

O MANEJO FAMILIAR DA CRIANÇA COM CONDIÇÕES CRÔNICAS SOB A ÓTICA DA TEORIA DA COMPLEXIDADE DE EDGAR MORIN

THE FAMILY MANAGEMENT OF CHILDREN WITH CHRONIC CONDITIONS ACCORDING TO EDGAR MORIN'S COMPLEXITY THEORY

EL MANEJO FAMILIAR DEL NIÑO CON CONDICIONES CRÓNICAS BAJO LA ÓTICA DE LA TEORÍA DE LA COMPLEJIDAD DE EDGAR MORIN

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RESUMO

Objetivo: O objetivo desse estudo foi refletir acerca do manejo familiar da criança com condições crônicas. **Método:** O cuidado familiar mostra-se imprevisível, por isso, utilizou-se a “Complexidade de Edgar Morin”, como embasamento para esta reflexão, visando contribuir para a melhor compreensão das ações desenvolvidas pelo enfermeiro no cuidado a estas famílias. **Resultados:** A partir das ideias temáticas dos artigos analisados que responderam ao objetivo proposto, surgiram três categorias para a reflexão: “As condições crônicas da criança”, “O manejo familiar da criança com condições crônicas” e a “Complexidade de Edgar Morin” e o “Cuidado familiar”. **Conclusão:** As questões examinadas neste ensaio podem subsidiar a reflexão dos profissionais de enfermagem, buscando um olhar para o todo, sem fragmentar a realidade vivenciada por estas famílias, rompendo com a visão simplificadora e permitindo uma compreensão mais próxima do real.

Descritores: Família; Crianças; Doença crônica; Dinâmica não linear; Enfermagem.

ABSTRACT

Objective: The aim of this study was to reflect about the family management of children with chronic conditions. **Method:** Family care is unpredictable, thus, we used the “Edgar Morin’s Complexity”, as the basis for the reflection, aiming at contributing to a better understanding of nurses’ actions in the care of these families. **Results:** From the thematic ideas of the analyzed articles that responded to the proposed objective, three categories emerged for reflection: “Children’s chronic conditions”, “The family management of children with chronic conditions” and “Edgar Morin's Complexity and family care”. **Conclusion:** The issues examined in this paper can support nursing professionals’ reflection, seeking a look at the whole, without fragmenting the reality experienced by these families, breaking with the simplifying view and allowing a closer understanding of the reality.

Descriptors: Family; Children; Chronic disease; Nonlinear dynamics; Nursing.

RESUMEN

Objetivo: Este estudio tuvo por objeto reflexionar sobre la gestión de la familia de los niños con enfermedades crónicas. **Método:** El cuidado de la familia resulta impredecible, así que usa la complejidad de Edgar Morin, como base para la discusión y pretende contribuir a un mejor conocimiento de las acciones tomadas por los enfermeros en la atención de estas familias. **Resultados:** A partir de las ideas temáticas de los artículos analizados que respondieron al objetivo propuesto, había tres categorías para la reflexión: “Las condiciones crónicas del Niño”, “La gestión de la familia del niño con condiciones crónicas” y la “Complejidad de Edgar Morin” y el “Cuidado de la familia”. **Conclusión:** Los temas examinados en este trabajo pueden apoyar la reflexión de los profesionales de enfermería, en busca de una mirada al conjunto sin fragmentar la realidad que viven estas familias, rompiendo con la visión simplificada y permite una mejor comprensión de la realidad.

Descritores: Familia; Niños; Enfermedad crónica; Dinámicas no lineales; Enfermería.

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INTRODUCTION

Although the North-American culture has used the term family management for decades, it is still unusual in our culture. Family management is defined as “the family’s role while responding actively to the disease and the different situations of health care”⁽¹⁾.

The study of this concept began with Kathleen Knafl and Janet Deatrck, in 1990, in the United States, when they developed the Family Management Style Framework (FMSF) as initial structure model for understanding how family unit incorporated the demands of the child’s disease in family life. Later, the concept was translated and adapted to the Brazilian culture, and has been used in several studies in the area of pediatric nursing⁽²⁻⁴⁾.

Based on a literature review, the original model of the FMSF aimed to identify relevant aspects of how the family unit respond to the child’s chronic illness. This model was highly abstract, given the limited literature of the time, and did not allow preparing the content of the three main dimensions: defining the situation, managing behaviour and the socio-cultural context, not explicitly identifying the style of management used by the family^(1,3-4).

Researches has been carried out since the publication of its initial structure and provided evidence of its usefulness in developing models that provided the family’s answers or reactions to the experience of disease.

Subsequently, there was an attempt to elaborate FMSF dimensions from a new study of literature review, with the objective of meeting the advances of the researches on the family’s responses to the child’s chronic illness. The review allowed refining the FMSF structure and proposing a definition for the family’s management of the child’s chronic disease and health, bringing advances to nursing evaluation and intervention with families⁽¹⁾.

The management model was extended in order to promote a theoretical structure, creating patterns of behavior that can be evaluated more effectively, generating interventions that meet the family’s demands in various contexts of chronic disease⁽¹⁾. Since they brought the identification of broad spectrum of family management styles and specification of unique strengths and areas of family difficulties in handling the child’s chronic illness, these studies were important to enhance the FMSF usefulness

as a guide to expand the understanding of the factors that contribute to the functioning of the individual and the family in the context of chronic disease⁽¹⁾.

The FMSF model identifies cognitive and behavioral aspects of the experience of families of children with chronic illness and serves to emphasize the areas of strengths and difficulties. In addition, it allows conceptualizing the management style formed by individual perceptions and behaviours of family members. Researches using this model are indicated for expanding knowledge in the area⁽¹⁾.

The interest in knowing the different styles of family management, in various situations of disease and with diverse approaches, has grown in recent years. Although still little known in Brazil, international literature has used the expression “family management style” to refer to a relatively consistent pattern of response of the family unit to any disease condition. The term “management” reinforces the focus on behavioral response familiar active ingredient, differentiating it from other components of the family dynamics, as communication and decision making⁽³⁾.

Researches show that understanding the family dynamics and functioning is essential to identify strategies to promote effective care and quality⁽⁵⁾, as well as understanding the variability of the experience of families of children with disease chronic. Therefore, changes that affect these families and their children provides nursing professionals with an opportunity to broaden the support and resources to those who experience this condition.

This dynamic process consists of constructing, deconstructing and reconstructing, demanding the family a reorganization of roles on the child’s needs. These changes bring significant consequences for family life⁽⁶⁾.

The reflection about family management of children with chronic conditions becomes necessary to offer these families this appropriation and special aid⁽⁶⁻⁷⁾, in order to understand the term “family management” for the nurses’ closest approach to the child/family in these conditions. Thus, this theoretical and philosophical study aimed to reflect the complexity of family management of children with chronic conditions, using the “Edgar Morin’s Complexity” as basis.

METHOD

This is a theoretical-philosophical reflection of family management of children with chronic conditions, using “Edgar Morin’s Complexity” as basis.

“Complexity” is a way of understanding the world, being able to integrate, in reality, relationships that support the coexistence among beings in the universe, enabling the recognition of order and disorder; of single and diverse, stability and change, anyway: the complexity carries with it the actions, interactions and determinations that constitute the world of phenomena and, mainly, the notion of uncertainty⁽⁸⁾.

The complex thought integrates ways of thinking, opposing to reductionist mechanisms. It is a mental activity that seeks to integrate linear and systemic, simplifying and totalling thinking modes of the modern era, in an effort to promote union, operating with diversity of thoughts: the simple and the complex⁽⁹⁾.

The greatest question of complex thought is to combine simplicity with complexity, exercising the contextualization. Obviously, the precariousness of knowledge raises the difficulty of contextualization. Contextualizing and globalizing are exercises necessary to everyday life and indispensable in our planetary era, when there are no important problems of a nation not connected to others of global nature⁽⁹⁾.

For Morin, complexity is seen as a type of thought that does not separate, but connect and search necessary and interdependent relations of all aspects of human life. It integrates different ways of thinking, as opposed to reductionist, simplifying and separating mechanisms⁽¹⁰⁾.

The subject, in Morin’s vision of complexity, is able to self-organize and establish relations with each other, transforming continuously. In this alterity relationship, he/she finds self-transcendence, surpassing, interfering with and modifying his/her environment in a self-eco-organization from his/her ethical dimension, which is not universally or culturally imposed to every individual, but reflects his/her choices, perceptions, values and ideals⁽¹⁰⁾.

Therefore, the reflection about family management of children with chronic conditions becomes necessary for appropriation and has been used in researches in Brazilian culture⁽⁷⁾, aimed at understanding the term “family management” for the nurses’ closest approach with the child/family in these conditions.

RESULTS AND DISCUSSION

From the thematic ideas contained in articles analyzed to understand the study object, three categories emerged: “Children’s chronic conditions”, “The family management of children with chronic conditions” and “Edgar Morin’s Complexity and family care”.

Children’s chronic conditions

Chronic diseases have long duration and generally slow progression. Some examples are cardiac diseases, cerebrovascular accident, cancer, respiratory diseases and diabetes, and they stand out as causes of mortality in Brazil, representing 74% of all deaths in 2014⁽¹¹⁾. However, we have not adequately collected data about the prevalence and mortality of chronic disease and child health. The U.S.A. estimates that 20 to 30% of children and adolescents suffer from some chronic disease or chronic health condition. These conditions can affect children throughout their lives, also affecting the family unit.

The improvement of necessary routine care, systematic activities for the management of the disease, the lifestyle and the family dynamics, individual or collective, may influence the health outcomes in long term⁽¹²⁾. Most children with chronic disease live at home, causing great impact on the family system, in addition to usually requiring health services.

Chronic diseases change children’s daily life. These changes often relate to limitations, especially physical, due to signs and symptoms of the disease, which may lead to hospitalizations, as the disease progresses⁽¹³⁾.

Despite scientific and technological advances, some diseases, especially chronic ones, promote organic, emotional and social changes, resulting in several repercussions on life and family dynamics, requiring constant care and adjustment of the patient and his/her family to the new reality, thus significantly affecting family functioning⁽¹⁴⁾.

A study review on adolescents living with chronic illness shows that this situation can change the development, besides delaying planning for the future, which may be due to frequent hospitalizations, among other causes⁽¹⁵⁾.

Chronic illness in childhood affects the patient’s existential dimension, involving many facets; it can affect social participation, education, sports, leisure, relationships with family members, group and interpersonal

relations and also financial status⁽¹⁶⁾, making essential a proper support network for better coping this condition⁽¹⁷⁾.

Given the situations arising from chronic disease, a multidisciplinary approach becomes essential, involving not only its clinical aspects, but also the psychological and social repercussions, for both the child as the family. Furthermore, health professionals shall consider the importance of the aforementioned issues, in addition to staying always attentive to aspects that transcend the child's medical treatment. The comprehensive overview of the evolution of the disease, knowledge and considerations of the child's relations with significant figures surrounding him/her, can determine the success of the treatment⁽¹⁸⁾.

In this case, nurses play a key role in the families' adaptation to the disease, to assist them to find the best way to confront this difficult task.

The family management of children with chronic conditions

Brazilian researchers have emphasized the importance of studying the family and its coping and coexistence strategies with the sick child. The chronic disease affects the family as a whole, including the child. Both the sick child as his/her family undergo a process of adaptation and coping strategies to manage and cope with changes due to the chronic disease. Thus, each one experiences this process differently. Those changes end up imposing changes in family life, providing readaptations imposed by phases of transition and strategies creation to face the new situation^(14-17,19).

The search for adaptations and redefinitions of roles is necessary and studies show the complexity of these amendments, because, in this moment, with the new reality of living with chronic illness, the family needs to resign its identity as a family group⁽¹⁹⁾.

The new condition requires mobilization of families that are often more able to tolerate changes and, in this situation, assume functions, solve problems effectively and are able to utilize external resources⁽¹⁷⁾. Some families strengthen their relationship with the sick child, making these relationships also stronger between parents, between children and among other family members.

However, these strategies used by the family to face the child's new condition can be positive or negative for managing the disease and

for better quality of family life, being related to the way those involved understand the world and relate to the society⁽²⁰⁾. To achieve this goal, families need to construct the meaning of the child's illness in their lives, besides demarcating the perception and behaviors related to the experience of living with the new condition, always aiming at the maintenance of life⁽²¹⁾.

Knowing the family's demands can minimize the feeling of helplessness and loneliness. Accordingly, the family must be aided and encouraged to find resources that help dealing with the child's disease condition by pursuing its own demands and confronting challenges at every stage of the process. Therefore, it can become better adapted and competent to care for the child and to be able to manage the situation they all live, with less suffering⁽¹⁹⁾. Thus, nursing knowledge should seek family dynamics, in order to empower it to deal with the burden caused by disease and help to take on the protagonism of its history⁽¹³⁾.

Controlling and managing chronic disease relate to the preparation and trust of the family in relation to the disease. Nevertheless, the complexity and the stage of the disease can influence this control⁽²²⁾. Stimulating family autonomy and decreasing dependency on health services is extremely beneficial for these families because the management capacity is directly linked to family safety when dealing with the sick child⁽¹⁹⁾.

The nursing staff is responsible for identifying and valuing sources of social support to families with children with chronic conditions in the community, in order to promote articulated and integral care to these people, since they will be permanent and central focus in their lives⁽¹⁹⁾.

Edgar Morin's Complexity and family care

In the light of complexity, thinking about family management of children with chronic diseases requires considering elements such as structuring and destructuring familiar as important elements, since linearity of facts can be replaced by circularity or recursion, all parts and the whole have equal weight, making important to consider them together⁽²³⁾.

In the face of the child's chronic disease, the family's construction and deconstruction occur, with continuous changes and dependent on the stage of disease and the phases of family life. Thus, complexity is a type of thinking that

considers incoming, internal and external influences, faces uncertainty and contradiction, and lives with the solidarity of the existing phenomena. It emphasizes the problem and not the question that has a linear solution. As the man, a complex being, so is the thought⁽⁸⁾.

Context, global, multidimensional and complex need to become visible, because information and data need to be placed in their context to acquire meaning. Just like each singular point of a hologram contains all information of what it represents, every human being contains, in an hologrammatic manner, the whole of which he/she is part⁽⁹⁾. In this way, the child with chronic disease is, at the same time, whole and part of his/her family.

We need to consider that complex units, like the human being and society, are multidimensional, because the human being is, at the same time, biological, psychic, social, affective and rational. Therefore, relevant knowledge must face complexity; remembering that there is complexity when different elements are inseparable constituting the whole, such as economic, political, sociological, psychological, affective, mythological aspects. In these cases, there is, then, an interdependent, interactive and inter-retroactive tissue between the knowledge object and its context, the parts and the whole, the whole and the parts, and among parts⁽⁸⁾.

When understanding the human being as a complex being, the care directed to him/her is also a complex interdisciplinary action, targeting to transdisciplinarity. This way of thinking makes improving the question of the complexity of problems of human health desirable, using the aid of rewiring knowledge for developing actions⁽²³⁾.

A study on the relation between gerontogeriatric nursing and complexity showed the elder as a being with unique specificity and multidimensionality that cannot be disregarded, since we cannot take care of the elder in a reductionist manner, considering the paradigm that believes to be the objective, right and organized knowledge, but permeated by uncertainty and disorder, which not only exist, as indeed play productive paper in the universe, directing the real complex thought, which stares in the face, using a new look and experiencing the disorder and uncertainty⁽²⁴⁾. The same occurs with family care, when the family becomes the object of care and should be considered as a

whole and not fragmented, since one sick member affects the family dimension.

For properly developing nursing care to the family of the child with chronic disease, some paths need to be considered, such as: maintenance of the family's well-being and autonomous life of family, whenever possible, in the home environment and where such care focuses on the needs of the child and family, not only on the disease; development of a multi, inter and transdisciplinary work and sharing responsibilities⁽²⁴⁾.

Disorder and changes in the life cycle are facts present in the context of these families and, consequently, this dialogic, order and disorder, is also in the process of nursing work, in family care of children with chronic conditions.

The care of the child with chronic disease raises demands on the family, redefining roles, time availability, financial and tasks reorganization. It considers a complex care, requiring the family the implementation of coping strategies⁽⁵⁾. Given this care complexity, we base on Edgar Morin's theory for a better understanding of this phenomenon.

In health field, in which phenomena that involve health-disease process feature multiple dimensions with other public policies and even in the way society develops and organizes the sector, the complex thought reveals itself as an important approach to understand these phenomena in their multiple dimensions, reconnecting them, joining them⁽²⁵⁾.

CONCLUSION

Considering family management of a child with chronic conditions as a complex situation, this theoretical and philosophical reflection defends the proximity of this practice with the assumptions of Edgar Morin's Complexity. The family is able to suffer influences received, is able to adapt or not to established condition, able to unite or fragment when one of its members is sick.

The nursing staff needs to consider, in family care, the understanding that reality is complex and requires the vision quest of the whole, breaking with the simplistic vision of the experienced reality: only the child's illness.

Rethinking the family management of the child with chronic conditions, considering complexity, is to understand nursing care as something that goes beyond, fully offered, soaked by empirical and scientific

knowledge/influenced by the present/past of this family, relationships with others and with itself. A look at this family according to the complexity is looking in the eye, leaving prejudices and judgments behind, in order to understand the family as a unique, complete and complex being and in need for a sympathetic look.

Understanding complexity allows identifying key elements of family answers, such as the situation definition, the behavior of family management and the consequences perceived by the family regarding the child's chronic conditions, and contributing to interventions that will promote the strengthening and the better management of family to the new condition.

In this situation, we described the need to develop a strategic attitude, based on the perspective of complexity that aims at a complete service to a child with chronic illness/family. In this way, we have used Morin's complexity to understand better the family's condition and, thus, prevent fragmented care in the context of the child's chronic disease.

Thus, it requires relating complexity and family health-related management, considering the complexity of the family's situation and the needs to improve the attendance from the analysis of the experience meaning. The disease process needs to be understood as a set of facts resulting from this process and its implications on the life of the child/family.

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