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Original Article

Chronic disease and treatment by the adolescent's view: considerations from a life story

O adoecimento crônico e o tratamento pelo olhar do adolescente: considerações com base em uma história de vida

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Abstract

Introduction: Chronic diseases have increased worldwide, demanding more and more the understanding of their complexity and the particularities of each life cycle. Chronic illness in adolescence, in turn, presents challenges given the issues specific to this phase of life. **Objective:** To know how an adolescent understands the process of illness and hospitalization throughout his life trajectory and how the illness permeates his daily life. **Method:** An exploratory, descriptive and reflective study was conducted through oral history. The collection took place through an interview with a teenager diagnosed with sickle cell anemia since his childhood. After collecting the oral history, the phases of transcription, textualization, transcreation, and validation were carried out with the participant and, finally, thematic analysis of the story was undertaken. **Results:** The study identified three main thematic categories: the experience of growing up with illness; impacts of illness on everyday life, and the relationship with the family permeated by chronic disease. The results revealed the experience of a young person facing a life permeated by chronic illness and the life strategies he uses to produce meaning, facing the challenges brought by the demands of permanent care and the conflicts inherent in adolescence. **Conclusion:** Even though the results are unique, Marvel's story represents in several ways the experience of adolescents with chronic illness, making it possible to understand the impacts of living with chronic illness, the care needs, and restrictions imposed by the illness.

Keywords: Adolescent, Chronic Disease, Life History Traits, Activities of Daily Living, Occupational Therapy.

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Resumo

Introdução: As doenças crônicas têm aumentado mundialmente, exigindo cada vez mais a compreensão de sua complexidade e das particularidades dos ciclos da vida. O adoecimento crônico na adolescência, por sua vez, apresenta desafios diante das questões próprias desta fase da vida. **Objetivo:** Conhecer como um adolescente compreende o processo de adoecimento e hospitalização ao longo de sua trajetória de vida e de que maneira o adoecimento perpassa seu cotidiano. **Método:** Foi realizado estudo exploratório, descritivo e reflexivo, por meio de história oral. A coleta se deu por meio de uma entrevista com um adolescente diagnosticado com anemia falciforme desde sua infância. Após a coleta da história oral, foram realizadas as fases de transcrição, textualização, transcriação e validação com o participante e, por fim, de análise temática da história. **Resultados:** O estudo identificou três categorias temáticas principais: a experiência de crescer com o adoecimento; impactos do adoecimento no cotidiano e a relação com a família perpassada pela doença crônica. Os resultados revelaram a experiência de um jovem diante de uma vida perpassada pelo adoecimento crônico e as estratégias de vida que utiliza para produção de sentido, o enfrentamento dos desafios trazidos pelas demandas de cuidado permanente e os conflitos próprios da adolescência. **Conclusão:** Mesmo que os resultados sejam singulares, a história de Marvel representa de vários modos a vivência de adolescentes com doença crônica, possibilitando compreender os impactos do viver como adoecimento crônico e com as necessidades de cuidado e restrições impostas pela doença.

Palavras-chave: Adolescência, Doença Crônica, Traços de História de Vida, Atividades Cotidianas, Terapia Ocupacional.

To Marvel (2002-2020),
who inspired this study with his life.

Introduction

The prevalence of chronic diseases has increased around the world. Currently, people diagnosed with chronic disease live longer than in the past, and their care requires long and sometimes painful treatment. Chronic health conditions can result from distinct health-disease processes, with diseases "characterized by a gradual onset, with a usually uncertain prognosis, with a long or indefinite duration" (Brasil, 2013, p. 5). The chronic disease requires continuous monitoring, as it changes along its course, alternating periods of exacerbation and stability, which can result in temporary or permanent disabilities. Despite therapeutic advances enabling improvements, the treatment is still considered exhausting and tiring, presenting significant marks in the daily life of this person (Lima & Almohalha, 2011; Lourenço et al., 2017; Santos et al., 2018).

Chronic illness in adolescence needs to be understood based on the complexity of this stage of life. After all, adolescence is characterized as a period in which there are numerous transformations, discoveries, and adaptations of the young person to a new bodily and identity condition, involving marked subjective and social changes, which are experienced in a unique way (Silva et al., 2016).

During this phase of life, there is a deconstruction of childhood and a reconstruction of a world permeated by a different way of thinking, acting, and being. The rapid and intense transformations impact the process of identity formation and the search for a new role to be played in society, establishing new relationships with oneself and with the social environment (Leal & Queiroz, 2015).

In Brazil, Nóbrega et al. (2017) indicate that 11% of adolescents, between 14 and 19 years old, concerning the general population in this age group, have a chronic disease. These data point to the need and relevance of studies that seek to understand the experience of adolescents with a chronic illness, to provide support for the care offered to them.

In addition to the demands linked to physical, psychological, and social changes, chronic disease for adolescents can be an additional challenge to be faced (Silva et al., 2016; Woodgate, 1998). For adolescents who experience chronic illness since childhood, the process of growing up can influence the way they come to understand and deal with their condition. After all, the adolescent's maturation and development process in the face of life favors changes in the perception of his disease and the care required for treatment, directly impacting his way of dealing with this experience (Leal & Queiroz, 2015).

Recognizing the importance of knowing how adolescents understand their experience providing subsidies for the attention of occupational therapy offered to this age group, this work aimed to study how an adolescent understands his process of chronic illness and hospitalization throughout his life trajectory and how the illness permeates his daily life. The life trajectory can be marked by the life experiences of the individuals, and the opportunities and social obstacles they face.

> Life trajectories are woven into the composition of individual elements, of their microcosm, with the macrosystem defined by the context in which they operate [...], being inseparable from the relationship between culture, socioeconomic situation, and the private universe of life (Malfitano et al., 2011, p. 702).

Therefore, the study of the juvenile life trajectories seeks to understand the relationship between the unique transitions in the individuals' life stories with the changes in historical time, being influenced by the social context in which the young person is inserted (Rosa, 2018).

Life trajectories are constituted in everyday life, here understood as a socio-historical construction that reveals the concreteness of life (Francisco,1988), which can be conceptualized as:

> a space-time in which the individual or collective subject, immediately and not always consciously, accesses opportunities and resources, faces adversity and limits, makes decisions, adopts resistance mechanisms, and invents new ways of being, living, and doing (Galheigo, 2020, p.15).

In this sense, this study aimed to describe the experience of hospitalized adolescents regarding the impacts of chronic illness and treatment in their daily life, regardless of the specificities of a particular disease.

Method

The research is an exploratory, descriptive and reflective study of a qualitative nature, carried out through the methodology of oral history, as this modality allows the study of subjective phenomena, such as human perceptions, covering narratives and reports told by the participant in front of his experience, allowing a unique look at his life trajectory (Minayo, 2014; Silva & Barros, 2010).

The research setting was a pediatric specialty ward of a highly complex public hospital, linked to a teaching institution, located in the city of São Paulo-SP. The study was approved by the Research Ethics Committee of the hospital, under opinion number 3,458,627, reporting date on 06/17/2019.

The participant was recruited through a selection for convenience after the researcher analyzed the medical records of patients admitted to the institution together with the occupational therapist of reference in the ward.

We interviewed an adolescent called Marvel, 15 years old, single, 1st-grade high school student, an only child, residing in the metropolitan region of Belo Horizonte, with the following inclusion criteria: (i) diagnosed with a chronic disease during his childhood: sickle cell anemia; (ii) with a previous hospitalization history; (iii) with prior contact with the researcher and; (iv) agreed to participate and sign the Informed Consent Ascent and the Informed Consent Term by his legal representative. The name used and the place of residence are fictitious and any information that could allow his identification has been hidden.

Data collection took place in the second half of 2019, from two individual meetings with the participant. We collected sociodemographic data to know the participant's profile and the interview was conducted through questions that aimed to understand the adolescent's illness experience. The central triggering question was: "Could you tell me your story before and after your diagnosis?", plus facilitating questions: "What was it like to be hospitalized as a child?", "What is it like now as an adolescent to be hospitalized?", "What's different?", "What was the impact on your daily life?", "Could you talk more about this?" and "Would you have something to add?".

We recorded the interview and, after transcription, we discarded it. The research procedure involved the following steps: (i) collection of oral history; (ii) transcription (transformation of recorded material into written text); (iii) textualization (removal of questions and preparation of a single text); (iv) transcreation (construction of a new text through the incorporation of extratextual elements to highlight the sensations provoked by the contact); (v) validation of the oral history with the interview participant; (vi) thematic analysis of the contents of the stories collected; (vii) synthesis and writing of the final results (Meihy & Ribeiro, 2011).

The thematic analysis was carried out to know the meaning cores manifested in Marvel's oral history. This analysis was carried out in three stages: (a) pre-analysis, in which the text was skimmed to understand the entire history studied, and reflect it based on the research objectives; (b) exploration of the material, aiming to obtain the core of understanding of the text and the delineation of analytical categories with their subsequent reduction; (c) the treatment and interpretation of results when inferences were proposed and interpretations made in dialogue with the existing literature (Minayo, 2014). At the end of this process, we identified three main categories, each with two subcategories (Table 1).

Table 1. Thematic categories and subcategories identified in the analysis process.

CATEGORIES	SUBCATEGORIES
1. The experience of growing up with illness	**1.1** Discovering and appropriating.
	1.2 living and giving new meaning.
2. Impacts of illness in everyday life	**2.1** Living with the disruptions.
	2.2 Relating and belonging.
3. The relationship with the family permeated by the chronic disease	**3.1** Sharing the illness.
	3.2 Gaining autonomy and protagonism in his care.

Results and Discussion

Category 1: The Experience of Growing With Illness

Considering Marvel's statements, we identified the way that illness permeates his life trajectory, presenting milestones in his development and maturation process. Because he had a diagnosis when he was still one year old, his report shows the way he was dealing with the care needs and restrictions associated with his treatment, demarcating a discovery and an appropriation process given the awareness of what is to have and grow up with a chronic illness. For this reason, the first subcategory brings reflections on this experience.

Subcategory 1.1 - Discovering and appropriating: "I didn't even know what the disease was, you know?!"

Each person has an idea and experience regarding the illness process, experiencing it in different ways. Fráguas et al. (2008), when studying families of people with diabetic nephropathies, reported that the stage of development impacts how the individual faces the discovery of his/her diagnosis and seeks resources to help him/her deal with the demands required by the chronic disease. This observation also applies to how Marvel understands the changes in perception about his illness throughout his life trajectory:

> *When did I get my diagnosis? Hmm... when I had it, I was a child, I was about a year old. So, I didn't even know what the disease was, you know?! But later my father and mother explained to me* [...](Marvel).

Because he had an early diagnosis, Marvel had the help of his parents to elucidate what he had and what was happening to his body. As he grew up, he was able to understand more clearly, and little by little he appropriated the lived process. Costa et al. (2009) point out that the degree of assimilation and adherence to treatment is diverse for each person and occurs over the time that he and his family absorb information from health professionals, other people in the same condition, and experiences accumulated during treatment. However, Araújo et al. (2011) emphasize that guidance on the disease, treatment, and care alone are not enough, as the person needs to build his knowledge, individually weaving his ideas of living with illness.

Marvel showed that he has experienced this process of appropriation and elaboration of his diagnosis, knowing how to refer to what his illness is and how it reverberates in his daily life.

> *Sickle cell anemia is a disease that genetically modifies your fetal red blood cells and hemoglobin, so it takes a while for a person to understand what it is. I understood when I grew older, older and more mature* [...] (Marvel).

Knowing and understanding the diagnosis helps adolescents to be more active and autonomous in the treatment process, but when the diagnosis occurs during childhood, the process occurs gradually (Araújo et al., 2011). When children respond superficially and punctually about their diagnosis and treatment, the authors Setz et al. (2005) understand that they did not have the opportunity to develop a complete knowledge of their health situation and treatment. Thus, according to the authors, it is necessary to find strategies to guide them to favor the appropriation of their condition.

Patients with a chronic disease, such as sickle cell anemia, live with limitations caused by the illness since the first months of their lives, which directly and indirectly influence the exercise of their daily lives (Cordeiro et al., 2014). In the case of sickle cell anemia, as it is a genetic disease that causes an abnormality of the hemoglobin present in red blood cells, the body is deficient in oxygenation and consequently presents problems such as ischemia, pain, tissue necrosis, and dysfunctions, bringing repercussions throughout life.

In this sense, there is a search for care promotion strategies aimed at longevity, promoting actions that are not just about ensuring that people live longer, but so that they live better (Segava & Cavalcanti, 2011). For this reason, the course of life and the way it unfolds represent the construction of a unique everyday, like Marvel's, better described in the following subcategory.

Subcategory 1.2 – Living and giving new meaning: "Whoever has a chronic disease is already a doctor from the age of 10 onwards"

Appropriating the illness becomes a need of the person with a chronic disease since the process experienced significantly impacts his life. Due to the illness, a set of experiences becomes present and constant: bodily changes; the discomfort and pain resulting from the disease, invasive procedures, and medication; the invasion of privacy during treatment and hospitalizations; the need to adapt to the routine and occupational roles; and the appearance of feelings such as fear, anguish, and anxiety, experienced in the face of the fragility of life (Araújo et al., 2011; Kudo et al., 2018; Kudo et al., 2012; Angeli et al., 2012).

> *The chronic patient ends up being more annoying, who feels pain, you know? It's not even our fault, but it's the disease's fault that ends up being annoying to us* (Marvel).

By contemplating the experience of those who experience the disease, the phenomenon of illness in a person's life is better understood. It is precisely those who fell ill and remained ill that can talk about how the disease is experienced, interpreted, constructed, and how each individual responds to its manifestations and effects (Palmeira & Chaves, 2018). Though Marvel's account, we can understand the way his illness reverberates in his life:

> *We end up knowing things we were not supposed to know about treatment, about the term of life, you know? How many years will we live and several other things? Not that I don't think we shouldn't know about the disease, I think we do have to know, but I think there are things that, it's just that too much knowledge is sometimes not very good, they are great powers and big responsibilities* (Marvel).

The report of his experience with his diagnosis exposes his learning, demonstrating that new meanings were created, which express his maturation and changes in the way he sees life.

The restrictions imposed by the illness in his life made Marvel design self-government strategies because of his desires and motivations, which made him develop ways to deal with and live with the disease, demonstrating the way that corresponds to the manifestations and effects of the illness process in his daily lives (Silva et al., 2016; Palmeira & Chaves, 2018).

The understanding of the illness process by adolescents also incorporates their reflection about other social factors that are associated with the disease and that also interfere in daily life, such as economic and racial prejudices. In his story, Marvel revealed his reading of the association of sickle cell anemia with poverty and racial discrimination, which means that there is less sympathy for its patients.

> *Because sickle cell anemia is a disease of the lower class population, you know? Cancer doesn't...cancer affects anyone, and you can't prevent it, only if you know you have cancer and keep the cure for yourself, right? Now, sickle cell anemia affects the black race more, poorer people, it's difficult for you to see a whiter person with sickle cell anemia, but I have the black race from my mother and father too, I think. Then this is the difference in treatment too, I think that people are more united with cancer, now if you say it's sickle cell anemia, people think it's anemia in the blood, don't you think?* (Marvel).

Category 2: Impacts of Illness in Daily Life

The redefinition of a process of chronic illness does not only consist in accepting the suffering or condition that was imposed on it but finding a way to live with what cannot be changed, which makes this experience can be faced in different ways (Silva et al., 2016).

3.2.1 Subcategory 2.1 - Living with disruptions: "That's something you'll have to take for the rest of your life"

The chronic illness caused countless changes in Marvel's daily life. Suddenly, he had to adjust to a reality permeated by restrictions and needs that affected the different areas of his life and impacted his daily life. Deprivations imposed by the disease, particularly pain, became the first and main issue to be reported by adolescents, which reflects what is found in the literature (Silva et al., 2016).

> *Today I use a wheelchair, I can walk, but I get tired and my foot hurts too, so it's better to use a wheelchair, but before, I played table tennis and soccer at school, it was actually for school competitions. But I used to do it in the city where I live, and there it is, it's... where you train. Then it was Thursday and Friday, I think, it was something like that. It was a place I trained, really cool. I played there when I was about 12 years old. Well, I did sport and in general and table tennis, uhm, I did that, soccer, volleyball, everything. Now I don't play anymore, I miss playing a lot, I think that's what I miss the most, because before I had pain, but the pain was something relative. When the pain was strong, I didn't think about anything else. I thought it would get better and pass, I don't know, and before that, I even played more, but then after the femur problem I couldn't. It was about when I was 10 that the pain started and I stopped doing impact sports* (Marvel).

Chronic illness shows a long and complex treatment, which starts as an acute condition, apparently insignificant, and which lasts throughout life. Due to its chronicity, it presents moments of exacerbation that can aggravate the state of health. Thus, there are gradual and progressive losses that interfere with physical and mental health and with the adolescent's coexistence and social participation (Araújo et al., 2011).

> *Due to the disease, I even had necrosis in the femur, but the doctor said it would be temporary, I believed in it and I cured, but then I had necrosis in the femur, because of the use of corticosteroids* [...] *The impact in my daily life was... I used to do one thing, for example, I made table tennis and I loved doing it, I did sports in general, then I had to stop, do sports without impact, yeah... then I stopped doing it because of the femur* (Marvel).

Chronic illness provokes the need to adjust to a new reality. With each change in the course of illness or exacerbation of the underlying disease, the person may face the need to readjust their activities of interest (Kudo et al., 2018). Changes in the way of seeing life and those brought about by development and maturation also imply new readjustments:

> *So, I always played soccer with my father, I already felt a lot of pain, but I didn't care, it was a pain that compensated, you know?! I did not like it, nobody likes to feel pain, but it was a pain that I think compensated and I was willing to face it. Not anymore, but if I were to do some sport, anything, I would be willing again, but I'm not willing to feel a pain that I don't want. I think you can understand. If I had to feel a pain 10 to play soccer, I would do it every day, you know?* (Marvel).

As we observed, the impacts of chronic illness caused changes in Marvel's daily life, who may have been more impoverished in terms of experience, or more suffered by having to give up activities that he liked to do and that made sense to him, but, given this, a new daily life was also emerging. A daily life marked by treatment demands, hospital routine, and pain, but also by the capacity for (re)creation and resistance to keep something that had or to create something new.

This resignification process enabled Marvel to build coping strategies, in which the search and bargaining with losses occurred. Thus, when portraying his story, the young man composed lists of possible benefits he could obtain from his illness:

> *The only advantage of the disease that I think is the fact that you don't queue up and can fulfill your dream. Who doesn't have money to buy an iPhone, since it's expensive, like me, I got my iPhone at Make-a-wish* (Marvel).
>
> *The good thing about having a disease is getting in line at the cinema, paying half, paying half at the show...* (Marvel).

Subcategory 2.2 – Relating and belonging: "I find it difficult when you have an illness to have enough friends"

Thus, the adolescent needs to readjust and is forced to separate from the activities of his social group and his momentary interests, due to the symptoms he feels and the constant medical consultations, hospitalizations, and procedures. Thus, chronic disease can negatively impact the development of social relationships, due to the restrictions imposed by the disease on the performance of daily activities and also the impacts it brings to body image (Silva et al., 2016).

> *I find it difficult when you have an illness to have enough friends. Your friend is your parents. My friend is my cousin, but apart from family, no* (Marvel).

When a person experiences a process of illness due to the need for treatment, the entire structure and dynamics of the spaces he attends change, whether physical, psychological, and social, as reported below, where Marvel shows the way the school organized for him to be in that space.

> *Sometimes it was kind of boring you know? Because I went to school, then there was a list of people who wanted to stay up there with me during the break, it was even nice, but it was boring because I had to go up to the sport, the teacher was just talking to me. Everyone was going to play, there was no pity. Some people were on a list, it was a list of people who wanted to be in the room with me. They took turns, but then after it was over, it was over, you know? Few people wanted to stay, the girls who wanted to talk to each other, and the boys playing downstairs. When I didn't have that, I was alone and I don't know, you keep thinking, you know? Thinking bad, oh like, I'm alone, nobody's here with me, could be...that's it! Having the list was boring at first because you couldn't choose, you know? They even fought: 'Oh, I want to be with him, I want to be with him', the girls more, right? The boys were relaxed. But then it was annoying because there were girls who stayed there every day, there are some that I didn't want them to stay, there are some that did. My relationship with people was even good when I was a child, then it grew and got bad. Because after the child grows up, it gets boring, I think that's it! The child is real, not the adult. This is something you notice over time* (Marvel).

The limitations of the disease involved everyone around Marvel, whether colleagues or teachers, impacting the establishment of social relationships for him and the construction of his self-image. Therefore, despite Marvel's efforts to try to maintain a lifestyle considered normal, he was faced with the reaction that others expressed to the restrictions imposed by his illness, which for him reflects as a form of prejudice.

> *What changes is the prejudice that exists, right? It's either, like, to have a friendship, or to have something else, people look at you with a different look, you know? But my father and mother say that I can't keep thinking about that side. Everything that is not normal, people tend to have a prejudice, right?! For example, a person with a limp, people will be prejudiced against him because of that, or because of a mark on the neck that the person has because they had a catheter... Such stupid things, you know?* (Marvel).

The repercussion of the stereotype of the adolescent is the one who presents unstable behaviors, with frequent identity crises and intense conflicts with himself and his social environment, causes changes to occur in the way he is treated. The same occurs with Marvel's complaints regarding his illness, who expressed feeling a difference in the treatment he received when he was a child, referring to how much his pain is often discredited.

> *What differs in the treatment is that they no longer look like a child, they look like an adult. Sometimes it's bad because sometimes they think I'm not in pain, that I'm*

> *lying, the treatment changes a little, it's more rigid. I get worried, half thinking, I think it will be a torment when in our lives when we are an adult... I think that illnesses, in general, cannot be compared, you know? Like comparing the pain of the other, you can't compare it...* (Marvel).

Changes in the adolescence phase are not restricted to biological aspects. It is also considered a phase of emotional and social transition. During this period, the search for new identifications occurs so the adolescent searches for his peers, there is a need to belong to a social group, marked by self-reference - where the adolescent observes everything from his perspective and believes that everyone knows what is going through his head – and the ambivalence associated with the maturation process, where there are times when he has autonomy and others when he depends on someone (Araújo et al., 2011).

> *They even defended me once at school, when a boy tripped over me, then I cried, I started crying, anguish, but then they defended me... then the whole class started defending, in that, I started to see that I had someone that I could count on, you know? But I think I counted on people a lot and I always expect a lot* (Marvel).

During this transitional context, adolescents with chronic illness are faced with the complexity of their illness, which makes them face a daily life that is not always consistent with their growth and development process, which can trigger a process of emotional fragility and isolation (Araújo et al., 2011).

There is a tension between the challenges imposed by his illness and the natural process of maturation. This tension was shown by the adolescent in the face of his confused relationships with his colleagues, making Marvel see himself available for these relationships, and sometimes distant and isolated.

> *People are complicated, right?! Relationships? I've never had a girlfriend, I've liked a girl at my school, but then I... I'm not one to get to the person, you know? But I didn't, I had no regrets. I think it's better to live alone. I don't want to get hurt either, hurting my heart. Life is made up of several moments, but it should be better than bad, right?* (Marvel).

Category 3: The Relationship with the Family Passed by Chronic Disease.

When a child or adolescent is diagnosed with a chronic disease and requires complex treatment, the entire family structure is affected. The constant visits to hospitals, the need for care, and the vast restrictions experienced by the children affect family dynamics, which are forced to meet the care guidelines inherent in the treatment process. Thus, it is not only the adolescent who is affected by chronic illness but also his entire family, which needs to adjust to provide care (Castro & Piccinini, 2002; Souza et al., 2016). Therefore, this category brings reflections on how illness permeates the adolescent's relationship with his parents.

Subcategory 3.1 - Sharing the illness: "My father and mother did their best to have fun, you know?"

The illness process requires the construction of networks that can provide sustainability and support, affective and material, to the person with chronic illness. In this aspect, the presence of family members is important for the creation of an affective support network for the adolescent.

Faced with the impacts of chronic disease on adolescents, the family is directly affected in their daily lives with the intense need for continuous care, experiencing the need for rearrangements to deal with the physical and emotional exhaustion of witnessing the suffering up close and exercising an important care role (Castro & Piccinini, 2002; Souza et al., 2016; Silva et al., 2013).

The family appears very constantly in Marvel's story, which portrays the importance of the presence of the mother and father throughout his treatment, as well as his uncle's frequent visits to the hospital.

> *My mother stayed with me, my father would visit me with my uncle. He had a 'walk talky', like those radio communicators, so we kept playing. He was behind the door, I'd say: "Where are you?" And he would answer: "I'm coming", but he was already there, right? He was from Power Ranger, I remember to this day... but my father and mother always did everything for me, even sometimes, they always helped me as much as possible* (Marvel).

The literature emphasizes that feelings of uncertainty, expectation, apprehension, doubt, and fear are present among caregivers, directly impacting the process of adaptation to daily care, being factors that enhance their stress, weakening the relationships between the patient-caregiver, and causing the feeling of demanding the parental role more intense than with healthy children (Castro & Piccinini, 2002; Souza et al., 2016). However, Marvel highlights the importance of parental support and does not indicate greater family conflicts.

Silva et al. (2013) report that, in addition to adolescents needing to learn to live with sickle cell anemia from an early age, the parents shape their lives and the domestic routine to meet the diverse and intense demands of care required by their child's illness. In this sense, Marvel expresses his strong connection with his parents, which permeates his affections and his treatment.

> *I think I end up depending a lot on my parents in my care. I think I'm a little more independent than when I was a kid, but I still depend a lot* (Marvel).

Marvel describes that his parents have, throughout his history, played the role of administrators of his care and, although he recognizes that he still needs help, he expresses a desire for independence.

> *When I was younger, I needed more help, like a baby, changing clothes, changing diapers... not that I don't need help anymore* (Marvel).

Marvel, in several of his speeches, describes the strong relationship he has with his parents, expressing a feeling of reciprocity in meeting his parents' possible care needs. He expresses his feelings of concern about the impact of the illness on his family's daily life, especially on his parents' lives.

> *I get really worried about my parents, they think not, but I think so, I get worried too, sometimes I just wanted to see them happy, you know? It's something every child wants to see, their mother and father be happy. I think they are happy, but I think we could be more if we had better conditions to live in, you know? I'm talking about every way, health, everything... in every way, financial, health, happiness. Not only financially, because why having money and not having happiness?* (Marvel).

Each family member experiences a process of adaptation to the demands of chronic disease, presenting different resources in coping with the process of treatment and illness, and often end up relegating biopsychosocial aspects of family life (Fráguas et al., 2008). Marvel, in the transition that adolescence implies, begins to understand the costs of illness for the family.

Subcategory 3.2 – Gaining autonomy and protagonism in his care: "When you are a child, you change concerning decisions. Now I choose things…"

Although Marvel identifies his interdependent relationship with his parents, he also identifies that in his trajectory, over the years, he gained autonomy and prominence in the management of his health.

> *I could have had surgery on the femur. My parents really wanted me to do it, but I ended up not wanting it, and I'm unfortunately not going to please them. I didn't want to undergo the surgery because I was afraid of dying, I don't know what day or time I'm going to die, but I didn't want to know either, as it was dangerous, I chose not to do it* (Marvel).

The importance of developing and expanding autonomy and protagonism in youth life trajectories has been highlighted in studies carried out by occupational therapy on this age group (Malfitano et al., 2011; Rosa, 2018; Silva, 2011) and pointed out as notions that support critical thinking in Brazilian occupational therapy (Galheigo et al., 2018). However, such studies do not offer a conceptualization of these terms. Thus, the understanding of autonomy referred to here is consistent with discussions in the field of mental health, for which autonomy should be:

> understood as the ability of an individual to generate norms for his life, according to the different situations experienced in his daily life. This autonomy can be identified by the daily activities that it performs, such as its possibility and freedom to circulate in social spaces to manage its daily life [...]. It also involves the management of personal and domestic life: decision-making (…) without the need for technical help or other caregivers (Mângia & Ricci, 2011, p. 185).

On the other hand, the understanding of youth protagonism referred to here, refers to the studies by Costa & Vieira (2000) in the socio-educational context, which highlight the value of active and constructive participation of young people in their lives and the context in which they are inserted, whether it is in their home, school or community.

Marvel's story reveals how the young man was positioning with gradual autonomy and increased prominence in terms of his health care, with due respect from his parents who accepted his decision. Even so, although Marvel claims his participation in matters concerning his life, he also seeks to accommodate some of his decisions so as not to hurt his parents.

> […] *most things I do when it's in my best interest. It's only with my mom and dad that I don't do all my interests if I have to say something to my mom's family, I take it and I try not to hurt them, you know? I sometimes try to think, 'Will it hurt if I do this?' I think a lot* (Marvel).

In summary, the existence of disease causes profound changes in the life of the person and his family, triggering expectations of different natures. Thus, the family needs to restructuring its daily life and ways of living life, relearning how to take care of its dear member at each stage of life and to depend on the course of the disease.

Final Considerations

Marvel's story reveals how chronic illness impacts the various activities throughout life and demands constant adjustments in the daily lives of adolescents and their families. Thus, we can notice the changes demanded by the restrictions inherent to illness and treatment, and the physical changes that impacted the performance of activities in their daily life, requiring adaptation or discontinuity. Because of the illness, a new reality of life and family dynamics was necessary, demanding different adjustments at each stage of the illness process.

One of the limitations of the study may be the fact that it was carried out with only one participant. However, the results can help to understand how adolescents experience the process of chronic illness in the care needs and restrictions imposed by the disease. Although each person has his resources and reactions to deal with and face the illness, fears, impacts, loss of autonomy, and suffering are present in all processes experienced. Furthermore, it is important to remember that in the trajectories of life, the ways of coping, overcoming of limits, the development, and expansion of autonomy and protagonism, and the production of a life that is being built every day are also revealed, as Marvel could tell us.

Thus, even if the results are unique, Marvel's story can represent, in many ways, the experience with chronic illness. Marvel's ability is highlighted here – like that of so many other adolescents that occupational therapists find in their professional practices – to transform a daily life permeated by disease and pain, in which, every day, he claims a dignified and pleasurable life, permeated with meaning and meaning. His sharing contributes to the care practice of occupational therapists and other health professionals for adolescents with chronic illnesses, provoking a more empathetic and welcoming look at his life stories.

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Thaís Breternitz Lino participated in carrying out the intervention, obtaining, analyzing, discussing, and interpreting the data, in addition to preparing, writing, and reviewing the article. Luana Ramalho Jacob was co-advisor of the research and participated in the review of the work. Sandra Maria Galheiro guided the development of the work, participated in the analysis, discussion, and

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