

**CHANGES IN THE EVERYDAY OF THE ADOLESCENT WITH CHRONIC CONDITION
AND OF HIS FAMILIARS: A REFLECTIVE ANALYSIS**

MUDANÇAS NO COTIDIANO DO ADOLESCENTE COM CONDIÇÃO CRÔNICA E DE SEUS FAMILIARES:

UMA ANÁLISE REFLEXIVA

CAMBIOS EN EL COTIDIANO DE ADOLESCENTE CON CONDICIÓN CRÓNICA Y DE SUS FAMILIARES:

UN ANÁLISIS REFLEXIVO

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ABSTRACT

Objective: To reflect on the modifications in the pattern of everyday life of adolescent with chronic disease and of their relatives after the diagnosis. **Development:** The experience of adolescents and their relatives with regard to the chronic disease are permeated by different feelings, guided, mainly with the coexistence stage with the disease. The diagnostic time is described as hard and painful. Afterwards the awareness occurs about the necessity of modifying lifestyle and the behaviors, to recover and maintenance the quality of a greater life, which evokes a feeling of "life goes on". In all over the adaptive process, healthcare professionals possess a crucial role in the humanized host to the adolescents and their family. **Final Considerations:** The alterations of the daily adolescents with chronic disease and their relatives point for the need of an attendance in more qualified health with views to facilitate the living with the initial moment and adaptation to the new routine.

Descriptors: Adolescent; Chronic Disease; Family; Nursing.

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RESUMO

Objetivo: refletir sobre as modificações no padrão cotidiano de vida de adolescentes com condição crônica e de seus familiares a partir do diagnóstico. **Desenvolvimento:** a vivência dos adolescentes e seus familiares com relação à condição crônica são permeados por diferentes sentimentos, pautados, principalmente, no estágio de convivência com a doença. O momento do diagnóstico é descrito como difícil e doloroso. Posteriormente, ocorre a sensibilização acerca da necessidade de modificar o estilo de vida e os comportamentos cotidianos, para a recuperação e manutenção de uma maior qualidade de vida, o que desperta um sentimento de "vida que segue". Em todo esse processo adaptativo os profissionais de saúde possuem papel crucial no acolhimento humanizado ao adolescente e sua família. **Considerações finais:** as alterações no cotidiano do adolescente com condição crônica e de seus familiares apontam para a necessidade de uma assistência em saúde mais qualificada com vistas a facilitar a vivência do momento inicial e a adaptação a nova rotina de vida.

Descritores: Adolescente; Doença Crônica; Família; Enfermagem.

RESUMEN

Objetivo: reflexionar sobre los cambios en el patrón cotidiano de vida de adolescentes con condición crónica y de sus familiares a partir del diagnóstico. **Desarrollo:** la vivencia de los adolescentes y sus familiares con relación a la condición crónica son permeados por diferentes sentimientos, pautados, principalmente, en el período de convivencia con la enfermedad. El momento del diagnóstico es descrito como difícil y doloroso. Posteriormente, ocurre la sensibilización acerca de la necesidad de cambiar el estilo de vida y los comportamientos cotidianos, para la recuperación y mantenimiento de una mayor calidad de vida, lo que despierta un sentimiento de "vida que sigue". En todo ese proceso adaptativo los profesionales sanitarios poseen rol crucial en el acogimiento humanizado al adolescente y su familia. **Consideraciones finales:** las alteraciones en el cotidiano del adolescente con condición crónica y de sus familiares apuntan para la necesidad de una asistencia en salud más calificada con el intuito de facilitar la vivencia del momento inicial y la adaptación a la nueva rutina de vida.

Descritores: Adolescente; Enfermedad Crónica; Familia; Enfermería

INTRODUCTION

The chronic disease has been configuring theme of great relevance to the reflection of the living process of human being, considering that this, even with the scientific advancement and technological in the extent of the precocious diagnosis and therapy instituted which allow, many times, the control of the evolution and healing, this group of disease promotes organic changes, emotional and social that requires care and adaptation⁽¹⁾.

The chronic disease can be defined as health problems which require ongoing management for a long period. Analyzed from this perspective the "chronic disease" covers a category extremely large of grievances that apparently could not have any relationship amongst themselves, as HIV/AIDS, cardiovascular

diseases, cancer, diabetes, amputation, blindness and articulations disorder⁽²⁾.

Given these characteristics that permeate the chronic diseases, the experience of these situations gains greater relevance when tackle an adolescent. In these cases, there is an alteration in the flow of the day-to-day life of the individual, because in the phase of the adolescence is characterized as a hard moment to the human being, since, in addition to build a new period of transition between the childhood and adulthood, it still is a moment with a lot of changings which occur in physical, and cognitive, and emotional and social aspects⁽³⁾.

This way, the chronic diseases in a teenager has potential to cause a rupture with the social world this subject is inserted. Its life pace is changed and the restrictions imposed on this teenager impede them to perform the activities those before were allowed, and it

establishes the necessity of actions which allows the daily life inside of the acceptable presumptions and parameters⁽⁴⁾.

However, besides affecting the adolescent, the diagnostic impact on the relatives and the experience of the disease involve social, economics, affective and behavioral aspects, in most cases, because of the existence of the inherent complications to the grievance⁽³⁾. Furthermore, is necessary that the relatives learn how to deal the symptoms and therapeutic procedures and to develop skills to the learning of the control and management of the disease⁽¹⁾.

This increased demand of the number of adolescents with chronic disease and the magnitude of the alterations in their lives and relatives, which reveals the importance of the qualifications of the primary attention services to health and its professionals, in order to promote competences in the assistance, consistent to the necessities of this disease, constituting a wide and current challenge to the health services and its professionals⁽⁵⁾, in view of modify the paradigm of the medical care to the flare up and to the heal, to the continuous caring the chronic disease and the attention to the health of the citizen and the society involved, it is, for sure, a big blank to be exceeded⁽⁶⁾.

Then, to contemplate on the theme is pressing, so much for the fact of the increase of the chronic diseases among the adolescents, as for that population portion, most of the time, to be renounced to second plan inside of the health services, because these units seem to be better prepared to operate with the children, women and elderly people.

Before the exposed, this proposes the realization of this reflexive rehearsal that has had the aim to reflect about the modifications in the daily pattern of life of the adolescents with chronic disease and of their relatives starting from the diagnosis.

DEVELOPMENT

This rehearsal was based in the existence of the authors in the

development of researches in the area of the health and nursing that have as central theme the chronic processes of fall ill and the family experience of care. On the other hand it was also considered the current and pertinent literature on the theme, being made a systematized research of the texts being used the descriptors: relatives, adolescents and chronic conditions.

It can be noticed that for the adolescents and their relatives the chronicity situation shelters a series of private existences, but in most of the cases, permeated by different feelings, that vary, mainly, in agreement with the clinical picture and the coexistence apprenticeship with the chronic condition. This way, the moment of the diagnosis represents a difficult and painful phase for the family-patient combination.

Afterwards, with elapsing of the time, it happens the sensitization that it is necessary to spend changes in the lifestyle, in the feeding and in the daily behaviors for the recovery and maintenance of a better life quality. With that sensitization there is a "life goes on" and the chronic disease starts to be part of the life, so much of the adolescent, as of their relatives.

Finally, it was noticed that the professionals of health possess crucial paper since the moment of the diagnosis, supporting the adolescent and their relatives, aiding them elaborate the possible rearrangements in their lives, looking for the handling of the situations which come so much in the periods of silencing of the disease, as exacerbation. This allows the integration in the daily.

So that didactically it would become more comprehensible to the reader the ideas presented in this rehearsal, the authors classified the main discoveries of the current investigations and the reflexive collating in thematic categories.

The diagnosis of a chronic condition: the existence of the adolescents and their relatives

The adolescents and their relatives face together, when discovered a chronic condition and of the institution of the first therapeutic interventions, complex and new situations, many times, incomprehensible and unacceptable, of

deep transformation in the daily life. This because, the newly diagnosed illness will request special cares for a lifetime, unchaining in the adolescent suffering when receiving the diagnosis of the disease⁽⁷⁾.

Study accomplished in a municipal district of the Brazilian northeast with 11 adolescents who had Diabetes mellitus (DM) evidenced that the reports of the subjects, from the first symptoms to the first internment, they were always permeated by surprise, sadness and difficulties imposed by the necessary daily routines to the initial cares with the disease. Other mentioned reactions were nervousness, concern and reduction, because there was the fear of the complications arising of the disease⁽⁸⁾. It can be inferred that the diagnosis of DM in the adolescence brings a relevant psychic impact, since in that period it appears a series of paradoxical feelings, doubts and dreams, which can be reduced with the diagnosis of a chronic condition.

Beyond the adolescent, the relatives, before the diagnosis, they try a miscellany of feelings as sadness, anxiety, uncertainties and fear of the future. A study accomplished with five adolescents and their mothers in a municipal district of the south area of Brazil evidenced that they portrayed the moment of the diagnosis as being of plenty difficulty for the whole family chest. This because, the families had to adapt to a new pattern to feed, accomplishment of physical activities, handling of the treatment with medicines and insulin and to the attendance routine to health services⁽³⁾.

Studies accomplished with relatives of the adolescents with anemia sickle cell anemia⁽⁹⁾ and the mother of children/adolescents hospitalized by exacerbation of chronic conditions⁽¹⁰⁾ they have showed that the daily of the relatives is largely modified after the diagnosis due to the intense need of continuous cares, that before were ignored and the preparation lack to receive in the home a son with special conditions of care and feeding^(9,10).

Thus, in practice it is observed that not just the patient feels the consequences of the diagnosis of a chronic disease, because the family also

can, in certain way to "fall ill" with him. The changes imposed by the diagnosis end for being extended to the relatives, the ones which initially react with anguish and despair before the sensation of they have little control about their lives and about their sick relative⁽¹¹⁾.

Therefore, of course the focus of attention and the professionals' of health care. so much in the clinical atmosphere that, in many cases diagnose the chronic condition, as the members of the team multidisciplinary of the Family Health Strategy, that accompany him. It should be the family unit and not just the subject with the diagnosis of some chronic condition, because a care that is rendered in way integral, homelike and that contemplates the whole family tends the best to satisfy the needs and individual and family longings.

Changes in routine and personal and family lifestyle

The chronic condition causes significant changes in the life of the adolescent and their families, demanding changes, often radical, in the lifestyle. In this perspective, studies carried out in Brazil showed that among the necessary modifications in the daily life of adolescents with chronic conditions, the most difficult to follow is the differentiated diet^(1,4). Different chronic conditions require adaptations and/or dietary restrictions and incorporation of new habits, which can bring difficulties and suffering. The adolescent needs to change his or her behavior, whether in the face of old habits or behavior in moments with friends⁽⁸⁾.

The adolescents' lifestyle undergoes several influences, such as those exerted by family life, friends, media and social pressure. It takes strength of will and discipline to maintain a food routine different from other people. The teenager feels sad, different from others and wronged for being the only one deprived of normal eating, and at times, especially at leisure with friends, he yields to food cravings, although aware of the repercussions that this can cause in maintaining the balance of the health-disease process⁽⁴⁾.

The incorporation of new eating and life habits, and the introduction of a new routine to be followed, have

consequences that may be more difficult to be experienced and worked in adolescence due to issues such as maturity level, need for independence and autonomy, and sense of group identity and the idea of indestructibility⁽¹¹⁾. We recognize that adults and the elderly, when diagnosed with a chronic condition, require quality professional interventions. This is because they are also known to experience difficulties in coping with chronic illness and management of the chronic condition profoundly affects the various dimensions of the life of the sick person. However, special focus should be given to adolescents, since in most cases they are more exposed to coping with more suffering.

It is still necessary to consider that many adolescents interpret the facts according to what they mean at present, not considering the consequences that they may present in the future. Therefore, they do not recognize preventive care as a priority, taking behaviors characterized by families as irresponsible and uncompromising. However, this type of behavior has been reported as typical of this phase and the adolescent often has difficulties in measuring the consequences of his actions⁽⁴⁾.

In these cases, health professionals should seek to understand the behavior of the adolescent and not make value judgments or repression of the acts, but rather to know the adolescent and his family closely so that, together, they can find the possible solutions to the needs of both. It is worth emphasizing that such needs are always changeable in time and space, and therefore we must continually renew our guidelines on the consequences for the future of momentary actions. For this awareness activity, the family and, more strongly, the boyfriend and friends can positively influence the behavior of the adolescent, and these should be an integral part of the actions and activities planned by the health teams with the adolescents with conditions.

Another aggravating factor is the fact that adolescents generally have more difficulty accepting the disease when compared to children, because while

adolescents still depend more heavily on the care of their parents or guardians, adolescents are called to make them responsible self-health. Their immaturity may appear at the moment when they have to take some care, such as medication administration and follow-up of a strict diet and physical activity^(8,12-13).

In these difficult moments in the face of disease, treatment and modification in lifestyle, the subjects report that life with the chronic condition, "is a life that hurts and hurts"⁽¹³⁾. These periods can be understood as those of greatest physical and / or emotional fragility, but which can be mitigated and reduced through the support of health professionals and the family, especially if there is sensitivity and affective involvement by health professionals

Another study also points out that changes in the child's / adolescent's self-image are reasons for discomfort during the experience of the chronic condition in the family⁽¹⁾. There is no way to think of adolescence without making an immediate analogy with the body changes that occur in this period and how these changes are reflected in the minds of adolescents. Thus, the intense physical transformations unique to this age, influence the whole psychosocial process of formation of the adolescent's identity. The construction of a personal identity in this period necessarily includes the relation with the body itself, which is often affected by the chronic condition⁽¹⁴⁾.

A qualitative study carried out in a city in the southern region of Brazil, with nine mothers living in care for adolescents with technology dependence, demonstrated that their lives changed to meet the demands presented by the child and this generated several stressful situations, the relationship man x woman had changed after the illness of the son. Thus, the authors concluded that women have identified the installation of multidimensional and daily changes in the lives of their families and mainly in their own lives, since they have assumed almost completely the care, they have abandoned professional work, leisure and of "being a woman"⁽¹⁵⁾.

It is worth mentioning that the number of studies investigating the quality of life of adolescents with DM

demonstrates the impact of this disease on their daily lives⁽¹⁶⁾. However, research studies or even integrative reviews of the literature and reflective analyzes on the family's role in the chronic condition of this population are still scarce. We believe that this may be due to the fact that the adolescent has less importance in the health service and the academy, mainly because health professionals, teachers and researchers are not accustomed to working with the conical condition in this population. This is reflected in the formation of new health professionals, who are not sufficiently prepared to act with adolescents, remaining this circle-vicious, in which the adolescent with chronic condition and his family are the most harmed.

Given the various modifications that the teenager with a chronic condition is subject to experiencing, it is believed that the family can play a very important role, since it has the possibility of contributing to a better adaptation. In fact, investigations indicate that adolescents recognize that the family helps in their adaptive process, especially regarding emotional, financial and social support. However, on the other hand, the adolescents also reveal that, at times, the family can harm their coexistence with the new reality, when it places itself as overprotective and regulating their actions⁽³⁾.

It is perceived the importance of including and supporting the family, in order to make it a cooperative element in the process of adaptation and coexistence of the adolescent with the new reality, in view of the changes occurred in their daily life, however, in the correct measure so that do not overprotect the adolescent. In this way, if well oriented, the family can be a facilitator in the diagnosis, as well as in the period that follows, mainly in relation to the sensitization of the need for change in lifestyle, which favors the acquisition of higher quality of life on the part of adolescents. We recognize that families manage and produce care for the sick person with the potential he or she has, often without any support/support from health services and professionals. Thus, it does not seek to blame families for overprotection of adolescents, but rather to point out that when not

adequately accompanied, they can conduct care in a very protective way, which should be considered during the follow-up of families and adolescents with chronic conditions.

"Life that follows": the moment of adaptation and the return of the quality of life

With the beginning of treatment, an improvement in the quality of life of adolescents occurs, because with the use of medications, the previously very distressing changes begin to decrease. Thus, the adolescent is able to perform self-care activities that he did not perform before, such as driving the diet and regular physical activity. In this sense, a study conducted in Rio de Janeiro (RJ) with 14 adolescents who experienced a chronic condition evidenced that, after the institution of treatment and initial clinical improvement, they believed that sadness and crying would not solve the problem, because they needed to be strengthened to treat correctly⁽¹⁷⁾.

The time of living with the disease and its periods of remission and exacerbation, as well as the search for new knowledge about the pathology are allied to overcome the family dysstrumentation that the diagnosis brings with it and implies an improvement in the quality of life of adolescents and their families. In addition, it is verified that the family union represents a foundation for coping with the chronic condition of the adolescent, which results in better overcoming the difficulties. When interviewed, mothers affirm that stressful moments and the difficulties generated by the child's chronic condition lead to greater family unity and favor the discovery of a personal and familiar internal force that they did not know⁽¹⁰⁾.

Another key point that deserves to be reflected, regarding the adaptation of the adolescent with chronic condition, is the school attendance, since the adolescent needs to reorganize his life within the new possibilities that are before his eyes. One aspect frequently changed in this situation concerns schooling. The disease, its treatment and the side effects interfere in the school performance of the adolescent, making difficult its attendance to the classes and its

adaptation and accompaniment of the school rhythm⁽⁴⁾.

It is well known that school is an important place in the life of adolescents, being the field of different types of learning and interpersonal relationships. It represents not only the first institution to maintain contact with the adolescent from infancy, it provides the experimentation of the formation of social webs and identity, besides the family (4). Thus, it is inferred that the school plays a significant role in the transitional development from childhood to adolescence, since it has an identity and social function, contributing to the promotion of adolescent psychological development, as it becomes recognized as a part of a group and share meanings that will strongly influence their personal identity in adult life.

When the adolescent with a chronic condition presents a complication in his/her clinical situation that necessitates hospitalization, consequently, even if the right to the maintenance of the study for children and adolescents during the hospitalization process is ensured, their removal from the school environment occurs. This situation is of great importance in the case of adolescents who, due to their own characteristics of the disease or because they do not adequately follow the drug and non-drug therapy, require repeated hospitalizations in a short period of time. This is undoubtedly reflected in several faults in school, leading to serious difficulties in acquiring knowledge and in monitoring the school year⁽¹⁸⁾.

Thus, the school should be a space of strengthening, support and care, and should contribute to the good development of adolescents. Therefore, health professionals who accompany the adolescent with a chronic condition need to be in constant contact with the school, grounding the knowledge about the health conditions, needs and limitations of the adolescent, which greatly facilitates their stay in this place, making him able to print a school of security and gregariousness at school. On the other hand, it is reiterated that the unpreparedness of the school to meet the needs of this adolescent can transform a pleasant and stimulating social environment in a stressful environment⁽⁴⁾.

Also emphasized in this reflection is the need for families to understand the chronic condition as a process composed of different moments: first, it is necessary that the family member is willing to learn, that is, to acquire knowledge of what is not known; Second, careful observation of what happens in society is necessary, and the family member is aware of what happens in the adolescent's daily life. Thirdly, one must respect the situation and accept the condition in which the family and the adolescent meet, and then face it; and fourth, the moment when the acceptance becomes part of the person himself, thus, one faces and one lives the situation facing. After experiencing these different phases, mothers are convinced of the situation and make decisions about how to live with the chronic condition in the home⁽¹⁰⁾.

We consider here that the "acceptance" of the family's illness does not follow watertight and rigid phases, but it is occurring in the day-to-day life of the coexistence and the provision of care, in which one learns possible ways of caring, always very personal and with the resources and potentials that families have. Therefore, it is evident that health professionals should consider these different steps to work with mothers of adolescents with chronic conditions, as they also suffer and need time to reflect on what is happening to their child, their family and his own life. The respect to the time of adaptation of each family to the chronic condition is essential for the professional performance qualified, resolute and without value judgment.

Role of health professionals in working with adolescents with chronic conditions and their families

Finally, it is important to reflect in this essay on the role of health professionals when working with their families and especially with adolescents with chronic conditions. Based on our professional experiences in primary care, we have noticed that adolescents have constituted a small population that is not contemplated in health services. In this way, their care often does not consider the integrality of their being, which is composed of innumerable doubts, anxieties and fears, feelings that are

enhanced by the experience of a chronic condition.

Health professionals must first know the adolescent and his family in what they present with potentialities and difficulties for care. Only from this understanding can they think of ways to support, with their own practices, the daily care taken by the family and the adolescent. For example, a study carried out in a Brazilian northeast capital with four children/adolescents between 8 and 13 years old who had chronic kidney disease, pointed out that there were deficits in relation to the basic requirements of self-care, with the most frequent nursing diagnoses, were: risk for compromised feeding; ineffective control of therapy and diminished health knowledge⁽¹⁾.

It can be inferred that it is difficult for the child/adolescent to cope with the changes required by the disease, especially when they lack information that subsidizes care. However, since they are not capable of responding to the care process in a complete way, it is necessary that those responsible for their care also assume the condition of therapeutic self-care agent. However, it is necessary that family members have adequate tools to deal with the situations caused by the disease, which correspond to access to information, guidance and materials that aid in the surveillance and control of the disease⁽¹⁾.

The information provided by the professionals regarding the health-disease conditions are essential for the adolescent affected by a chronic condition and for his relative. Thus, they can become responsible for individual and social care, being able to make important decisions about the health behaviors that are most favorable to them, leading to the acquisition of a higher quality of life⁽³⁾.

A case study showed that in the process of daily coexistence with the chronic condition of the adolescent within the family, the family weaves networks that confer some sustainability and support; however, it was found that health services and professionals have limited and limited participation in care for the person and the family⁽⁹⁾. Thus, understanding the daily routine of family care subsidizes the modeling of professional practices with greater effectiveness,

based on integral care, that can meet the intense and changeable needs that each adolescent presents.

Knowledge of the existential experience of being a family member with a chronic condition is essential for the family, researchers, teachers, students and care professionals, in the planning of effective and efficient interventions in the practice of care. The need for a unique perspicacity in the approach of families of adolescents with chronic condition, supported by an active and qualified listening process by health professionals, is emphasized. In this process, the genuine value of each experience must be elevated and endorsed in the construction of knowledge, since beliefs, culture and values of the trajectory of each family are the starting point in the teaching-learning processes⁽¹⁸⁾.

Knowing the importance of the socio-emotional support provided by the health professional, it is necessary to keep in mind how important it is to provide a comfortable and welcoming environment to the patient and to maintain a relation of trust and respect with the patient, since, often, that with those professionals is the only place where you can receive support. The chronic condition weakens the adolescents and their families, and it is essential that the health service they attend is warm and pleasant, where they can share anxieties, uncertainties and fears without being repressed, based on a humanized and individualized care⁽¹⁹⁾.

Thus, caring culturally congruent with the needs of adolescents with chronic conditions can be described as an intentional action of care established by the interaction of scientific knowledge and the valuation of cultural knowledges of this clientele that is developed through actions and care decisions emanating from the needs of the subjects and their families, from the moment they received the diagnosis of the disease until recovery of autonomy before the treatment⁽⁷⁾.

Therefore, it is up to the professionals to develop interventions in order to help the family to resume and maintain the balance of physiological, psychological, sociocultural, developmental and spiritual variables, so that they can adapt and readapt to the situations that appear in their lives towards their health/well-being

even while experiencing a chronic condition among their members. Thus, in a special way, the nurse should be able to offer differentiated care, through approaches of approach, qualified listening and understanding of the experience of adolescents and their families.

FINAL CONSIDERATIONS

In this reflexive essay, it can be understood that adolescents and their families experiencing the diagnosis of a chronic condition experience difficult and turbulent moments, mainly due to lack of knowledge and fear of the disease. However, when they perceive as necessary the changes imposed by the disease, such as changes in diet, physical exercise and medication use, adolescents

and their families seek to strengthen themselves, which is reflected in the resumption of daily life and improvement quality of life.

In this complex and multi-finished process, health professionals play a crucial role in strengthening family relationships and providing care for the acquisition of knowledge by adolescents and their families. However, it is reiterated that it is necessary to include adolescents with chronic conditions and their families in the curricula of training of health professionals, as well as, to give greater emphasis to this population in order to investigate their experiences, anxieties, anxieties and fears. It is believed that only in this way is it possible to break the vicious circle of poor inclusion of adolescents and their families in health services.

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