

Waiting for a Transplant: The Perception of Adolescents with Chronic Kidney Disease

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Abstract

Introduction: The study aimed to understand how adolescents face chronic kidney disease (CKD), its treatment and renal replacement therapy (RRT) over time. **Methodology:** Qualitative study in the capital of the Brazilian Northeast with 20 adolescents with CKD. Five focus groups were held addressing the process of living with the disease. Content analysis was carried out in the Thematic modality. **Results and Discussions:** The adolescents brought their meanings of disease, ruptures and changes, desires and projects and the resignification of health and disease. Three categories were found: "A heavy cross"; Getting rid of the disease: "a life without hemodialysis"; "Normal as an ordinary person". **Conclusion:** Adolescents with chronic kidney disease demonstrated strong determination to adapt, giving new meaning to health and illness and expressing desires and plans. The narrative they created for their lives was not necessarily tragic and many spoke of health among the disease.

Keywords: Adolescent; Renal Insufficiency; Chronic; Attitude to Health; Health-Disease Process; Quality of Life

Introduction

Chronic Kidney Disease (CKD) is the progressive and irreversible loss of kidney function, which, in its most advanced form, loses the individual's ability to sustain life [1]. The evolution of kidney disease takes place in five stages. In the first four stages, treatment is clinical and conservative, with attention to the use of medications and changes in lifestyle habits. In the last stage, the kidneys fail to function, requiring the initiation of treatment for renal replacement function (RRT) [2].

RRT comprises hemodialysis, peritoneal dialysis and kidney transplantation. Hemodialysis is a process of removing fluids and toxic substances from the blood by connecting the patient, through a venous access, to the hemodialysis machine. It must be performed in a specialized clinic, three to four times a week, and lasts approximately four hours. Peritoneal dialysis is a filtration technique that introduces dialysis fluid into the peritoneal cavity through an indwelling catheter, which can be performed at home. Kidney transplantation means a graft from a kidney received through a donation, and it is necessary to maintain immunosuppression therapy so that the body does not reject it [3].

Adolescence comprises the age group from 10 to 19 years old. It is a period in which there is crystallization and formation of outstanding values, attitudes, behaviors and habits [4]. When adolescents are faced with a chronic disease, they need to adjust to a reality that affects their life and development. There are subjective and objective impacts, their habits need to be readjusted and the adolescent starts to live with numerous limitations [5].

Bury [6] proposed that chronic disease causes a biographical rupture, that is, there is such a radical change in the subject's life that it establishes a definitive break in his life experience. For Leach [7], the changes caused by the passage of time are experienced and perceived sometimes as a rupture, so that the present moment does not bring links with the previous one, sometimes as a continuity, that is, as a sequence of changes understood as unfoldings.

Coping with CKD imposes a series of restrictions that can influence treatment adherence and the adolescent's social inclusion [5]. Dependence on therapies interferes with life plans, the long period of treatment crosses the experience of these patients and produces uncertainty about the future. Illness is at the center of their social relationships with the socialized outside and acts as a mediator of these relationships [8].

In order to devise effective strategies for dealing with these issues, it is important to understand, from the actors involved, the changes produced in the adolescent's life from the treatment of CKD. How does the treatment affect your life and that of your families? Which changes are perceived as ruptures and which others are experienced as changes relevant to everyday life? How do these teenagers refer to the suffering situated in the past, how do they approach the present moment, their achievements and challenges, what future perspectives do they envision?

Thus, the objective of this study was to understand how adolescents on RRT face CKD and its treatment over time.

Methodology

The research was carried out with 20 adolescents diagnosed with CKD on RRT in its three modalities, in haemodialysis centres of a capital in the Northeast, in 2013. A qualitative approach was used, allowing access, from the subjectivities of the subjects, to perceptions and unique ways of dealing with their daily experiences [9].

Data collection and analysis were performed by a team consisting of the main researcher and 07 medical students. Two research strategies were used: closed interview and focus group. The closed interview, in the form of a structured questionnaire with closed questions covering socioeconomic, demographic and cultural characteristics of the participants.

The Focus Group, a qualitative research technique characterized by data collection through group interactions and with the aim of discussing a question proposed by the researcher, approached adolescents about the process of living with chronic kidney disease. Five focus groups were carried out, with the presence of the researcher in the role of moderator of the group and an academic, acting as an observer. Adolescents were divided into subgroups according to the criteria of age group (10 to 14 years and 15 to 19 years) and types of RRT, with four groups being carried out with adolescents on dialysis and one with transplant recipients.

The focus groups were audio-recorded, which were later transcribed. Content analysis was carried out in the thematic modality, following the steps: pre-analysis (transcription of interviews, exhaustive, floating and interrogative reading of the material, apprehension of central ideas and determination of the registration unit and context unit), categorization and exploration (apprehension of the text comprehension core, search for expressions or significant words, around which the speeches were organized) and interpretation. At the end of the analysis, three Nuclei of Sense were extracted that guided the discussion: "A heavy cross (...) something that never ends"; Get rid of the disease: "a life without hemodialysis"; "Normal like an ordinary person".

The interviews and focus groups were carried out after the adolescents and their guardians signed the Terms of Free and Informed Consent (FICF) and the Terms of Assent. This research was approved by the Research Ethics Committee of the University Hospital where the study was carried out according to protocol 002459/2011-00. The names of the participants were replaced by fictitious names, guaranteeing the anonymity and confidentiality of the information.

Results and Discussion

Participants were aged between 10 and 19 years. Of the 20 teenagers, one was from another state, two from the capital where the research was carried out, and 17 were from the interior of the state. Four reported not following religion, while 14 followed Catholic or Protestant Christianity and two did not report whether or not they followed religion. Regarding the study, five adolescents did not attend school. With regard to TRS, 14 were on hemodialysis, 02 of them had already been transplanted and lost the graft, 02 were on peritoneal dialysis and 04 had been transplanted.

The speeches presented by the adolescents referred to the burdens and meanings they gave to the disease, the ruptures and changes that the disease caused, the desires and projects they had and the redefinition of what health and disease meant for them. Thus, the results were divided into three categories, to be presented below.

“A heavy cross”

The meanings attributed by adolescents to CKD and to the respective therapies are multiple, but they bring with them the imagery representation of the burden imposed on them:

“It’s a cross. Heavy! We talk in terms of something that never ends.” (Tina, 18 years old, hemodialysis).

Adolescents and young people with CKD have different feelings about the disease and its treatment. These feelings are part of the adaptation processes and can change throughout the illness process [10]. In the interviewees’ experience, one of the feelings present at the beginning of the illness was anger. Rafael commented on how he reacted to the beginning of treatment:

“[...] At the beginning I didn’t accept it, I was very angry with my mother... I said things without thinking. My older brother, I would go to beat him, I would say he was guilty of my being sick. I was disgusted with everyone in my family.” (Rafael, 18 years old, hemodialysis)

After the initial change caused by the diagnosis and marked by individual and family changes resulting from the treatment, the interviewed adolescents reported the beginning of another phase in which the disease and therapy started to be interpreted as obstacles to be overcome.

“It’s a hindrance and also, thus, it’s a difficulty that has to be overcome.” (Naldo, 17 years old, hemodialysis)

“Kidney disease for me, I don’t know, maybe it’s just an obstacle that I go over every day, and let’s say it’s a race that I have to win every day, losing sometimes, but life is made up of defeats and the next day we win again. Just one goal to hit!” (Ilson, 19 years old, transplant)

“I used to think like that, I kept wondering why this disease had entered my life, I was always blaming myself, but then I said no! If God put her in my life, it’s because He knows I’m able to take it.” (Quel, 19 years old, hemodialysis)

This idea of overcoming difficulties also encompassed the notion of resistance in the sense of supporting changes in personal and family life. Resisting means not victimizing oneself in the face of illness, but, on the contrary, bearing this cross: a test of the moral strength and faith of young people through the suffering brought by the disease.

Adherence to treatment, that is, its acceptance, did not necessarily imply a rational choice by a subject characterized by autonomy and freedom. In the case of the interviewed adolescents, accepting also meant resigning, submitting and conforming to what they understand to be a lack of option.

"Because I only had two options: Either accept or die! We don't accept it, we conform." (Quel, 19 years old, hemodialysis)

For Silva, *et al.* [11] feelings in relation to the treatment of CKD are guided by the knowledge process, bringing an understanding that it is necessary to undergo treatment to maintain life and make the sessions less painful.

In this sense, the disruptions in lifestyles caused by the disease were presented as a watershed that established a before and after diagnosis and treatment adherence.

"It's just that I liked camping a lot, my mother liked it [...] we spent five days, overnight, three days[...] this part seems to have been ripped from me." (Tina, 18 years old, hemodialysis)

"I can't do my thing anymore. It gets in the way of doing the things I used to do." (Marco, 15 years old, hemodialysis)

"I also think it had an influence on my adolescence, because there in my city I had a lot of friends and here it's harder for us to go out somewhere." (May, 15 years old, hemodialysis)

The daily life experience of people living with and despite the disease, especially those who pose a threat to individuals' lives, has been the object of sociological analysis since the 1970s [8] The idea that chronic disease constitutes a disruptive event is addressed by Bury ⁶ who considers it as an experience that breaks the structures of everyday life and the forms of knowledge that support them.

Priority treatment withdraws previously experienced pleasures. Adolescents with CKD on RRT can experience a double face of treatment: a means of survival, but also an obstacle in their routines and life dynamics [10]. Hemodialysis, for example, is seen by many patients as a debilitating experience, of dependence and loss of autonomy [12]. Frequent visits to the hospital for hemodialysis sessions, consultations and exams, administration of medications, dietary restrictions were changes that imprinted the meanings of transformation in daily life:

"We had to make another life here! [in the hospital]" (May, 15 years old, hemodialysis)

The concentration of RRT services in certain regions forced the routine displacement of adolescents from their hometowns to centers that offer dialysis services. This contributed negatively to the perceptions of changes in the lives of the young people interviewed and their families. The distance from family, school and friends was experienced as a significant loss. Spending periods in city hall support houses, in the homes of relatives or even causing, in the family, an increase in financial expenses as a result of the treatment, contributed to producing the referred burden.

"When we are taken from there [from the countryside], we come here [...]. Being without friends overnight..." (Tina, 18 years old, hemodialysis)

"Because if there were machines in nearby places, it would be better, at least we wouldn't distance ourselves that much from the family. I also think that we would face it better." (Quel, 19 years old, hemodialysis)

"I don't go to school every day." (Prior, 17 years old, hemodialysis)

Almost all teenagers had their parents as central supportive figures, regardless of family constitution. During the entire course of treatment, the formation of a dyad was observed: son/mother, son/father. Regular follow-up of the child to the hospital produced changes

in family dynamics, as it imposes on parents to divide themselves between this child and the others who remained at home. One of the teenagers who lived in a shelter and did not have this support, demonstrated how much help he felt from his father and mother:

"I don't have help... I thought about my father helping me and my mother supporting me... I don't want to talk anymore." (Di, 15 years old, hemodialysis)

For children and adolescents with chronic illnesses, the importance of the support network is highlighted, which is, in general, made up of individuals who make up their social network. Relatives, both from the nuclear family and from the extended family; health professionals; and friends, especially schoolmates, can make up this network. However, the network is not always strengthened and capable of offering the necessary support to cope with the disease, which can generate more suffering [13].

Get rid of the disease: "a life without hemodialysis"

Throughout the illness and treatment process, one thought was common to the group of teenagers interviewed: the desire for "a life without hemodialysis". This is the premise of a greater desire, latent in teenagers that feeds them in the day-to-day life of renal replacement therapy. By internalizing this idea, they created a coping strategy. Thus, there is an existential project, generating vital forces and impulse to support hemodialysis or peritoneal dialysis, in a relationship with the machine as an intermediary, transitory and necessary for the achievement of this project.

"Our desire... one day to be free of the disease, certainly helps me feel free... I think about a much better future for me, a much better life... life without hemodialysis." (Naldo, 17 years old, hemodialysis)

"I've already done what I can, I faced the problems of being a kidney patient. I'm waiting for the transplant, I look forward to it." (Quel, 19 years old, hemodialysis)

This desire for a transplant, however, was not expressed by everyone. In some cases, there was a personal refusal based on feelings and beliefs related to the intervention itself or to life after the transplant:

"I don't want to have a transplant, I can't even play! I'm afraid, it was in the newspaper that a girl went to change and she died." (Karina, 10 years old, hemodialysis)

Amid the idea of kidney transplantation, feelings already experienced at the beginning of the treatment reappear: fear and uncertainties about the future. When deciding to join the transplant list, some take into account the uncertainties regarding the adaptation of the transplant, the fear of graft rejection and death [14].

Among the participants, two adolescents were transplanted, but later had graft loss. One of them brings the momentary refusal on a second call to perform the procedure:

"I was called again to do the transplant. It could do it, it could work, but it also might not work like the last time. Mom said it was my decision and I decided not to have a transplant." (Naldo, 17 years old, hemodialysis)

The failure of a transplanted kidney is a difficult experience, which causes suffering, impotence and the need to return to hemodialysis. This experience has an impact on the decision to refuse new treatment [14]. The failure of the procedure generates dissatisfaction and uncertainty about a new donor, a new surgery and a new rejection [15]. However, the experience of great suffering and frustration in the postoperative period did not completely distance him from the desire for a new transplant:

"I believe that in the future, sometime from now, I can transplant again, but now, not now." (Naldo, 17 years old, hemodialysis)

When he reported having refused the kidney that was available, he heard an immediate response from one of the group members:

"You have to take the opportunity. I even want to say that I was kind of like that, when he [Naldo] spoke about the transplant [refused]. Because there are people who don't care, who have the opportunity for a transplant and don't care." (Quel, 19 years old, hemodialysis)

Quel's desire was immense, so he couldn't understand Naldo's refusal. Based on the information she had, her discomfort with hemodialysis and her expectation of being called for a transplant, she saw in it the only way out of her current situation. Naldo, in turn, lived an experience that broadened his view of the implications of a kidney transplant, and the meaning of being transplanted. The rejection did not mean that Naldo did not want the transplant. He was exercising his freedom of choice and evaluating his personal readiness to face something that brings risks and restrictions, for him, already known.

Kidney transplantation can help the patient from a clinical and psychological point of view, but not always. It should not be associated with the solution, as even after the transplant, children and adolescents continue to be treated, with limitations, crossed by memories of pain, consultations and hospitalizations [16].

Even so, for adolescents undergoing dialysis treatment, having a kidney transplant represented the possibility of repairing the losses caused by the disease and fulfilling the expectation for a better future. In fact, among transplanted adolescents, an improvement in quality of life has been reported.

"Being transplanted and going back inside because I like it so much." (May, 15 years old, hemodialysis)

"I think about a better future for me, a much better life." (Naldo, 17 years old, hemodialysis)

"The transplant took away that thing that made us weak..." (Ilson, 19 years old, transplant)

"Now for me the transplant is much better, because I can live with my practically normal life. Not before, it was very difficult." (Lane, 17 years old, transplant)

Many understand transplantation as a possibility to regain control over their lives. A return to life before kidney disease [16]. However, improvements occur, especially in physical condition and school activities, however, in the social and emotional aspect, significant differences are not always noticed between transplantation and hemodialysis [16,17].

After the transplant, the adolescents were still immersed in a situation of continued treatment permeated by other difficulties. In addition, external pressure emerged regarding the necessary care for the maintenance of the grafts, in the form of demands and rules on how they should behave. It is a supervised adolescence. This issue was even more evident considering that among the transplanted adolescents, all had their mothers as donors. Gradually, they internalized this pressure, which came to exist as a constant and disturbing concern, combined with the fear of graft loss.

"Sometimes I think... of losing, of going through it all over again, of suffering, not just for us, for the mother who did everything to donate her kidney. Going through another suffering again." (Andy, 16 years old, transplant)

"My family has always been on my side, although they always charge me, right? That if I don't take the medicine, then Mom says: Look, if I miss this one, there's no way I can give you another one... because she was the one who donated it to me. My sister, who was also willing, says: Look, if you forget to take the medicine and lose your kidneys, I won't give you mine. You're throwing Mom's away, you're not going to throw it in the trash." (Ilson, 19 years old, transplant)

A complexity of this situation is the fact that after transplantation it is possible to form a hierarchy between donor and recipient. It is a dynamic exchange of care system, both of which are complementary elements of the same totality. The donor, through the act of donating, reaffirms his importance in the family and temporarily establishes himself in a superior position [18] and the recipient starts to feel a perpetual duty to demonstrate gratitude to the donor [19].

“Normal like an ordinary person”

More than a life without hemodialysis, adolescents, in the process of coping with CKD, sought normality in their lives with the disease.

“Living with the disease is normal, we go out, study... normal, if we live a normal life [...] I feel normal like an ordinary person.” (Caíque, 17 years old, peritoneal dialysis)

This search mobilized them in the cognitive, emotional and behavioral spheres, constituting a strategy for coping with the disease and treatment.

“Normal as an ordinary person” – what might this prerogative mean to these teenagers? Hearing someone with a chronic illness say that living with it is normal resonates with those who listen, causing a feeling of estrangement. This is because there is a socially expected behavior from those who have a disease.

This discussion is based on Canguilhem’s [20] reflections on the concept of normality. For this author, both health and disease are normal, as normal is not an average correlating to a social concept, nor is it a judgment of reality. It is a value judgment.

Health and illness are not the opposite. They don’t talk about the same thing or the same way. Recognizing health and disease as polar situations, identifying them according to the same rationality, is as limiting to the understanding of both and related practices, as denying the close relationship between them in everyday life [21].

Canguilhem [20] speaks of an individual health standard, characterized by the ability to establish norms and go beyond a pre-established concept of normal, giving new answers in coping with the disease, as Caique stated.

An adolescent pointed out the complexity of the perception of the health-disease process, demonstrating the coexistence of disease and normality:

“I feel sick, sometimes not. I feel when I look at my arm [fistula]. When I have to be careful, then... do dialysis... then we know it’s different. Because I have a normal life... I have a normal life, because I’m sick, but I have it. It’s not because I’m sick that I’m going to stay at home, locked up.” (Rafael, 18 years old, hemodialysis)

Rafael talks about the body marked by the treatment, the need for self-care and the routine of hemodialysis sessions as proof that he has a disease, but it also highlights the possibility of a normal life, determined by his capacity for action, to experience his choices, to go beyond, according to Canguilhem [20], the pre-established concept of normal.

Opposing the definition of normality taken from physiology, whose intent is to diagnose in order to cure and return to normal, Canguilhem [20] proposed a new dimension for health, not reducing it to an imposing normative discourse.

Understood in this way, it can be understood that Raphael creates possibilities for self-acceptance.

“Then I started to reflect, there was no use in all this anger, it wouldn’t do any good... My illness wasn’t going to go away. So I started to participate more in my mom’s conversation, and naturally accept that I’m like that. I’ve got used to it, it’s no use being disgusted by it.” (Rafael, 18 years old, hemodialysis)

It is observed that it is not about accepting the disease itself, but about oneself with a disease from which he cannot distance himself – “I am like that”. The acceptance of oneself as different is an essential factor for a solid construction of identity, including “corporeal”²² and for the recognition of health in disease [20].

Seeking normality in their lives, the interviewed adolescents demonstrated the attempt to maintain the image they have of themselves, seeking to preserve the lifestyle they had before the disease and a place of belonging. They wanted to blend in with their peers, without being different, making the effort to fit into a pattern that is socially recognized as normal.

“Ah... [laughs]. I go everywhere... I go out a lot with my colleagues, I love it! I don't like being at home.” (Naldo, 17 years old, hemodialysis)

“I go to the beach, to reggae, that's why I say that this treatment hasn't affected me that much... much, because I go out a lot. I didn't let myself be affected by a simple illness.” (Quel, 19 years old, hemodialysis)

This reflection suggests that the adolescent's search for normality can be a strategy for coping with a chronic disease, empowering them in light of the demands placed on them.

However, it is necessary to expand this discussion taking into account another aspect of great impact. Is this whole process of seeking normality a mechanism for denying the disease? In some cases, the experience of normality led to the departure from self-care and the adoption of inappropriate behaviors to the situation, generating a process of non-adherence to treatment:

“Sometimes I feel very normal and I end up doing things I couldn't do...” (Ilson, 19, transplant)

“Ah! Of feeling so good... that he does something wrong.” (Andy, 16 years old, transplant)

In a research with adolescents on RRT, the alterations brought about by the CKD made the adolescent perceive himself as different from others, suffering, in many cases, from situations of bullying. Thus, there was a search to get closer to normality, sometimes denying the disease, sometimes facing or trying to minimize its consequences [15].

Some recognize that for marks on the body there was no escape.

“Because everyone who looks at me with this here [fistula] gets scared and gets away from it... they look at me with a weird face and get away from it. And the worst thing is that I get angry.” (Di, 15 years old, hemodialysis)

“When people look at me and ask, I say what it is. I explain everything to them... what I realize is that I tell them, they tell the other person who is with them and they walk ahead and whisper to each other, without me listening.” (Rafael, 18 years old, hemodialysis)

People's reaction to an arm modified by a fistula, or to someone using a visible catheter, generated different interpretations and attitudes in adolescents. It is the discomfort caused by a body that bears the marks of an illness. Feeling discriminated against or not, all expressed how negative the experience is.

Another reported inconvenience was the short stature caused by the disease

“Sometimes people are looking at us... I think they think: This boy is small! I think so, I don't know. Maybe it's my bullshit.” (Caique, 17 years old, peritoneal dialysis)

Growth impairment is common in children and adolescents with CKD and tends to be more intense according to the more advanced stage of the kidney disease [23].

The perception of oneself as different can be a difficult experience for a teenager. After all, at this stage of life, they want to belong to the standard in order to be accepted and valued [24]. In this research, adolescents who had gone through the kidney transplantation process expressed less discomfort with their bodies, although there is evidence in the literature that even after the transplant, problems with their body image remain [25].

It is understandable that there is a desire to escape the patient's image, after all, in contemporary society the disease is assimilated as harmful and depriving. It is an abnormality or anomaly that must be avoided, it is a social deviation and the patient is seen by others and sees himself as a socially devalued being [26].

In addition, the process of self-assertion and seeking appreciation and acceptance among peers may have contributed to non-adherence to immunosuppressive therapy.

"In the beginning I had a bag that I always carried with it, and it was full of medicine, but sometimes I would take it, then my colleagues would see those huge pills, and as I was used to it, I sometimes swallowed it without water, the which is not advisable. The colleagues looked at me there, it seemed like a horror scene..." (Ilson, 19 years old, transplant)

This scene is terrifying for who? For his colleagues, or for himself? Perhaps one can think of a denial of the disease, but not for oneself, but for the other.

For an adolescent, having a chronic disease is living in a continuum of a condition that by nature has a long duration, causes residual disability and disability, requires more palliative effort, favors the onset of multiple diseases, needs continuous monitoring [2]. How to deny what remains? How to act within this perspective? Chronic kidney disease and its treatment mainly affect the lives of adolescents undergoing dialysis, a tiring and exhausting routine that repeats itself day after day.

Despite this, the interviewees' statements were permeated with hope and desire for a better future, with plans to build a family, have children, gain a profession and work.

"I am a boy who loves to study. I want to graduate, grow in life." (Caique, 17 years old, peritoneal dialysis)

"We keep thinking like this: I have dialysis, but what if my life suddenly changes like it did the first time? Like all of a sudden I get a transplant and when I wake up I'll be disease free? So, what did I do? Where is my dream, understand? How much time has passed? I keep thinking about myself. That time will come. Thinking like that, the will is there with us... That we will be able to change things and that we will not just let time go by." (Tina, 18 years old, hemodialysis)

In Tina's words, there is the life project, the desire for something to be conquered. We close this work with his speech, supported by Deleuze²⁷ when he states that it is possible to make repetition itself something new, linking it to a test and placing it as the supreme object of will and freedom.

Conclusion

Bringing together the interviewed adolescents allowed a place to exchange experiences, where they could share their doubts, anxieties and pains. They were able, together, to think about the meanings and feelings that the illness caused them.

Chronic kidney disease was represented as an obstacle to be overcome. However, they showed a strong determination to adapt, giving new meanings to health and disease and manifesting desires and life projects.

Adolescents with chronic kidney disease seek different ways to deal with the disease and treatment, and many flee from a socially expected pattern of suffering. The narrative they created for their lives was not necessarily tragic and many spoke of health in disease.

Development Agencies

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