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ORIGINAL ARTICLE

EVALUATION OF FAMILY MANAGEMENT OF AN ADOLESCENT WITH SICKLE CELL DISEASE

AVALIAÇÃO DO MANEJO FAMILIAR DE UMA ADOLESCENTE COM DOENÇA FALCIFORME EVALUACIÓN DEL MANEJO FAMILIAR DE UNA ADOLESCENTE CON ENFERMEDAD FALCIFORME

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ABSTRACT

Objective: to describe the experience of the family management of an adolescent with sickle cell disease. **Method:** case study, which used the theoretical model of the Family Management Style Framework (FMSF). Data was collected through interviews with the mother and documental analysis and, previously, being submitted to hybrid thematic analysis. **Results:** the family defines that they are adapted to the situation. The management behaviors are shaped according to the unpredictability of the disease, which, consequently lead to a "fighting" management style. **Conclusion:** the mother is the main caregiver of the adolescent, is overloaded, and presents difficulties regarding the therapeutic regimen. Mother and daughter are afraid of the disease, which contributes to the low self-esteem of the adolescent, limiting it in the performance of activities, and both are with impaired quality of life. **Descriptors:** Family; Adolescent; Sickle Cell Anemia.

RESUMO

Objetivo: descrever a experiência do manejo familiar de uma adolescente com doença falciforme. **Método:** estudo de caso, que utilizou o modelo teórico do *Family Management Style Framework* (FMSF). Os dados foram coletados por meio de entrevistas com a mãe e análise documental e, posteriormente, submetidos à análise temática híbrida. **Resultados:** a família define que está adaptada à situação. Os comportamentos de manejo são moldados de acordo com as imprevisibilidades da doença que, conseqüentemente, os leva a um estilo de manejo "lutando". **Conclusão:** a mãe é a principal cuidadora da adolescente, está sobrecarregada, e apresenta dificuldades em relação ao regime terapêutico. Mãe e filha têm medo da doença, o que contribui com a baixa autoestima da adolescente, limitando-a no desempenho de atividades, e ambas estão com a qualidade de vida prejudicada. **Descritores:** Família; Adolescente; Anemia Falciforme.

RESUMEN

Objetivo: describir la experiencia del manejo familiar de una adolescente con enfermedad falciforme. **Método:** estudio de caso, que utilizó el modelo teórico *Family Management Style Framework* (FMSF). Los datos se recogieron por medio de entrevistas con la madre y análisis documental y, después siendo sometidos a un análisis temático híbrida. **Resultados:** la familia define que está adaptada con la situación. Los comportamientos de manejo son moldados de acuerdo con las imprevisibilidades de la enfermedad, que conseqüentemente, los llevan a un estilo de manejo "luchando". **Conclusión:** la madre es la principal cuidadora de la adolescente, está sobrecargada, y presenta dificultades en relación al régimen terapéutico. Madre e hija tienen miedo de la enfermedad, lo que contribuye con la baja autoestima de la adolescente, a limitando en el rendimiento de las actividades, y las dos están con la calidad de vida perjudicada. **Descriptores:** Familia; Adolescente; Anemia De Células Falciformes.

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INTRODUCTION

Sickle cell disease (SCD) is a hereditary hemoglobinopathy characterized by a mutation in the hemoglobin gene (HbA), in which the amino acid glutamic acid is replaced by valine, hemoglobin (HbS). This physical-chemical alteration alters the shape of the erythrocytes, that take the form of a scythe.¹

The falcization of red cells leads to chronic hemolysis and vaso-occlusive phenomena that determine clinical manifestations in multiple organs, and may affect patients throughout their lives.¹

Studies indicate that the SCD, because of its chronic condition, changes the daily life of families, by changing the lives of those who have the disease and also that of their members. These changes are triggered by a new daily life surrounded by hospitalizations and care for the control of the disease.²⁻³

Although the life expectancy of patients with SCD has improved due to the actions that involve the diagnosis, tracking and follow-up, it will be considered that more children are reaching adolescence, and this requires training and qualification of the health teams,⁴ among them, of the Nursing professional, to deal with this demand for such specific care.

Thus, evaluating the families that go through this situation is necessary, and, for this, the use of family assessment models can help professionals to know these experiences by proposing personalized interventions. Thus, the objective of this study was:

- To describe the family management experience of an adolescent with sickle cell disease.

METHOD

Case study, in which the FMSF⁵ reference was used, a theoretical model that guides the evaluation and data collection with the families. In this way, it allows to know and to understand the management experience that each family has, based on three dimensions: definition of the situation (they are the subjective meanings that the members of the family attribute to important elements of their situation); (are the efforts and adaptation of family life to meet the demands related to the disease) and perceived consequences (are current and expected of the family, child and disease outcomes that modulate management behaviors).

From this knowledge, it is possible to trace effective actions to family groups, which contributes to Nursing practice.⁵ In Brazil,

researchers from the Interdisciplinary Center for Research on Loss and Grief (ICRLG), University of São Paulo School of Nursing (USPNS) have been carrying out studies about the theoretical model and the Family Management Measure (FaMM) instrument derived from this model, highlighting a study of cultural adaptation of the FaMM⁷ instrument and the applicability of the FMSF model in different contexts of chronic pediatric disease.

This article is a summary of a research in development that aims to know the family management experience of children with sickle cell disease. The primary study is being developed together with nine families that have one or more children with SCD, registered in a Regional Hemonucleus of Minas Gerais. It is emphasized that, in order to preserve the identity of the study participants, they were identified with fictitious names.

The case study presented here is from Isabel's family, chosen because it was the only family that was experiencing the management experience with the daughter who was already adolescent and that there was a conflict due to the absence of the father in the process of managing the disease.

The mother of the adolescent who agreed and signed the Informed Consent Form participated in the study. The study was approved by the Research Ethics Committee of the USPNS and the Foundation Center of Hematology and Hemotherapy of Minas Gerais-Hemominas (opinion: 1,433,679).

The data of this case were collected in three moments: the first one had the objective of searching for elements to identify the family. Then an open interview was held to comprehend the experience of having and caring for a child with SCD.

In the second moment, the semi-structured interview was conducted, based on FMSF questions,⁵ in order to understand the phenomenon. As sources of evidence, documents⁶, were used as discharge summaries and exams. The third moment occurred to elucidate doubts and close the case.

All meetings took place in September 2015, being previously scheduled, and, for the convenience and privacy of the interviewee, she chose her domicile. The interviews were recorded and transcribed in full, soon after their execution.

Data processing and analysis were guided by the hybrid model of thematic analysis,¹⁰ using the deduction from a template [here,

Gesteira ER, Bousso RS, Ichikawa CRF et al.

the theoretical model of the FMSF was used] extracted directly from the data and, then, encoded in an inductive way. In this process, there is the search for themes that are more important for the description of the phenomenon, and the identification of themes occurs through careful reading and re-reading of the data that will become the categories of analysis.¹⁰

In the final stage, the themes that were initially created are grouped together. At this stage, the previous steps are rigorously examined so that the pooled themes actually represent the initial analysis of the data and the codes to which they were assigned, which characterizes the confirmation phase.¹⁰

RESULTS

◆ Presentation of the case of Isabel

◆ Trajectory of disease in the family

Isabel, 12 years and nine months, daughter of Marta (mother), 34 years old and Léo (father), 40 years old, born in a municipality in the interior of Minas Gerais, received the diagnosis of SCD - (HbSS) - Sickle Cell Anemia fourteen days after Neonatal screening test. Her parents were married for ten years, and Isabel lived with her father until the age of seven. After the separation, Léo left the family, and mother and daughter began to live alone, without their financial support.

Knowing that it was a chronic disease, the family, who had never heard of the disease experienced the fear of the unknown and doubts about the future of the child. It was only after the first consultation, at Hemominas Foundation's Hymenoprotein that the family began to understand the disease and to manage the situation more safely.

The first painful crisis that Isabel had was eight months of age, staying hospitalized for two days, followed by a new hospitalization, at the same time, for pneumonia, which culminated in a hospitalization of 15 days. In the period between 2004 and 2014, the adolescent underwent several blood transfusion sessions, and more than five times, during this same period, she had to be hospitalized for pain, bronchitis and pneumonia.

At age nine, due to biliary lithiasis, the child underwent cholecystectomy. At the same time, autoesplenectomy was diagnosed, a process of spleen degeneration, caused by crises of falcization and splenic sequestration.¹

Today, the adolescent is facing painful crises that are concentrated in the upper and lower limbs, from moderate to intense

Evaluation of family management of an adolescent...

intensity, which causes her anguish and great suffering.

◆◆ Family Management Experience

◆ Situation definition

The family defines Isabel as a responsible, docile child, affectively deprived of her father's absence. The mother sees the daughter as special, focusing not only on the illness, but also on the role that Isabel represents in her life:

Ah is a docile, kind, needy person, no matter how much you care, she wants more, studious, intelligent [...] it seems she wants to tell me not to send her.

The mother feels that her daughter is normal like other adolescents, but the SCD leads to some deprivation, as in leisure activities and games with friends:

She is the same, only the question that she is not enough to play, is different [she] has fear, she's afraid of sickle cell anemia.

The family has faith and hope in healing the disease. The mother reports:

I thought it would be something like that, incurable [...] As they say it is, but for me it will never be, because God is first for me. I hope one day she will heal from this disease.

According to the maternal view, Isabel is limited to activities that she would like to do as other adolescents of the same age, showing low self-esteem:

She is very afraid, [...] to practice a sport, she is not afraid to hurt, afraid to go wrong [...] sometimes when she goes wrong, she says: ah! Mother [...] I do not know why I'm still alive, because I did not die.

After splenectomy and cholecystectomy, painful abdominal crises have ceased, however, the adolescent continues to cope with pain crises known as "hand and foot syndrome."¹

Nowadays, in the family mentality, they know how to recognize the intensity of pain, knowing how to handle the symptoms at home. On the other hand, they recognize that intense pain needs hospital care.

There is, according to the family, a difficulty of the health team in defining what type of medication to administer when reporting that the adolescent has SCD. This reality generates insecurity for the family that needs to have the skills to follow the therapeutic regimen after the care.

The crises she has are difficult [...] you take to the doctor, they do not know what it is, you have to explain it ... they do not know how to deal with the medication they must pass or they pass the medicine and Tell them to come, they do not take care.

Gesteira ER, Bousso RS, Ichikawa CRF et al.

The painful crises that need access to the emergency care units, are experienced by the mother in anguish and suffering.

I had to have more understanding of the doctors [...] If they have priority, why stay there holding the patient, [...] until I wait, I do not know how many people in the front. [...] There have been times when my girl is rolling in the chair of pain and asking for a bed!

Although the mother receives guidance from the Hemominas Foundation, it is difficult to understand the results of the tests and to evaluate whether or not the therapeutic regimen is effective, which is a challenge in daily care.

I think they had to explain more detailed to us. Just like that examination of ferritin [when] it is , [...] increased [...] I'm half lost on this issue. Because there is an hour that it can even be that we are provoking this issue because of the food that we are giving the child. Because you do not know what she can.

There is also difficulty accessing the major vaccines. The mother reports that the health team questions whether or not they can administer the vaccines in the adolescent with sickle cell disease. Still, there is a fight for the acquisition of special vaccines: the family needs to move intensely in search of their rights.

[...] we run after the vaccines [...] the posts there also do not give a right what they [need] to take [...] that influenza vaccine [...] every year is a fight for I give it to her. Being that it is in the calendar. [...] most of them are difficult. Because they think the person can not take [because of the disease], but they have the right.

Another aspect that hinders the ability of the family to follow the therapeutic regimen is restricted to the fact that Isabel does not like foods, such as fruits and vegetables, which makes it difficult to exercise self-care in this matter.

[...] I do what I can, I've already looked for a nutritionist for her, I try to do what she likes, but not everything she eats [...] She does not like vegetables, does not like fruit [...]] It is difficult to live with the person who does not eat anything.

Add to this the fact that Isabel is in the phase of adolescence, a period of intense growth and maturation, requiring, of the organism, essential nutrients for development. The mother is alone in this process, without the financial and affective help of the father, which can increase the risk of complications of SCD.⁴

Because Isabel's parents are divorced, the child had intimate contact with the father

Evaluation of family management of an adolescent...

only until the age of seven, but a weak bond due to alcoholism.

I always had the lead. Her father, was going to visit, but she never gave much assistance. I always had the support of his mother, who always paid for a health plan, now, I have, I paid for it. But it was always me.

The daily care of the child is offered by the mother, with the support of her maternal grandparents. Yet Marta must work to support her and her daughter.

I'm on [her] account, but I work too, because if I do not work, how am I going to live? - because she has no attention from her father, he does not help me, so I have to keep and keep her. So it's heavy [...] it's just hard.

♦ Driving Behaviors

Isabel's mother is aware of the day-to-day care of her daughter and sees her efforts to be effective, but there are difficulties, as the family has defined the situation before.

In the daily routine, one of the challenges is pain control. The mother knows what the main drugs are. Only when all the alternatives are exhausted is she taking the adolescent to the hospital.

[...] it is very difficult for me to give very strong medicine. Most of the time it is dipirona®. Only when it is very strong even though I give Tylenol® and, if it has not improved, I already run with her to the hospital, because then I already know that the crisis is advanced.

Another target of day-to-day care of the family is the school, the second space where Isabel spends much of her time. Marta, every beginning of the class, communicates the board and teachers about the demands of the daughter, alerting the professionals about the severity of the disease.

At school, [...] I always notice, it went wrong, ask her to call me, because she will not stay in school, she will give work for you, then she will call me, or she already asks, "I want to call For my mother, I'm not well". So I'll go and find her.

As much as Marta has the support of her sister, the child's godmother, who cares for Isabel after the lesson period, Lúcia (aunt) warns when the child is not well. But the strategy adopted to manage the situation is to communicate with Marta, as mentioned:

Yeah, she just looks at her not being alone, because she is smaller, but in the matter of illness, to take her to the doctor, it's always me, she calls me, I'll take it.

Every target of the therapeutic regime is summed up in daily care performed almost exclusively by Isabel's mother. In Marta's view the family routine was normal before the

Gesteira ER, Bousso RS, Ichikawa CRF et al.

discovery of the disease. Now, they are adapting to the new situation, but are aware that some things have changed their routine to attend to the care that Isabel needs. Their handling behavior is always a "alert state".

Still, in her assessment of the changes after the discovery of the disease, Marta points out that reality is "terrible", the routine is surrounded by fear and by the perception about the possible occurrence of SCD crisis, mainly related to painful reactions. And he says:

[...] others live as if nothing had happened, because only mother knows what happens, because I'm closer. [...] there is time that I [speak]: today she is not well, she's going to have some pain, some crisis.

◆ Perceived Consequences

The results reveal that the family incorporated the care with the adolescent. Even living with the challenges, the family, especially the mother, fight for Isabel to live with less suffering.

[...] I think I should have a little card, something like that to facilitate the trip to Belo Horizonte [to do exams], I know there's [the car] of the City Hall, but you have to stay there all day [...] is tiresome [...] sometimes I prefer to pay someone, like every year I pay, to go and return, so I do not have to stay there until late.

Marta evaluates that her life is totally devoted to the care with her daughter. In all aspects of her life, what is more important is Isabel's life.

[...] as if she were a special person, and she is, for me, she is a special person [...] if I have to leave my service there and run away, I leave, [...] she is My only daughter, if I do not do it for her, who will?

For Marta, the fears and uncertainties of the disease add up to the vulnerabilities surrounding adolescence.

I'm afraid [...] some talk like this: ah you'll see [...]she's going to live to be 18, [...] I was talking to myself: "She's growing up, [...] she's got so many years for her to live, [...] I think like this: in her future now, in the matter of [drugs] in this world so it is difficult for us to live.

When it is projected into the future, the mother awaits the cure of the disease.

I hope there is a cure, my hope is this, that it is not only for her, for everyone who has this disease" sickle cell anemia [...] And I hope that her future is better.

DISCUSSION

The families that live in SCD struggle daily to adapt to the condition of having a member afflicted by a chronic disease, since their

Evaluation of family management of an adolescent...

routines are modified to attend the sick child.²⁻³

Each family assumes a style of family management, a term used in the international literature, which has been studied in different disease situations, and which means the family unit's response to the experience of chronic disease.^{5,9}

Faced with this reality, it is important for the nurse to know how the family faces the disease, the care and its dynamism, in order to help them to reorganize themselves, in search of a better balance, in the face of the difficulties that present themselves.

The FMSF model assists health professionals in understanding the process of disease management. So in this case study of the Isabel family, the management style was classified as "struggling", a term used in national and international surveys on management.^{5,9}

The "fighting" style is characterized by difficulties. The family, specifically Isabel's mother, lives exclusively for the daughter. All their efforts are directed to provide a better quality of life for the adolescent, but there are limitations, in comparison to other adolescents of the same age, then, there is a daily struggle to achieve normality.^{7,9}

Although the family defines the situation as normal, it is perceived that Marta tries to overprotect the daughter, by surrounding her with care. Only one person, the girl's godmother, stays with her, while the mother works. Yet she does not share the specific care of sickle cell disease. If Isabel has any symptoms, the mother is immediately notified. Thus, there is an overload of the primary caregiver.²

Isabel experiences moments of low self-esteem related to the fear of the SCD. The limitation imposed by the disease, requires special attention. The adolescent with chronic illness feels different from the others, this experience can trigger feelings of contestation, typical of the adolescence phase,¹¹ besides depressive symptoms, and can compromise even the follow-up of the therapeutic regimen and leading to a poor quality of life.²⁻³

Martha is also afraid of the repercussions of the disease, and is encouraged by faith in God. In SCD, as in any other chronic disease, families are expected to seek strategies to deal with the adversities imposed by the situation. Among coping strategies, is the spirituality expressed by what the person lives and believes.³

Marta trusts that her performance as a primary caregiver is within everything she can do for her daughter. Even in the face of financial hardship, she unfolds to pay for a health plan for the teenager. There is also, another difficulty revealed: Isabel does not feed adequately, which further accentuates the overload on the mother.

In view of the definition of the situation presented by the family, the management behaviors focus on a routine that was modified from the diagnosis of Isabel, a daily life surrounded by recurrent hospitalizations, painful crises, the search for special vaccines, the search for exams Concerns about the acquisition of a private health plan and maternal efforts for adequate food. These confrontations are already incorporated by the family of Isabel, but, when there are interurrences, the family becomes unstructured, and the routine is modified again.^{7-8,12}

In the relationship between the family and the community, it is evaluated that the day-to-day life of the adolescent is directed to the activities of the school, maintaining a moderate bond. She interacts little with her friends, due to the limitations of the disease, as already mentioned and, consequently, establishes a weak bond with them, does not attend church and other spaces of coexistence.

The link between mother and daughter is strong, as the family's interaction with the external community is weak, restricting only the health network. This aspect modulates a management behavior geared almost exclusively to the disease of the adolescent. This process is seen on both sides: both mother, and daughter reserve and do not seek new directions that can be part of daily life, such as leisure activities.

Regarding the future, Marta believes in curing the disease. However, the only curative treatment for FD is hematopoietic stem cell transplantation, but serious sickle cell disease is limited, and its principles and indications are currently being discussed, as well as accessibility, rejection mechanisms, and quality of life conditions for the transplanted.

Thus, in order to better serve this family, it is important for health professionals to explain, in a clear and cohesive way, the doubts presented by the main caregiver in order to outline actions that might encourage her in the management with the teenage daughter. Regarding the financial issue, Marta must enter a process for acquiring the sickness aid, since the SCD holders have this

right, even more, in Isabel, who does not have the paternal pension.

Thus, this article brings the contribution to health professionals who work with families who live the SCD, and who need to apply an evaluation guide to design and carry out actions necessary for the management daily.

CONCLUSION

The case presents the family management experience of an adolescent with sickle cell disease. Faced with the family's definitions of the adolescent, the disease and her abilities in care management, the family has acquired a behavior towards the demands of the disease. There has been an adaptation to a new routine since the discovery of the disease, which is seen as normal, but that, in the face of interurrences, they move to a "fighting" style of management in order to regain equilibrium. As a consequence, the mother, who is the main caregiver of the adolescent is overloaded and has doubts regarding the therapeutic regimen, even though the adolescent has difficulties in accepting an adequate diet.

In addition, both the young woman and her mother are afraid of the disease, which contributes to the low self-esteem of the adolescent and, consequently, deprivations in the performance of activities, further damaging their quality of life, and also of their mother.

The limitation of this study is related to not permitting generalization of results or establishment of cause and effect relationships.

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Evaluation of family management of an adolescent...

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