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## **Coping strategies for caregivers of children with a chronic disease: a methodological study**

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### **ABSTRACT**

**Aim:** To develop a decision support model to identify coping strategies for caregivers, with regard to chronic diseases in childhood.

**Method:** methodological study carried out in two stages: detecting the problem and establishing rules for making decisions. It was based on a study conducted with the caregivers of children with chronic diseases.

**Result:** it is logical model for decision support.

**Discussion:** coping strategies focused on the problem, seeking support with the aid of religious and social support networks, act positively in terms of adapting to chronic diseases; however, strategies focusing on emotion generate a negative response.

**Conclusion:** the model of decision support can assist health professionals in identifying coping strategies that facilitate or hinder the adaptation of caregivers concerning chronic diseases in childhood.

**Descriptors:** Chronic disease; Child; Family; Decision Support Techniques.

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## **INTRODUCTION**

Advancements in the scientific process of diagnosis and therapy are factors that have contributed to a shift in the paradigm in health care. Previously it was centered on the treatment of acute severe diseases, but now it focuses on care, and seeks the best prognosis and quality of life for individuals with chronic diseases. This new feature is associated, among other things, with improvements in the area of immunotherapy as well as the early identification of chronic diseases<sup>(1)</sup>. In this context, healthcare work must be expanded in terms of the provision of full care to enable the accomplishment of a degree of happiness for the individual, since a cure is not possible.

Chronic disease can be understood in terms of the time variable, as it is likely to last for an extended period of time, and may be incurable<sup>(2-3)</sup>. A chronic condition in childhood interferes with the functioning of the body of the child, requiring follow-up and assistance from health professionals; it reflects in the process of the growth and development of the child and affects their daily life and that of their family<sup>(4)</sup>.

Considering this concept, the family also becomes the object of care, because its structure undergoes changes to accommodate the needs of the sick child, with a redistribution of roles in the family micro system and changes in the way they relate internally and with regard to society. Besides the changes in the household, the family must adapt to the new dynamics of living associated with constant visits to healthcare services and hospitalizations related to the chronic condition in childhood, distancing the child and his caregiver from the other members of the family, which may cause suffering<sup>(4)</sup>.

Thus, the family needs to receive care and support for coping with the new situation that is presented<sup>(5)</sup>. Therefore, health professionals need to be trained to meet the demands of family care from an integral perspective and to respect the uniqueness of those involved in this process.

Responsibility for the care provided to children with a chronic disease belongs to the family who, by assuming this responsibility, acts to prevent complications<sup>(3)</sup>. However, the majority of care and support for the sick individual tends to be performed by only one

family member – the primary caregiver/family member<sup>(3)</sup>. This individual, even informally, provides basic care in a full or partial manner, to a close relative in such a way that it presents some type of dependence<sup>(6)</sup>.

Although the health concept recognizes the psychosocial influences on the establishment and maintenance of the disease, the prevailing practice in pediatrics is still focused on meeting the biological needs of the child. However the caregiver, by not being understood as an object of study, remains on the fringe of events<sup>(6)</sup>. Thus, the role of family caregivers and the implications for their health needs to be the targets of scientific study in order to understand the pressures arising from the continuous care of children with chronic diseases.

This way, we try to think of new forms of work organization in health that understand the child-family dyad in its singularity. Therefore, it is necessary that health professionals meet the specific demands of caregivers - whether physical, emotional, affective or social, namely, the subjective factors - that may be difficult to realize in practice, since it requires the possibility for a horizontal dialogue and qualified listening time. These are indispensable issues for the expansion of health care in such a context.

As health professionals we value technical perfection. Consequently, we may acknowledge that we have difficulty working with subjectivity and things that cannot be measured. Therefore, the development of a logical model to support decision making in health becomes of great importance. Thus, the proposed model of decision support can use the knowledge of experts in order to formulate rules, which will provide a structure for existing knowledge and which will assist practitioners in their decision making<sup>(7)</sup>.

Decision making in healthcare is a complex task as it involves human beings who are not, normally, purely rational. The behavior of such individuals is not intentional and dispassionate. Rather, it is governed by emotions and involves potentially inconsistent and conflicting values, influenced by their relationship with one another in society<sup>(8)</sup>. One factor that may hinder decision making in healthcare is the uniqueness of the individuals concerned, as the particularity of each patient precludes generalizations.

Although the rationality of human beings is limited, it is very difficult for some individuals to work in what are uncertain conditions and which depends on perception. In this sense, the model of rule-based decision support is a systematic one that clearly defines the aspects or stages to be considered by the decision-maker in order to obtain a satisfactory result that is easy to understand and to use<sup>(9)</sup>.

In this type of model, the rules do not define cause-effect relationships, working only as a resource for decision making that, when tested using the inference mechanism, can be combined to make a proper decision with high probability of success<sup>(10)</sup>. Therefore, the knowledge represented through rules should be organized on the computer in an easy to understand format, by using the logical operators "IF" and "THEN". The first indicates the condition for the rule to be activated, and the second shows the conclusion in the event that the condition was satisfactory<sup>(11)</sup>. The use of this type of model allows new rules to be added to the knowledge base without affecting the existing rules<sup>(11)</sup> through the connectives "AND" and "OR", which allows the formulation of a chain of rules.

Believing that the development of a rule-based decision support model can assist the healthcare team to differentiate potential coping strategies, the aim of this study was to develop a model for decision support to identify such coping strategies for caregivers associated with chronic diseases in childhood.

## **METHOD**

This is a methodological study using a Decision Support Model based on rules to identify the coping strategies of caregivers associated with chronic diseases in childhood. For the formulation of this model, some steps need to be considered. The first is the detection of the problem<sup>(9)</sup>, that is, to identify the situation to be resolved which requires a proper decision making process. In the case of this study, it was found that the coping strategies developed by family caregivers are not always positive and, therefore, may cause damage to the health of the caregiver, delaying the process of adaptation to the child's chronic condition<sup>(12)</sup>.

The second step for the construction of the decision support model is the development of a decision-making flow, that is, the formulation of the rules that will assist decision-making<sup>(9)</sup>. Therefore, it is necessary to collect information and analyze it carefully in order to identify alternatives that ensure the legitimacy of the decision. The development of this model was based on research<sup>(2,12-13)</sup> conducted with family caregivers and dealing with strategies for coping with chronic diseases in childhood. Therefore, targeting the rationality of decision-making often required in health work, the data discussed in the above mentioned studies will serve as a tool for the development, through rules, of a decision support model.

Although it is known that a person, especially a child, who is affected by an incurable condition affects the whole family micro system, this study will be focused on the figure of the primary caregiver, since the need for continuous care can be a burden, given its physical, psychological and cultural demands<sup>(14)</sup>.

In this sense, the speech of caregivers constituted the data for the formulation of the rules of the proposed model, in which the logical operators "IF" (x) and "THEN" (y) will be used, meaning that X represents the type of coping strategy developed by the caregiver, and Y represents a positive or negative feature of the strategy.

## RESULTS

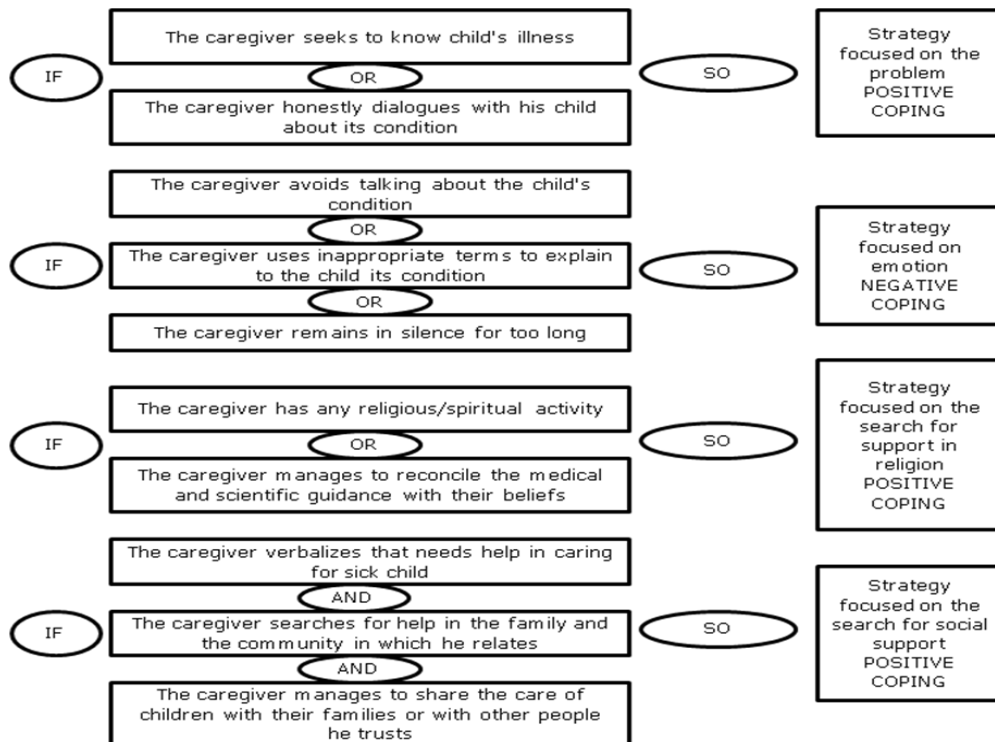
Coping strategies can be: a) focused on the problem associated with when the caregiver approaches the stressful situation, planning actions to control the perceived threat - the disease and its effects<sup>(12-13)</sup>; b) focused on the emotion in which, unlike the first, the primary caregiver detaches him/herself from the situation causing stress and acts according to his/her emotions, possibly representing a false control concerning the source<sup>(12-13)</sup>; c) focused on the search for support in religion, which is understood as the emphasis given to the thoughts and attitudes that bring spiritual peace and is usually related to some religious practice<sup>(12-13)</sup> and; taking into account the physical and emotional burden arising from the continuing care, primary care providers may focus on d) social support. This works as a

coping strategy and is associated with the search for family and/or community support, as well as instrumental, emotional or information backing<sup>(12)</sup>.

The results show that the search for knowledge or open dialogue with the child are coping strategies that focus on the problem and involves acting positively towards the process of adaptation to the child's chronic disease (Figure 1). Other positive coping strategies are the search for support from religion, and the search for social support. In this, we perceive the connection of the rules by the connective "AND", meaning that all rules must be satisfied so that coping will be positive, and will make the management of situations that cause stress easier.

Coping strategies focused on emotion are characterized by the silence of the caregiver, by the use of inappropriate terms by the caregiver to explain the disease to the child, or by the fact that the caregiver does not talk about the condition of the child. It is observed that these rules are connected by the connective "OR", which means the presence of one of these conditions alone is enough to characterize negative coping.

**Picture 1:** Model for decision support to identify coping strategies of family caregivers concerning chronic diseases in childhood. João Pessoa, Paraíba 2012



Source: Authors research

## **DISCUSSION**

### **Coping strategies developed by family caregivers of children with chronic diseases**

Coping can be defined as the set of strategies adopted to deal with, and adapt to, stressful situations or something that is perceived by the individual as an imminent threat, including cognitive processes and behavioral and emotional responses that aim to manage the crisis and reduce or modify the demands created by the situation<sup>(12)</sup>.

Confronting a chronic disease is an ongoing and necessary process, so an individual will be able to adapt him/herself to a permanent situation that may cause stress or constitute a threat<sup>(12)</sup>. The way in which caregivers deal with the child's illness varies greatly. There are those who turn themselves inward, others who express their feelings openly, some of whom look for information, while others expect people around them take the initiative with regard to the situation<sup>(5)</sup>. Thus, the strategies developed for coping can be considered positive or negative for managing the disease, and are related to the way those involved understand the world and relate to society.

The search for knowledge about the disease is an important step in the process of adaptation to a chronic condition in childhood, since the caregiver meets his/her need for information, understands the causes and the prognosis, as well as his/her responsibility regarding this situation<sup>(2)</sup>. Thus, seeking to know the disease is a strategy that focuses on the problem<sup>(12)</sup> and allows the development of positive coping with regard to the chronic disease (Picture 1).

When caregivers realize that there is something wrong with their child, they seek to understand the diagnosis, and often face a lack of information and a lack of staff training to provide the support they need. As a result, they experience doubts, uncertainties and anxieties<sup>(2)</sup>. Therefore they seek explanations alone in books or on websites, in an insatiable search<sup>(2)</sup>.

Thus, the healthcare team must play a part in this search process by clarifying doubts, providing research sources and providing guidance on precautions to be taken at home. It is important that the language used by the professionals is clear and easy to understand, avoiding superficial and/or strictly technical information. Thus, the caregiver can interact with

the child with greater security and autonomy<sup>(15)</sup>, since the care of children with chronic disease requires specific skills, can come to know the illness and its symptoms, thereby minimizing them. Therefore, knowledge can help family caregivers when it comes to meeting the demands arising from the illness in childhood<sup>(15)</sup>.

In addition, the knowledge about the disease strengthens the caregiver as, upon learning about the pathological process, prognosis and treatment, s/he starts to experience the disease through what appears at each moment, and not in terms of what might happen. This can contribute to reducing the burden of stress arising from the daily care of a child with a chronic disease<sup>(12)</sup>.

Faced with a difficult management situation, the caregiver and his/her family can avoid a dialogue with the child in an attempt to spare it from concerns and some degree of suffering. In a study on the impact of child liver transplantation with regard to family dynamics<sup>(16)</sup>, it was observed that the family may have doubts such as whether or not to talk about the disease with the child, and may prefer to remain silent or talk only among adults. However the caregiver who has an open dialogue with the child, explaining the characteristics of the disease, its treatment and the implications for their growth and development, faces the chronic condition in a positive way (Figure 1) through a strategy focused on the problem<sup>(12)</sup>.

However, when the family caregiver avoids talking with the child about the condition or uses words that stir its imagination, it means that s/he is focusing on facing emotions<sup>(11)</sup>, which can have negative repercussions for the process of adaptation to chronic illness in childhood (Figure 1).

It is in childhood that some basic themes of life acquire meaning<sup>(16)</sup> and the presence of a chronic disease brings perceptions about life, illness and death. The way these themes are handled in infancy defines the meaning and importance that the child assigns to these subjects<sup>(17)</sup>. Thus, it becomes essential that the child understands what is happening to its body, its illness and its treatment. Therefore, it may at least position itself as a protagonist in the situation that it experiences<sup>(17)</sup>.



We emphasize the importance of a multidisciplinary team approach that works dialogically, guiding the family in terms of a proper communication with the child, taking into account its age and its cognitive development, as the child could present difficulties when it comes to understanding the disease, taking into account that it is an unpleasant subject, and which the child has no control over.

The fact that family caregivers may have some religious or spiritual activities without becoming overwhelmed by specific religious dogmas and being able to reconcile the medical guidelines with their beliefs, mobilizes them to a positive coping approach with regard to the disease (Figure 1), through a strategy characterized as seeking support from religion<sup>(12)</sup>. This prevents a more intense physical and mental imbalance than might otherwise be the case<sup>(18)</sup>. Although spirituality and religion have different concepts and often appear intertwined, both strengthen the caregiver, contributing to the formation of values, social interactions, behaviors and healthy practices that help in coping with situations that cause stress<sup>(18)</sup>.

In religion and spirituality, family caregivers seek the comfort that science denies. While science may cause uncertainty due to an ominous prognosis, spirituality encourages the family and produces feelings of hope or acceptance of the conditions imposed by the child's illness<sup>(18)</sup>.

The healthcare team needs to know the religious and spiritual practices of the family, and to encourage them, provided they bring emotional comfort. The understanding that the health-disease process is influenced by biopsychosocial and spiritual factors demands the recognition of the healing power present in gestures, words and in faith itself<sup>(12)</sup>.

Religious institutions may be part of the social network in which caregivers are inserted, providing a source of social support. This can be understood as a process that occurs in interpersonal relationships and, through built bonds, provides material, emotional and affective support, contributing to the reciprocal welfare of the individuals involved<sup>(19)</sup>. Thus, the search for social support is a positive coping strategy<sup>(2,12,19)</sup> for the caregiver regarding the child's chronic condition (Figure 1).

This strategy is seldom practiced by family caregivers, because, although there is the emotional impact on their lives, it cannot be recognized or verbalized as, due to cultural

aspects, it is difficult for a mother or other family members to consider the child as a weight or a burden in their lives<sup>(14)</sup>. In addition, many caregivers demonstrate a reluctance to ask for, or accept, help as it may represent a sign of failure or be an opportunity to mitigate, by excessive caution, an unconscious guilt<sup>(3)</sup>.

Therefore, the fact that the family caregiver verbalizes the need for help is not enough to identify his/her coping strategy, requiring him/her to verbalize, seek help in his/her family or community, and accept a sharing of the demands associated with the continuous care of the child (Figure 1).

It is a responsibility of the healthcare staff to act in this process, encouraging caregivers to share their experiences as well as the care of their children and being available to assist the family in coping with the chronic disease of the child. Therefore, qualified listening and the construction or strengthening of social networks that provide support, are tools that contribute to reducing the caregivers' burden associated with the continuous exercise of their function.

Health professionals play an important role in the social network in which caregivers are inserted, because, besides the technical, instrumental, emotional, moral and affective support, they can act to reactivate social ties or stimulate the construction of these ties<sup>(20)</sup>. Recognizing the contribution of established relationships in social welfare for caregivers promotes the empowerment of community actors who, although always present, are not always valued as subjects that could help positively with the family's adaptation in the face of a chronic condition in childhood<sup>(20)</sup>.

## **CONCLUSION**

Knowing the difficulty that some health professionals have in grasping subjective elements that are capable of interfering in therapy, this model can provide support in terms of identifying positive or negative coping strategies.

The type of strategy developed by caregivers influences the process of adaptation to chronic illness in childhood, in which case the caregivers may exacerbate the suffering

resulting from the maintenance of practices that interfere with both the physical and emotional aspects of their lives.

Professionals who are able to realize the different ways in which the caregiver tackles the disease, may act by demystifying concepts and strengthening social networks that provide support, thus reducing the burden and suffering attached to living with a chronic disease in childhood.

We emphasize the importance of an interdisciplinary team approach, with professionals who act by articulating knowledge and experiences, recognizing the biopsychosocial processes of illness, and using a horizontal dialogue as an essential tool to build new possibilities of care in pediatrics.

It is recommended that other models for decision support can be developed, combining the quality of data and the use of logical mechanisms for knowledge discovery in order to enhance the decision-making of health professionals in the care of children with chronic disease. This study was based on qualitative research that represents the reality of the place where empirical data was collected. However, this may be insufficient to allow us apply the model in other realities, since, the qualitative research data involved is related to the subjectiveness of the research subjects.

It is worth mentioning that a decision support model based on rules does not replace practical wisdom. Nevertheless, it is capable of approaching reality through the use of existing data to create rules. Thus, the presence of the model is not sufficient for improving the quality of healthcare to caregivers of children with chronic diseases. The logical model facilitates the work of professionals, but they should not be limited to the model, since all humans are different and the professionals should respect such individuality. This certainly is a weakness of any model that aims at generalizations. Practices such as dialogue, qualified hearing, a confident approach and bonding are still needed for the expansion of care to the individuals under consideration in this study.

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