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EVERYDAY LIFE OF ADOLESCENTS AND YOUNG PEOPLE UNDERGOING HEMODIALYSIS TREATMENT IN THE LIGHT OF AGNES HELLER: A CASE STUDY

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ABSTRACT

Objective: to understand the everyday life of adolescents and young people with chronic kidney disease undergoing hemodialysis treatment.
Method: a qualitative research study of the Single Case Study type developed in a Renal Clinic from southern Brazil. Eight adolescents and young people aged between 18 and 24 years old undergoing hemodialysis treatment from February 5th, 2021, to January 26th, 2022. Data production was through semi-structured interviews, data from electronic medical records and participant observation through data triangulation. The observation was based on a script and field diary. The data were submitted to inductive thematic analysis and interpreted in the light of Agnes Heller's concept of everyday life.
Results: the everyday life of adolescents and young people experiencing chronic kidney disease is impacted from the moment they receive the diagnosis until they understand their health situation. The changes imposed by the treatment and maintenance of the care measures have repercussions as limits faced in their everyday life. As for self-care, the major concern refers to the laboratory test levels.
Conclusion: the everyday life of adolescents and young people on hemodialysis is permeated by unique changes in their existence and the construction of their own identity, added to the impact of the disease and the new condition imposed by the treatment. It is believed that the time they remain at the Clinic constitutes a strategy for health education, meeting the needs for diverse information about their chronic condition and treatment and contributing to the externalization of their humanity as a whole in this everyday routine.

DESCRIPTORS: Adolescent. Young adult. Chronic disease. Renal disease. Health care. Nursing.

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COTIDIANO DE ADOLESCENTES E JOVENS EM TRATAMENTO HEMODIALÍTICO À LUZ DE AGNES HELLER: ESTUDO DE CASO

RESUMO

Objetivo: compreender o cotidiano de adolescentes e jovens com doença renal crônica em tratamento hemodialítico.
Método: pesquisa qualitativa do tipo Estudo de Caso único desenvolvido em uma Clínica Renal do Sul do Brasil. Participaram oito adolescentes e jovens entre 18 e 24 anos em tratamento hemodialítico, no período de 05 de fevereiro de 2021 a 26 de janeiro de 2022. A produção de dados ocorreu por meio de entrevista semiestruturada, dados dos prontuários eletrônicos e observação participante por meio da triangulação de dados. A observação baseou-se em um roteiro e diário de campo. Os dados foram submetidos à análise temática indutiva e interpretados à luz do conceito de cotidiano de Agnes Heller.
Resultados: o cotidiano de adolescentes e jovens na vivência da doença renal crônica é impactado no momento que recebem o diagnóstico até a compreensão da sua situação de saúde. As mudanças impostas pelo tratamento e a manutenção dos cuidados repercutem como limites enfrentados em seu cotidiano. Quanto ao cuidado de si, a maior preocupação refere-se aos níveis dos exames laboratoriais.
Conclusão: o cotidiano de adolescentes e jovens em tratamento hemodialítico é permeado por alterações singulares da sua existência e pela construção de uma identidade própria, acrescido do impacto da doença e da nova condição imposta pelo tratamento. Acredita-se que o tempo que eles permanecem na Clínica constituiu-se em uma estratégia para a educação em saúde, atendendo às necessidades de informações acerca de sua condição crônica e tratamento, contribuindo para a exteriorização de sua humanidade por inteiro nessa cotidianidade.

DESCRITORES: Adolescente. Adulto jovem. Doença crônica. Doença renal. Cuidados de saúde. Enfermagem.

VIDA DIARIA DE ADOLESCENTES Y JÓVENES EN TRATAMIENTO DE HEMODIÁLISIS A LA LUZ DEL CONCEPTO PROPUESTO POR AGNES HELLER: ESTUDIO DE CASO

RESUMEN

Objetivo: comprender la vida diaria de adolescentes y jóvenes que padecen enfermedad renal crónica y se encuentran en tratamiento de hemodiálisis.
Método: investigación cualitativa del tipo Estudio de Caso único desarrollada en una Clínica Renal del sur do Brasil. Los participantes fueron ocho adolescentes y jóvenes de 18 a 24 años de edad en tratamiento de hemodiálisis entre el 5 de febrero de 2021 y el 26 de enero de 2022. La producción de datos tuvo lugar mediante entrevistas semiestructuradas, consultas en las historias clínicas observación participante por medio da triangulación de datos. La observación se basó en un guión de campo. Los datos se sometieron a análisis temático inductivo y se los interpretó a la luz del concepto de vida diaria de Agnes Heller.
Resultados: la vida diaria de adolescentes y jóvenes que viven con enfermedad renal crónica se ve afectada desde el momento en el que reciben el diagnóstico hasta que logran comprender su estado de salud. Los cambios impuestos por el tratamiento y el mantenimiento de las medidas de cuidado repercuten como límites que deben afrontar en su vida diaria. En cuanto al autocuidado, la mayor preocupación se refiere a los niveles de las pruebas de laboratorio.
Conclusión: la vida diaria de adolescentes y jóvenes en tratamiento de hemodiálisis se ve invadida por cambios singulares en su existencia y por la construcción de una identidad propia, intensificado por el efecto de la enfermedad y de la nueva condición impuesta por el tratamiento. Se cree que el tiempo que permanecen en la Clínica se erige como una estrategia para la educación en salud, respondiendo a las necesidades de contar con información acerca de su condición crónica y del tratamiento, además de contribuir a externalizar su humanidad por completo en dicha cotidianeidad.

DESCRIPTORES: Adolescente. Adulto joven. Enfermedad crónica. Enfermedad renal. Atención de la salud. Enfermería.

INTRODUCTION

Adolescence is permeated by physical, emotional, social and cultural changes, reflecting on the individual's behavior, with peculiarities in human development, as well as new feelings, attitudes and discoveries. On the other hand, young people have a more consolidated social identity according to their cultural and relational context, with more responsibilities and occupations in society[1].

The World Health Organization (WHO) demarcates the period between 10 and 19 years, 11 months and 29 days of age as adolescence and the phase between 15 and 24 years old as youth[2]. The Ministry of Health (*Ministério da Saúde*, MS) follows the WHO recommendations to regulate public policies and health programs[3]. Thus, this study followed the WHO recommendations.

There is increasing prevalence of chronic diseases at the global level, which are chronic conditions that require continuous monitoring, with uncertain prognoses and indefinite duration. Chronic diseases in adolescence and youth are characterized as a phenomenon of a complex nature, considering all the issues typical of these life phases. In Brazil, 11% of the adolescents aged from 14 to 19 years old have a chronic disease, in relation to the general population belonging to this age group[1].

In this context, Chronic Kidney Disease (CKD) stands out among the pathologies that affect adolescents and young people, being a disease of progressive evolution, which can generate limitations as well as social and psychological conflicts due to the need for treatment and the necessary changes in the patients' everyday life. Therefore, this phase becomes even more challenging, with the presence of a chronic disease[4].

In Brazil, hemodialysis is the Renal Replacement Treatment (RRT) modality most used among patients with kidney disease, including 92.5% of the cases, being indispensable for people with CKD. Hemodialysis treatment consists in removing liquids and toxic substances from the blood through a dialysis machine, helping the body maintain the balance of substances such as sodium, potassium, urea and creatinine[5–6].

For being a treatment that forces the patient to remain connected to a machine for extended hours and several days a week, the following was chosen as the problem of this study: Repercussions of RRT on the everyday life of adolescents and young people. Consulting the national and international scientific literature on the topic, a number of studies indicate the need for specific spaces for pediatric and young patients, as contact with peers can assist in management of the disease. The literature also points out the importance of the role of parents and health professionals in helping children with chronic kidney disease to make the transition to adolescence and youth, a period of life in which they would have to take responsibility for their self-care[7–8]. No studies were found that contemplated the everyday life of adolescents and young people with chronic kidney disease undergoing hemodialysis in Brazil.

Thus, in addition to the epidemiological reason and the gap in knowledge construction, this study is justified by the need to understand the repercussions of chronic kidney disease and hemodialysis treatment in a life phase characterized by the perspective of a professional and affective future. It is expected that the planning of care that meets the demands of this population segment during the time they remain at the Clinic connected to the hemodialysis machine, can contribute to management of the disease and for them to lead their lives despite the chronic condition.

To interpret the data of this study, Agnes Heller's concept of everyday life was used, in which everyday life involves subjects as a whole, including all their individuality and personality aspects. For the author, it is the "world of life" that is produced and reproduced in a continuous movement, with actions that take place in the world of objectifications. Among many authors who studied the concept of everyday life, Agnes Heller was chosen because she highlights each person in their individuality and the way in which they are inserted in their social environment, just as adolescents and young people undergoing hemodialysis treatment are inserted in the world of life despite the treatment. In addition, due to the fact that everyday life can be a receptive space for innovative achievements, with creative and transforming knowledge[9], which is aimed at this population that lives with a chronic condition and a treatment that can be limiting for their everyday life.

Based on this concept of everyday life, the question was how hemodialysis treatment affects the everyday lives of adolescents and young people with CKD? Development of this study is justified to understand the implications of CKD in the everyday life of adolescents and young people undergoing hemodialysis treatment, as well as the situations they experience, especially during their stay in the Clinic environment, with the objective of understanding the routines of adolescents and young people with chronic kidney disease undergoing hemodialysis treatment in the light of Agnes Heller's concept of everyday life.

The importance of this study is highlighted for the performance of nurses and the multidisciplinary team in knowing the everyday daily life of adolescents and young people with CKD in the hemodialysis treatment space, for better understanding the daily treatments and their needs, contributing to unique and individualized care in favor of better management of the disease and treatment for this group.

METHOD

A qualitative research study of the Single Case Study type, having Agnes Heller's concept of everyday life as its theoretical basis, which has the principle that, regardless of the place they occupies in society, each individual has am everyday life[9]. To ensure rigor of this study, the *Consolidated Criteria for Reporting Qualitative Research* (COREQ)[10] checklist was followed.

Single case studies consist of a type of research whose object is a unit that is deeply analyzed to investigate a contemporary phenomenon in its natural context, resulting in deepening and treatment of multiple dimensions, characterizing specificity of the case[11].

The Case: the study was carried out in a Renal Clinic from southern Brazil, which has two units, a matrix and a branch, and serves patients via the Unified Health System (*Sistema* Único *de Saúde*, SUS), health plans and privately. The Renal Clinic has a Nursing team made up of nurses specialized in Nephrology and nursing technicians, a medical team, a general services team, a nutritionist, social assistance, a psychologist, employees for the deposit and warehouse area and an employee for hemodialysis maintenance, in addition to an agreement with a clinical analysis laboratory. It operates from Monday to Saturday, distributed in three shifts: morning, afternoon and night.

The main unit has six rooms for hemodialysis treatment, treating around 200 patients/month in a regular hemodialysis program, with 30-37 patients per shift. The branch unit has two treatment rooms and treats around 143 patients/month in a regular hemodialysis program, with 28-30 patients per shift. The Renal Clinic under study is a reference for this type of care in the center of the state of RS; it receives patients from several cities in the Midwest macro-region. In addition, the nurses are responsible for showing the results of the monthly tests to the patients, in addition to providing guidelines and explanations about the exams, which occurs individually during treatment. Throughout this period, there is permanent presence of the Nursing team inside the rooms with the patients.

In this study, the research subjects should be, by selection criteria, adolescents and young people diagnosed with CKD on renal replacement treatment through hemodialysis who had been on hemodialysis for at least three months, aged between 10 and 24 years old. For recruiting the participants, a previous approach was made at the Clinic when the possible participants had an appointment, explaining the research and inviting them to participate. All participants were over 18 years of age since, although the Clinic provides assistance to children under 18 years old, there were none undergoing treatment during the research period.

The study included eight participants who met the selection criteria. It should be noted that this number represents all participants who were undergoing hemodialysis during the data collection period, and all adolescents and young people who were invited accepted to participate in the study. Data collection was conducted between February 2021 and January 2022.

Data production took place, as recommended by the case study method, by means of findings through the triangulation of data and results[11] using three techniques, namely: face-to-face and individual semi-structured interviews. The interview script that was prepared included questions about the everyday life of adolescents and young people and their care practices, through a semi-structured interview script with the following questions: "how did hemodialysis enter your life? What is your everyday life like after you started the hemodialysis treatment? How do you take care of your health on a daily basis? How do you use the medications that are prescribed? Can you explain me that? Which precautions/guidelines of your treatment do you find most difficult to follow? Why? Do you usually want to know and follow the results of your tests? Why?"

An instrument for sociodemographic and clinical characterization was also used, with data collected from the electronic medical records and diverse information collected directly from the participants, in case it was necessary to complement them, constituting the study documentary data. In addition to that, participant observation was carried out, in which the researcher was part of the scenario under study, with elaboration of an observation plan[11] that delimits the phenomenon to be studied, what should be observed, how to record it, and the period and duration of the process[11].

The interviews were scheduled according to the availability of each adolescent and young person, always on the same day of their treatment. The interviews were all carried out by the MSc student researcher, recorded with a cell phone and transcribed in full. The locus was inside the Clinic itself, in a room reserved for this purpose. The interviews lasted from 30 to 40 minutes, with a mean of 50 minutes.

The adolescents and young people were observed since their arrival, during and until the end of the hemodialysis treatment session, which took place three times a week, lasting four hours. The observations took place after the interview stage, and the pre-analysis of the interviews served as the basis for preparing the observation script. The intention of the study was exactly to observe the participants in this environment, not only to complement the interview information and documentary data, but also to survey subsidies that might contribute to planning the activities of these adolescents and young people during the time they remain at the Clinic, with the possibility of offering unique and personalized care to this type of clientele. For such purpose, the importance of observing it in this environment is advocated. With this, it was possible to confirm and reinforce the reports of the interviews during the observations made, which took place until the researchers considered that the study had reached sufficient theoretical density to meet its objective[12].

A field diary was used to record notes of the observations that were made in writing and digitally through voice recording. The observations took place from November 19th, 2021, to January 26th, 2022, totaling 156 observation hours, with a mean of 26 hours per participant.

Data analysis was performed through reflexive Inductive Thematic Analysis (ITA)[13]. The way in which the steps were carried out in this study is represented in Chart 1 below:

Chart 1 – Data analysis procedure. Santa Maria, RS, Brazil, 2022.

Analysis stage	Analysis of the interview data	Analysis of the observation data
Familiarization with the data	- Full transcription of the interviews in Microsoft Word, version 2010. - Reading and rereading of the transcripts.	- Transcription of the field notes in Microsoft Word, version 2010. - Reading and rereading of the field notes.
Initial code generation	- Grouping, by color, of significant fragments from the interviews in a systematic way, through the elaboration of a chart in Microsoft Word, version 2010.	- Systematical gathering of diverse information from the observations, through the elaboration of a chart in Microsoft Word, version 2010.
Search by topics	- Organization by color of the data from interviews with relevant information on possible topics.	- Arrangement of the data, by color, from the of observations with relevant information within possible topics.
Review of the topics	- Verification of the topics in relation to speech extracts and interview data.	- Verification of the topics in relation to the observation data.
Definition and naming of the meanings	- Refinement of each topic according to the data analysis, with generation of the names for each topic.	- Refinement of each topic according to the analysis of the observation data and the generation of the names for each topic.
Elaboration of the report	- Analysis of the extracts chosen according to the research question.	- Analysis of the field notes according to the research question.

Agnes Heller's concept of everyday life was applied since construction of the study object, starting from the assumption that the participants' everyday life is unique and individual, with its transformations and perspectives, and was applied in the phase of interpretation of the results, permeating the study discussion and conclusions.

This study followed all the ethical principles that guide the development of research studies human beings, in accordance with Resolution No. 466 of December 12th, 2012. The participants read and signed the Free and Informed Consent Form (FICF), as all participants were over 18 years old during the research period. The study was approved by the institution's Research Ethics Committee. To ensure anonymity, the participants were identified using the alphanumeric system, with P for Participant and the sequence of the interviews: P1, P2 and so on.

RESULTS

Of the eight research participants, four were female and four were male. Of them, only three lived in the city of Santa Maria; the other five came from other municipalities in the Midwest macro-region of the state. Their age varied from 18 to 24 years old. Five were single and three were married, and two had children. Only one worked, one was retired from the Army and the others received financial assistance from their family. Two participants initiated medical follow-up for the kidney problem in childhood, at age five and 11, respectively. Duration of the hemodialysis treatment varied between one and seven years. The public health service is the most used, and two participants also had a private health plan.

The results will be presented below according to the following thematic categories prepared: The disease: Discovering the CKD diagnosis: "[...] and the doctor said that I had kidney failure..."; Undergoing the hemodialysis treatment: "[...] You have to be patient..."; Care in the hemodialysis treatment day-to-day: Limits and possibilities.

The disease: Discovering the CKD diagnosis: “[...] and the doctor said that I had kidney failure...”

CKD was detected at different times in life, which could be in childhood or adolescence. Most of the times, the CKD diagnosis is made due to other illness situations and clinical investigations. With persistence of the symptoms, there is search for health services until the CKD diagnosis.

[...] *I was being tested for anemia* [...] *then it turned out that creatinine was very high. The doctor thought it was wrong until...* [...] *he did it again and it was the same thing, I had to go to the hospital* [...] (P2). […] *one week I started vomiting and vomiting, but I wouldn’t go to the doctor, I was putting aside, putting aside, then I couldn’t do it anymore, my father took me to the Emergency Room* [...] *then I went to the UPA, there they did the tests and they found out... from there I went to the university hospital* (P4).

[...] *I went to the Emergency Room, and the doctor said it was nothing, they just gave me some serum, then I went to the health center for a test and the doctor said that I had kidney failure* [...] (P7).

With discovery of the disease, changes in everyday life can begin in childhood, with commitments related to medical examinations, periodic consultations and restrictions and limitations in physical and social life, such as the memories in P6’s testimony:

[…] *since I was little, I used to do follow-up at the University Hospital, with the doctor* [...] *when I was about 5, 7 years old, I already remember doing it* [...]. *my mother always said that it was to take care of myself, not to eat junk food because it could worsen the situation* [...] (P6).

It is noticed that treatment initiation can start with medication use and monitoring of tests:

[…] *before, I only had treatment with corticosteroids and cyclosporine* [...] (P5).

Other times, hemodialysis treatment initiation is immediate, requiring hospitalization and catheter implantation, as shown in the statements below.

[...] *I got there and they put the catheter straight in... then I got better on my first day, you can see how the machine makes a difference...* (P7). […] *the Doctor told me that my kidney was getting worse and worse, and that I had to undergo hemodialysis. That it was a chronic disease, that it comes from the family, that is hereditary... Because my grandfather on my mother’s side, his brother had everything, “so-and-so” is my relative too* [...] (P6).

After the diagnosis, with the need to undergo hemodialysis, there is the news of performing the fistula, and the reality that would change their everyday life, as reported by P7: [...] *they just put me in the room, asked permission, everything. They said: “I don’t think your kidney is going to come back, it must be a chronic disease, because we couldn’t find out what happened, and the machine didn’t help...” and they just said: “you’re going to have the fistula in the arm...”. I was fine in there. The psychologist asked how I was feeling, but I’m not going to cry, it’s a reality... she’d go there all day to talk to me...* (P7).

Some participants reported receiving the news as something normal, others, that they had difficulty understanding what was happening.

[...] *when they told me that I had kidney problems, I just saw my mother crying on the side, but I didn’t understand anything. It’s just that I was really young, so I didn’t understand anything, I was 15...* (P1). […] *I accepted... normally... it was quite normal for me...* (P3).

[…] *it was bad, I didn’t know how it would be.* [...] *my parents were shaken, but it was what I had to do. They supported me* (P8).

The diagnosis news and the need to initiate treatment can be felt and experienced in different ways by adolescents and young people. The presence of a chronic disease in their everyday life has repercussions for their entire lives in an individualized way, exiting the world already made, and they need to assimilate some lessons for this new everyday reality.

Undergoing the hemodialysis treatment: "[...] *You have to be patient..."*

There is adaptation to the treatment time and the search to understand this new routine. Sleeping and using the cell phone are strategies that adolescents and young people use to help pass the time during the period they are undergoing treatment, as reported in the following statements: [...] *it's tiring to spend four hours, it's hard... if you don't sleep a little, you get tired... I play with my cell phone, I watch videos, on Tik-Tok, these things... I sleep a little, I talk... it's distracting and helps pass the time...* (P5).

P5's report was confirmed during the observation, as it was seen that she spent most of her time with her cell phone in several sessions. In addition, on other days during the observations, she slept most of the times, waking up immediately before the machine was turned off. This can be related to the fact that it is the first shift in the morning, as she travels a long distance to undergo the treatment because she lives in another municipality.

P6's and P7's testimonies are in line with what was observed: most of the times, P6 was on the cell phone; and P7 slept part of the time whereas another part was also on the cell phone, but both P6 and P7 slept during almost the entire session some days: [...] *I use my cell phone, I look at jokes to help pass the time, I really like to look at jokes* (speaks with laughter) (P6).

[…] *sometimes I sleep, then it goes faster. I use my cell phone. You have to be patient... before, they* (referring to the Nursing team) *took a while to call me and I got angry... now I don't care much about the time* (P7).

In addition to that, for some participants, they only understood hemodialysis treatment over time, requiring adaptation to this new routine: [...] *after a year* (emphasis) *I started to understand what it was, but at first I didn't understand anything, I thought it was a simple thing* (P1).

[…] *I freaked out! It was the first time, I sat next to the woman, she looked at me; I asked her what the needle pain was like and she said: "It's horrible! It never stops hurting." And I said: Nahh! But how so? Then, after I made the fistula, I saw that it wasn't all that* (emphasis) *which she spoke about.* [...] *I was still angry at the beginning of the treatment.* [...] *it seems that hemodialysis took my patience, but now it gave me patience...* (P7).

Most of the participants reported that their every life was modified with the treatment, with restrictions on going out, traveling and doing the activities they like: […] *I'm always tired, tired because it's far to come here for hemodialysis. I get home at night, eat something, take a shower and then go to bed, I don't do anything* [...] (P8). [...] *it's very complicated to travel and stay more days* [...]. *Sometimes I want to go out and I can't* [...]. *But I have to get used to it, it's no use...* (P1).

The treatment is seen as something that prevents them from going out freely. Due to the disease and the contamination risk, the COVID-19 virus pandemic context was an important factor in changing the everyday life of these adolescents and young people with chronic kidney disease: […] *I was more active before, I went out more... and now I can't even go out either, because of the pandemic* (P8).

[...] *I used to go out a lot, even if I was dating or not, now I just stay at home... it's changed a lot... and now with the pandemic I hardly ever leave the house* (P7). [...] *with the pandemic I really have to stay home, I can't step outside* [...] *now when they vaccinate the chronic ones... it's my turn...* (P5).

In addition to that, the hemodialysis treatment day-to-day requires routine organization, as it is necessary to comply with it to maintain health and for life itself. Many patients are from other municipalities and need to leave their homes very early to undergo the treatment, as reported in the following statement: […] *discouragement of wanting to come, then you wake up, today is the day, you have to go... there, everything is quite heavy.* [...] *you have to go, you have to do it... you have no other option, if not you die...* (P1).

On one of the days, it was observed that P1 was sitting in the armchair, looking forward in the distance, as if pensive, remaining that way for a few minutes; then she went back to lying down in the armchair again. On some days, she slept almost all the time, arrived, was punctured, laid down on the armchair, turned to the side and was already asleep, only waking up when it was time to leave.

With regard to the new everyday experience, certain adaptation on the part of these adolescents and young people is inevitable. The hemodialysis treatment day-to-day requires routine structuring, as they need to comply with the treatment: it is a commitment that cannot be missed.

Care in the hemodialysis treatment day-to-day: Limits and possibilities

In order to maintain health care, adolescents and young people experience several limits to be faced in their hemodialysis treatment day-to-day. In many of these limits, the search and desire for the care they need to preserve their health is noticed, as shown in the following statements: *The diet is very difficult, it's up to you to control it.* [...] *I don't urinate anymore, and the liquids are also difficult to control, I like "chimarrão" a lot, I'm stopping it... I try to control myself* (P1).

The concern with fluid intake and food is something frequently reported in the participants' testimonies regarding daily health care. The restrictions on liquids intensify mainly in the summer, when they need to be drunk very moderately. The following statements bring about these limits faced in everyday life: […] *controlling fluids is bad...it's just breakfast and water for the medications. I can't drink water when it's hot* [...] (P4).

[…] *I take care of the liquids issue, which you can't drink too much, I take the right medications and I take care of the food too* [...]. *Everything that has potassium and phosphorus, I always separate* [...] (P7).

As for self-care, it is extremely important to take care of the laboratory test levels, individually, to carry out and maintain the treatment in the patients' routines, which was observed in the following statements: […] *I like to follow-up my tests. Because I know that every now and then I'm always sick with anemia* (P1).

It was observed that, when passing the tests performed by the nurse in the hemodialysis room, P2 makes a point of writing down all the results on her cell phone and comparing them with those of previous months, checking whether they have changed or remained the same, which reveals care of her own health through the results of her blood tests. [...] *I write everything down so I can see the difference from the other month* (P2).

In addition, P5 reports that the nurses at the Clinic always inform the results, explaining all the tests, which corroborates the importance of this practice: [...] *here at the Clinic they explain it to me, the boss* (referring to the shift nurse), *she tells you all the tests, helps you know what you have* (P5).

In addition to the transformations related to the life phase experienced, the body faces the changes caused by the disease and the hemodialysis treatment. Therefore, there is a mix of feelings caused by the changes in the body.

P5 also reports that use of the catheter requires daily care, as there is risk of infection, especially when bathing, which must be done without wetting the catheter dressing, and because some tasks such as lifting a lot of weight cannot be performed to maintain fistula survival: […] *the catheter couldn't get wet, you had to be careful not to get an infection too. And you can't sleep on top of the fistula, can't carry weight...* (P5).

The hemodialysis treatment day-to-day can cause marks that can significantly affect the physical and emotional aspects of these adolescents and young people. The body issue is very important at this life phase, as shown by P7's testimony: […] *when I came here I was disgusted, because I saw the situation here and I kept looking at people's arms: Nahh; I don't want to be with my arm like that, God forbid! It was the psychological issue, I was disgusted* (P7).

[...] *it's more because of the arm, you know* [...] *because of the fistula* [...] *because of the "real lumps",* (referring to the fistula aneurysm), *and it makes me nervous to see.* [...] *I start to itch, and I get these wounds* (she shows the wounds on the face and arms) *and they ask me: did you hit yourself or did they hit you? But no, it's me, you know, I get nervous and take it all out on myself* [...] (P1).

It was observed that, at times, P1 actually scratched herself, leaving wounds on her face and arms. She recognizes this act as a way she has to relieve anxiety, causing herself pain and injury.

In addition, due to treatment initiation, some adolescents and young people had to leave behind some dreams and projects that they would like to carry out: [...] *before I started again* (he had already been dialyzed before, transplanted and lost the graft) *I was trying to do my clinical analysis technician course. Then I came back and everything went wrong, I didn't want to know about it anymore...* [...] (P1).

On the other hand, P6 had to initiate hemodialysis treatment, preventing projects of taking courses in the military area and remaining in the Army. The desire to pursue a military career is evident in the participant's testimony.

[...] *I was going to stay in the Army, I was already taking a course to become a corporal. In fact, I was already engaging, so I had to stop... but if I could go back I would* [...] (P6).

In addition, P4 mentioned his concern about how long he would still have to stay on hemodialysis before being able to undergo the transplant. There is the expectation of undergoing the transplant and no longer needing to follow the routine they have in their everyday lives.

[…] *what I'm worried about is how long the hemodialysis will last until I have the transplant... I want to have the transplant, get well again so I don't have to do it all my life too* [...] (P4).

Likewise, P7 pointed out his interest in attending college in an area that he enjoys, related to sports, but expressed the expectation of attending college only when he was no longer undergoing treatment: [...] *I like sports, I think that when I finish the treatment, I would try to study sports in college* [...] (P7).

Although the treatment routine is challenging for adolescents and young people, in their testimonies it is possible to identify that they have perspectives for the future. The possibility of having the transplant and no longer needing to undergo the treatment shows their hope to make their dreams come true.

DISCUSSION

From the data analyzed, it is understood that, in the chronic kidney disease experience, the everyday life of adolescents and young people undergoes changes, including several aspects of their lives, associated with the hemodialysis treatment. These modifications start from discovery of the disease and treatment initiation, going through the RRT performance, causing physical and emotional repercussions in their everyday life.

Some participants reported that the disease was not diagnosed in the first search for medical care, due to their symptoms, needing to return to the basic health service other times or be referred to the reference hospital to confirm the CKD diagnosis; others only sought a health service when the symptoms worsened, requiring immediate initiation of the hemodialysis treatment.

In a study carried out with 10 interviewees who had CKD, only three started to investigate the disease in basic health units, and the path taken by these patients was from the basic health unit to a specialist or directly to a hospital due to deterioration of the symptoms to then being diagnosed with CKD[14]. This corroborates with a study which shows that 7 of the 11 interviewees did not receive the CKD diagnosis in the basic health unit and that, due to deterioration of the symptoms, discovery of the disease and treatment initiation happened in urgent situations[15], which was also reported by some participants in this study, who only discovered CKD due to the search for medical care due to deterioration of their symptoms. According to Heller, everyday life is produced and reproduced dialectically, through everything experienced in its social context and through events and social relations, which is evidenced by the participants in discovery of the disease[9].

However, most of them received the news unexpectedly, generating mixed feelings and emotions, both on the part of the adolescents and young people and their families. This is mentioned in other studies, in which the many feelings experienced by these patients when discovering CKD are evident. Sensations such as fear and anxiety are present reactions and, at that first moment, many patients cannot understand severity of the disease or the future repercussions on their life[14–16]. Consequently, there is no way to separate existence from everyday life: human existence is an indispensable result of everyday life[9].

The participants also reported fear of pain and the unknown and lack of motivation to undergo treatment. In another study, it was mentioned that adaptation to and acceptance of the hemodialysis treatment is something progressive and does not have a determined time, being particular to each individual[17]. The everyday life of these adolescents and young people is associated with what is experienced through their senses, feelings, ideas and beliefs, as the heterogeneity of everyday life is attributed to the meaning of their treatment, which is associated with their own survival; which, hierarchically, is the most important aspect of their everyday life[9].

Everyday life is related to actions and choices, which is generally associated with a motivation for decision-making[9]. In general, adolescents chose to use their cell phones and sleep during the treatment. A study carried out in Italy with 212 young individuals aged between 13 and 24 years old with chronic diseases revealed that 94.8% used the Internet to research their disease and prognosis and 94.3% looked for friends with the same disease on Facebook®[18]. A Lebanese study, conducted with 428 young patients with kidney disease, found that 19.2% use social networks and apps to learn diverse information about their disease and treatment[19]. In this context and considering that they remain for extended periods of time in the Clinic space, using cell phones can mean a possibility to resort to them as a health education strategy through the development of smartphone apps of the educational technology type.

Heller's study points out that each individual participates in their everyday life within their individuality and personality, which shows the choice they make, using the cell phone or sleeping during the treatment, as a form of distraction and even to escape from the moment experienced[9].

In addition, the participants reported going out and traveling as something they could no longer do freely due to their commitment to the treatment. A study pointed out that most of the participants mentioned limitations in their everyday life with treatment initiation[20–21], with the difficulty of traveling among them, as it is a commitment that they cannot miss[22]. In addition, the participants reported the repercussions of the COVID-19 pandemic were reported as a barrier to going out of their homes, as they are part of a risk group for complications from the disease[23–24]. This reinforces a Spanish study conducted with 868 patients on RRT and infected with COVID-19, in which it was found that 85% required hospitalization and 8% required an intensive care unit, with a mortality rate of 23%[25], which is also evidenced in the everyday life hierarchy, where their treatment is crucial, although in a unique and individual way[9]. People undergoing treatment point out the limitation to carry out other activities in their everyday life, which were common to them before and gave them pleasure. It is noted that these adolescents and young people had to give up what was most important in their everyday life to undergo RRT.

In addition, most of the adolescents and young people in this study reported an interest in their health, mainly with regard to the blood test results, although they also spoke about difficulties regarding fluid consumption and nutrition. Findings from another study indicate that nutrition is considered a factor that hinders the self-care of patients undergoing hemodialysis treatments due to the need to change habits and, for many people with CKD, it is the most difficult condition to face in their everyday life[26], as well as interdialytic weight gain[27–28]. Everyday life is related to the ability a person has to learn and introduce new habits and start to reproduce them[9], which affects something very common and pleasant in the lives of people belonging to this age group: going out to eat and drink freely with friends.

Many young people undergoing hemodialysis treatment seek to overcome the condition of the disease through desires and future dreams, with expectations of working, studying and getting a kidney transplant, with the wish to resume a normal life free of the disease and their everyday life as it was before the treatment[29]. The participants in this study reiterated their expectations for the future after transplantation, as if only then could they follow their dreams and projects, hoping to lead a life without restrictions. Heller states that, in everyday life, each individual acts on the probability and possibility of achieving satisfactory results or not. From the perspective of the participants included in this study, their aspirations would only be achieved after the transplant[9].

In everyday life, with presence of a chronic disease and a need for constant and imprisoning treatment, these adolescents and young people express their feelings, passions, intellectual knowledge, manual skills, ideas, ideologies, beliefs, tastes and aptitudes. There is no way to separate existence from everyday life: human existence is the indispensable result of everyday life. Studying everyday life makes it possible to analyze the influence of the pressures experienced by people, the impact on them and their relationship with the environment where they live. It is understood that the everyday life of these adolescents and young people is pragmatic, having faith and hope associated with the perspective of better days[9].

The change in people's lives as a result of the disease and hemodialysis treatment is complex, involves significant efforts and an acceptance process that can take years[30]. It is noticed how necessary it is for the Nephrology team, especially nurses, who stay with these adolescents and young people all the time, to be able to talk with them, highlighting important aspects of their everyday life, even when living with CKD and RRT, so that they do not miss essential moments of this phase of their lives, glimpsing at a distant or perhaps unreachable future.

Humanity is externalized in its entirety, in everyday life, through passions, senses, intellectual capacities, manual skills, manipulative skills, feelings, ideas, ideologies, beliefs and tastes[9].

The following is pointed out as a study limitation: the fact that it was carried out with a group of adolescents and young people who experience the hemodialysis treatment day-to-day in a renal clinic. It is suggested to develop studies with this group, seeking to understand their everyday life from other scenarios and in the light of other theoretical frameworks.

CONCLUSION

The everyday life of adolescents and young people undergoing hemodialysis treatment is permeated by confrontations constituted by unique changes in their existence and by the construction of their own identity, plus the impact of the disease and the new condition imposed by the treatment. This affects the everyday life of these adolescents and young people due to the fear of what is to come in their lives after discovering the chronic condition diagnosis, understanding what the pathology is and its implications.

The CKD diagnosis causes changes and requires assimilation of reality to enter the process of a new everyday life. For some people this took place in childhood; others only discovered the kidney disease when they needed to initiate treatment immediately, which reveals the importance of an early diagnosis as a way to prevent and reduce possible future complications.

Adolescents and young people present manifestations such as discouragement, sadness, fear, anxiety, depression, fear of pain and tiredness. From the observations made, it was found that the way they behaved during the treatment corroborated the data found, which was possible by triangulating the data. This triangulation made it possible to understand the Renal Clinic case as a space where adolescents and young people stay for extended periods of time to undergo RRT. It is believed that this time can be used as a strategy for health education through the clinical Nursing practice, to meet the needs for information about their chronic condition and treatment, contributing to externalizing their humanity as a whole in this everyday life.

The interest and the need to receive explanations about the results of their tests are highlighted as a way of appropriating diverse information to perform self-care. The limitations they pointed out were related to daily activities. And the possibilities were related to the desire to attend courses, enter the university and work, plans launched into the future, translating the way in which they wish to participate in everyday life with their individuality, intensity, personality, skills, capacity, feelings, passions and ideologies.

It is suggested to develop other studies with this group, seeking to understand their everyday life and the dynamics of their social network outside the Clinic environment, enabling the elaboration of strategies which minimize the transformations that permeate their everyday life having to undergo this treatment.

It can be concluded that adolescents and young people assisted in hemodialysis treatment have possibilities related to self-care and understanding of the disease and treatment, but also limits related to the deprivations inherent to their condition and that make them postpone plans and aspirations for the future. The Hellerian framework allowed reflecting on the change of attitude that these adolescents and young people need to have in order to achieve a social life, for ethical and political awareness of their social beings and, therefore, for shaping individual and collective revolutionary social subjects.

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NOTES

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Data collection: Siqueira FBS.
Data analysis and interpretation: Siqueira FBS, Neves ET, Ribeiro AC.
Discussion of the results: Siqueira FBS, Neves ET, Ribeiro AC.
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