [...]. I feel like a burden after I had cancer. I know I complicate my daughter's life; the poor girl has to do everything for me (P6F).*

The presence of a family member with a chronic illness that requires care, even if he is not dependent, causes discomfort and dissatisfaction to the patient, because he believes this brings physical and emotional overload to the caregiver's life,

directly affecting the family dynamics. Thereby, it is needed the entire family go through an adaptation process and be able to offer all the necessary support to this patient.<sup>14</sup>

Participation was also a relevant factor to the family dysfunction, whereas only four participants are satisfied with the way issues of common interest are discussed and the solution of problems is shared:

*[...] sometimes I want to solve things by myself, because this is my house, but I cannot decide anything. It seems I have to ask permission for everything. Even with all the problems I have [referring to the pathologies he has] I can still make some decisions [...] I do not like to be the last one to know things (P12F).*

*[...] it seems that after I was bedfast, my daughter thinks I have lost the way to handle things. She may have any trouble, but she never talks to me, I never know about anything [...] then, I find out and I feel bad [...] I feel useless here at home (P1F).*

In the statements of P12F and P1F, it was observed that the participants of the research believe their participation in decision making and family problem solving is reduced, and they associate that to their pathology. Still, in these statements, it was identified the loss of autonomy and freedom on decision making. The participation of chronic patients in matters of common interest and resolution of family problems is crucial to consider that family as functional, especially in cases where the patient is elderly. Therefore, the higher the satisfaction of this criterion, the greater the family functionality is before a crisis situation.<sup>9</sup>

When they were asked about the satisfaction with the freedom to change roles and start new activities, which were demonstrated in the category growth, it is observed that only five participants were almost always satisfied:

*[...] when I want to do something different I have to wait for my daughter's decision, I tell her that she is my mother and I am her daughter. I want to go out, do different things I do every day, but she says I have to stay at home and wait for her to arrive [...] (P6F).*

The disease appearing and the consequent need for a caregiver cause family restructuring and roles redefinition.<sup>15</sup> Nevertheless, this new role definition is not always experienced as something good, which can be verified in the testimony of P6F. Becoming a sick person includes the experience of a number of separations marked frequently by experiences of fragmentation and loss of autonomy over his own body. Autonomy

is a determining factor in the life quality, because it enables to make daily decisions.<sup>16</sup>

Chronic disease may act as a force that drives relatives to focus intensively on patient's care, relegate biopsychosocial aspects of the family life and elect the primary caregiver of that individual. This fact may, in some cases, generate the exchange of roles. So, the person who represents the family caregiver and provider becomes a weakened figure due to the chronic disease, and then, he requires care. These caregivers, in turn, become aware of their importance on patient's life, believing they are patient's tutors.<sup>3</sup>

Autonomy loss not only delineates daily practices or resolutions of family and domestic problems; it was also noted this goes much further, acknowledging the loss of subjects individual space:

*[...] they are always paying attention on me, wondering why I am quiet, without respecting my sadness and silence [...] it makes me feel uncomfortable [...] It seems they want to control my feelings (P6F).*

Through the testimony of P6F, it was observed again the autonomy loss feeling experienced by the interviewee. Because, it evidences that the family members do not allow moments of isolation and reserves stated as necessary by the participant. However, this same desire for isolation, in which being alone is more preferable than living with the family, might be a reflection of conflictive and unsatisfactory family relationship.

The elements affection and resolution presented the most critical results, because there were only three participants almost always satisfied with the emotional interaction in the family, and the way free time is shared. In relation to the affection, it was observed that the need for communication of facts and issues that bother them are seen as something individual and unnecessary to be shared. About the resolution, the P4M speech appears affected by the disease, since the patient can no longer have autonomy to solve alone everyday situations; it seems he lost the "power" to solve his own things and he depends on someone's care for any decision making:

*[...] my daughter has her things, my granddaughter, too, so I try not to bother them with any nonsense. When something is bothering me, I prefer to keep quiet [...] I wish I could take care of myself, then, I would be able to have my home and live alone, without bothering anyone's life (P4M).*

Before the family structures change, to "depend" on someone's care creates a situation of

discomfort that can be verified in the testimony of P4M. The need for a caregiver usually causes feelings of worthlessness, loneliness and constant desire to solve everything without “bothering” another person. But, when there is a good family relationship and greater degree of intimacy, with trust and respect this situation may be experienced differently.

Analyzing the topic resolution and trying to know the participants' satisfaction in the way free time is shared, it is observed, through the testimonies, the feeling of family loneliness especially in the marital relationship:

*[...] my husband just thinks of his problems. My daughter gives me some attention, but I cannot rely much on her [...] she has her life, her husband; she cannot take care of me. So, I feel very alone [crying] I wanted to be loved by my husband; I wanted someone who cared for me. That's it! (P2F).*

*my husband and my son, when they are not sleeping, they are in the street [...] they do not talk to me, I am my own company, so I get sad and depressed [...] then, they think I am faking, just to get their attention (P9F).*

The elderly seem to tolerate better the living conditions of aging when they have near them people who are affectively significant, emphasizing the family members and friends. Nevertheless, they sometimes experience an isolation situation and family abandonment, which creates feelings of loneliness, as it is discussed in this study.

However, for some participants, the isolation became something necessary and even considered as a mechanism of escape from reality, which inserts the autonomy loss along with roles exchange and loss of their function as family caregiver. Thus, it was common to hear from some participants that they preferred to be alone, isolated and it did not bother them. But, before the eyes of the researchers, it was possible to realize that was not their real desire, according to their facial expressions.

*I do not mind that they [referring to the family] do not give me attention, it does not bother me. I always try to be alone, to suffer alone. I do not talk about my feelings, I do not cry in the corners of the house (P3M).*

It is noteworthy that these individuals experience a “mix of feelings”. On the one hand, the person wants attention, affection, he feels alone, but at the same time, he does not want to “bother” his family members' lives. Moreover, the very existence of the disease may interfere and alter the emotional state, with feelings of sadness, loneliness, discouragement, lack of will, lack of motivation, nervousness and insecurity.<sup>17</sup>

All this problems experienced by the chronic ill person might lead to social isolation, depression increase and expectations of improvement decrease, contributing to a feeling of hopelessness and loneliness, which can be associated to the items detailed in the aspects of recreation and leisure.<sup>15</sup> However, when the opposite happens, the presence and support provided for the family become a healing factor in the process of maintaining the chronic pathology. This support offering appears in many different ways, including concern about health and well being, purchase of medicines, accompanying medical consultations and visits, among others:

*[...] when my daughter calls me and I am more quiet, she keeps asking me if I am sad [...] then, I say no and she says I should be feeling something and I do not want to worry her, even if sometimes I am in a low mood (P5F).*

*[...] whenever I have a problem I solve it with my husband. He is always very considerate with me [...] he gets my medicine, takes me to the hospital when I need to go. We have a relationship of companionship, and that is very good for me. My daughter calls me every week to know how I am [...] she also worries about me a lot. I feel very well cared [laughs] (P2F).*

Going from caregiver to be cared by the family is a difficult situation to experience, the reports of P5F and P2F show that depending on the type of family relationship, this new ‘phase’ can be experienced in a simple way, and considered as the greater “proof” of care and love on the part of relatives.

Family and friends influence in the disease control, treatment, diet and participating in a program of regular exercises. A study<sup>1</sup> has shown that people with *Diabetes Mellitus* who had adequate support from friends and family were more successful to self-care behaviors. Assessing patient's means of support might help to identify his needs and assistance in order to avoid the long term complications.<sup>18</sup> Thereby, it is important to know the context where the chronic patient is inserted and identify his family relationships for a good quality of care provided.

## FINAL CONSIDERATIONS

The expansion of the instrument APGAR of family and its application resulted important to assess the experience of an individual who was caregiver, and later he became cared by his family. It is important to highlight that this situation re-

quires a family restructuring, and many times, the meaning for one family might be totally different to another one. This happens due to the influence of the type of family relationship, besides the differences in social and cultural context.

Before that, it is quite important not only to assess family functionality, but also know how the patient behaves and perceives in the family life through the presence of a degenerative chronic disease, with the aim of performing interventions adapted to each observed reality in order to restore the balance in family relationships, and collaborate with the life quality improvement of the chronic patient.

It is believed that with sufficient time to establish a trusting relationship with the person, the verbalization of feelings might have been more explored and discussed aspect. But, the results showed how diverse the feelings are from the perspective of the chronic patient. Feeling as a burden to the family, experiencing roles change, feeling alone, and at the same time, looking for isolation and even feeling welcomed by the family are situations experienced by these patients who lose their role as caregiver and start to be cared.

It is crucial for health professionals to train caregivers and supervise the execution of daily care activities that are necessary to the chronic patient, until the family feels safe to assume them. The family must also be prepared to deal with feelings of guilt, frustration, anger, depression and others accompanying this responsibility, beyond the huge variety of feelings experienced by the patient. Therefore, procedures that encourage a reflection on becoming a person with care needs, certainly contribute to improve the quality to the human living process.

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