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# CUIDADO É FUNDAMENTAL

UNIVERSIDADE FEDERAL DO ESTADO DO RIO DE JANEIRO • ESCOLA DE ENFERMAGEM ALFREDO PINTO

RESEARCH

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## Expectativas sociais vivenciadas pelo adulto jovem com a doença renal crônica<sup>1</sup>

Social expectations experienced by young adults with chronic kidney disease

Expectativas sociales vivenciadas por el adulto joven con la enfermedad renal crónica

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## ABSTRACT

**Objective:** to point out the social expectations experienced by teenagers with chronic kidney disease. **Methods:** it is a qualitative, exploratory and descriptive study, which used the theoretical perspective of Geerts and Leininger. It was performed from June to August of 2013, having 8 teenagers as participants, who were under hemodialysis. **Results:** it was noticed that the informants' lives were related to their social expectations relative to this stage, with influences of values, beliefs, rules, and lifestyles. Thus, it was highlighted that the teenager life was constituted by the desire of a family formation, the performance of labor activities, studies, and leisure. **Final Conclusions:** as a lived stage by a teenager consists in a period marked by events and achievements, which have decisions and important choices, it is accentuated the necessity of a human, welcoming, and comprehensive professional attention.

**Descriptors:** chronic disease; renal insufficiency; chronic; young adult; nursing.

<sup>1</sup> Article drawn from the dissertation: The experience of chronic kidney disease for young adults on hemodialysis: a cultural perspective, in 2013, the Graduate Program in Nursing at the Federal University of Pelotas.

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## RESUMO

**Objetivo:** apontar as expectativas sociais vivenciadas pelo adulto jovem com a doença renal crônica. **Métodos:** trata-se de um estudo qualitativo, exploratório e descritivo, utilizando-se da perspectiva teórica de Geertz e Leininger. Foi realizado no período de junho a agosto de 2013, com oito adultos jovens que estavam em tratamento hemodialítico. **Resultados:** percebeu-se que a vida dos informantes estava relacionada com as expectativas sociais referentes a essa etapa, com influência dos valores, crenças, normas e modo de viver. Dessa maneira, evidenciou-se que a vida do adulto jovem foi constituída pelo desejo de formação da família, de realizar atividades laborais, de estudos e de lazer. **Conclusões:** como a etapa vivenciada pelo adulto jovem consiste em um período marcado por acontecimentos e realizações, havendo decisões e escolhas importantes, salienta-se a necessidade de uma atenção profissional humana, acolhedora e compreensiva.

**Descriptores:** doença crônica; insuficiência renal crônica; adulto jovem; enfermagem.

## RESUMEN

**Objetivo:** apuntar las expectativas sociales vivenciadas por el adulto joven con la enfermedad renal crónica. **Métodos:** se trata de un estudio cualitativo, exploratorio, y descriptivo, que utiliza la perspectiva teórica de Geertz y Leininger. Fue realizada de junio a agosto de 2013, con ocho adultos jóvenes que estaban en hemodiálisis. **Resultado:** se percibió que la vida de los informantes estaba relacionada con las expectativas sociales referentes a esa etapa, con influencia de los valores, creencias, normas y estilo de vida. De esta forma, se evidenció que la vida del adulto joven fue constituida por el deseo de formación de la familia, de realizar actividades laborales, de estudios y láser. **Conclusión:** como la etapa vivenciada por el adulto joven consiste en un periodo marcado por acontecimientos y realizaciones, habiendo decisiones y escojas importantes, se despega la necesidad de una atención profesional humana, acogedora, y comprensiva. **Descriptores:** enfermedad crónica; insuficiencia renal crónica; adulto joven; enfermería.

## INTRODUCTION

Chronic diseases were believed to be easily found in wealthy countries with elderly population. However, it is known that countries with high income, as well as poor countries, and young and middle-aged individuals also suffer with chronic health conditions.<sup>1</sup>

The increasing prevalence of chronic diseases concerns companies, organizations and individuals. The main reasons for this concern are the high costs generated for public and private healthcare systems, as well as the impact on life quality of individuals with these conditions.<sup>2</sup>

These chronic conditions cause difficulties in adhering to treatment, lifestyle changes, adaptation in family and social context, in addition to the need for hospital admission.<sup>3</sup> Also, they are related to an ageing society. Since lifestyle choices such as tobacco use, alcohol consumption, sexual behavior, improper diet, physical inactivity and genetic predisposition contribute with the development of diseases,<sup>1</sup> also in younger individuals.

Thus, the young adult can experience this illness process, associated to a stage in which he/she would normally search for personal valorization of their skills and capacities, so that people would positively assess them through the knowledge acquired and built. In this stage, he/she would search for compensations for the skills in the socioeconomic area and feel motivated at work and in constituting family, when recognized in his/her social medium.<sup>4</sup>

Thus, the start of adult life is the period in which the individual naturally has physical strength and vitality, usually associated to a level of education and economic Independence. Contrary to infirmity, incapacity and deformity, characteristics of chronic disease.<sup>5</sup>

However, chronic diseases may arise in this period, among them the Chronic Kidney Disease (CKD), which is a relevant public healthcare issue, marked by unsatisfactory results and high costs in health care. Also, it is a risk multiplier for individuals with diabetes, hypertension, cardiovascular diseases, which are the main causes of mortality and physical incapacity.<sup>6</sup>

CKD demands a treatment that replaces the kidney function. In this scenario, we can observe reports from patients under hemodialysis therapy about the changes that take place in their lives after the start of therapy. Among these, we can emphasize changes in self-image, reduction of activity, unemployment and role change or inversion at home. Thus, these changes imply negative situations in the lives of these individuals, reflecting in all aspects related to human conditions.<sup>7</sup>

In this perspective, time spent on therapy causes the rupture of the daily living of the individual with CKD, because the days are filled with activities related to the disease, which can even cause the social life to be disrupted.<sup>8</sup> Therefore, those who experience the hemodialysis therapy need to organize the time spent with the therapy established and the physical, psychological, social and family changes, which are possibly affected.<sup>9</sup>

These facts show the need to identify the conception of the individuals submitted to this treatment, questioning how their quality of life has been affected by the chronic disease and the therapy proposed.<sup>7</sup> In light of this context, this study has the purpose to identify the social expectations experienced by the young adult with chronic kidney disease.

## MÉTHODS

This is a qualitative, exploratory and descriptive study, theoretically based on concepts related to the Clifford Geertz's and Madelaine Leininger's culture.<sup>10-11</sup> The location in which the informants were contacted was a nephrology center, located in a city in southern Brazil, while the data collection was performed in the nephrology service and the home of two informants, who allowed the researcher to come to their homes. The data were collected between the months of June and August, 2013.

The study inclusion criteria were: age 20-41; under hemodialysis therapy for more than six months; permission to record the interviews; consent with the publishing of the data in scientific media. Thus, eight young adults participated in the study. The data collection instruments were narrative interviews<sup>12</sup> and non-systematic observation,<sup>13</sup> which was recorded in field diary notes.<sup>14</sup>

The interviews were recorded and later fully transcribed, with the purpose to maintain the data reliability. Data were assessed based on the practical proposal, according to the following stages: ordering, data classification and final assessment.<sup>14</sup>

To ensure anonymity, they were identified by the term informant, followed by the order of the interviews, age and hemodialysis time. The study was approved by an Ethics Committee, under the protocol number 195/2013.

The informants were informed on the research objectives and then requested to sign the Informed Consent Form in two copies, one for the informant and another filed by the researcher. The directives on researchers with humans, guided by Resolution 196/96 of the National Health Council, were respected.<sup>15</sup>

## RESULTS

### The young adult's life before CKD and the social expectations

In order to understand what were the changes imposed by CKD, it was necessary to know what the informant's lives were like before the disease. It should be noted that their lives were full of the social expectations related to this stage, influenced by values, beliefs, standards and ways of life, aspects oriented in the definition of culture.<sup>11</sup>

The contemporary experience culminates in the review of the development psychology conception, in which the life course is timed by a unilinear evolution, in which each stage has its own universal character, although there are particular social and cultural aspects.<sup>16</sup> Thus, it can be said that, as the years go by, expectations are attributed to the formation of individuals as able to live together. Depending on the age group, it is necessary to follow "rules".

Thus, it was established that the young adult's life should be comprised of constituting a family, work activities, studies and leisure, which can be evidenced in the narrative of the informants who told us about their lives before CKD. Some mentioned an idea of "normal life".

*I used to go downtown, pay the bills, do everything. It was really different, I went to school at night, went out during the day, I was always doing something [...]. (Informant 2, 25 years old, seven years in HT)*

*I played soccer, did sports, worked, went to balls, went to parties, everywhere. (Informant 1, 37 years old, 18 years in HT)*

*Before dialysis, I used to care for beauty contest horses [...]. I had nothing, worked regularly, played ball [...], I was almost called by Grêmio (professional Brazilian soccer team) [...], then, just when he wanted to take me there, I got sick [...]. (Informant 3, 35 years old, eight years in HT)*

*I always worked at a company and was really a partying guy. Parties, work and parties. [...] I left work early, arrived in the end of the afternoon, showered [...], played soccer on weekends, that's how I wanted to be, not here [silence]. I enjoyed hunting very much. I used to hunt a lot [...]. (Informant 7, 35 years old, five years of HT)*

We notice that the informants' lives were based on work, study, daily and leisure activities mentioned as part of their past, and the most frequently reported were parties and soccer. By their speeches, we believe that they were following a "standard" that is accepted and desired by the society of which they are part, which was possibly interrupted by the CKD, once none of them kept an employment bond, continued their studies or constituted a family.

In this sense, a study appointed the perceptions of 20 patients on CKD, and many provided negative expressions, such as: it causes limitations and difficulties; it causes bad consequences; it causes changes in life; it contributes to worsening their health.<sup>17</sup>

Hence, we emphasize that the experience of a young adult with a chronic condition is different than that of a healthy young adult. This fact marks the development of his/her identity, the way he/she related with the peers and his/her capacity to adapt in different environments.<sup>18</sup>

If we consider the stage in life in which the diagnosis is made, the suffering for the future expectations is even greater. As shown in a study, for some older individuals, we can see an emotional control that helps to adapt to the treatment, while for other individuals, it means an obstacle in their lives in a moment when they were ready to live.<sup>7</sup>

Thus, being adult comprises the achievement of a social position in consequence of the professional and family performance, in spite of modifications, such as the prolonging of studies, professional instability that makes it difficult to enter the work market and the later residential independence from the family of origin, influencing the age to form their own family.<sup>19</sup> However, the informants did not fulfill these social expectations, not because of these aspects, but because of the illness in their lives.

For such, finding out about this condition, in this stage of life, is a decisive and phenomenal event that impacts the ways of coping and fighting the chronic condition. In

this perspective, there are significant changes as concerns priorities, activities and perspectives.<sup>5</sup>

Also, the constitution of a family or even the presence of a partner has been attributed different meanings. Relationships were ended as consequence of the CKD.

*[...] It didn't last long [the relationship], after I was started on hemodialysis, it didn't last long. We broke up, she never really got used to it [...]. I think she didn't accept the type of disease, in this case. (Informant 1, 37 years old, 18 years on HT)*

*I divorced mostly because of the disease, that she (ex-wife) didn't accept. At the beginning, it was wonderful for us, she didn't accept the disease, then we started fighting and we divorced [...]. (Informant 3, 35 years old, eight years on HT)*

The hemodialysis therapy imposes significant life changes, not restricted to the moment of therapy, but that surpass their daily routine, with diet restrictions, continuous medications, caution with the vascular access and daily dislodgements.<sup>20</sup>

This routine, that follows their lives, causes difficulties, among them those concerning relationships. One of the informants reported the difficulty in finding a person that makes a serious commitment and also mentioned abandonment as consequence of the disease.

*And finding a person too, because most people here (on hemodialysis therapy) are left [...]. I've had [a partner], I do sometimes, but it's not what you imagine. Getting married, living together, there's not all that expectation, [...] it still hasn't happened to me [silence]. This is because of our routine, those who had a relationship, some remain, but others don't. This is also a commitment, because relating with a person, this person will have to live with your disease too, and it's complicated. (Informant 5, 41 years old, 10 years on HT)*

It is known that having children can be a perspective for many people in fertile age. However, for some of the informants in this study, this can mean a risk to die, to have to go to therapy every day, in addition to the fear of passing on the disease to their child.

*If I have a child now, I'll die. But they told me that I can, but I'll have to go to hemodialysis every day. Three times a week is sad, imagine every day [laughter]. (Informant 2, 25 years old, seven years on HT)*

*The child could inherit my condition, you never know! A child is a child, if you can avoid it, it's better this way. (Informant 7, 35 years old, five years on HT)*

Having children, or not having children, influences people's lives, since here is a cultural belief that they gather and procreate everywhere.<sup>10</sup> In this context experienced by the young adult, nursing needs to try to get to know the individual in his/her culture, so that there is always dialogue between them, because communication allows greater knowledge as regards the respect for feelings, emotions and opinions, permitting a relationship that favors the reduction of anxiety, because having a chronic condition, such as kidney disease, causes the individual to feel fragile and lonely.<sup>3</sup>

Also in the literature studied, and according to the report by Informant 2, there is a description of the pregnancy risks during hemodialysis therapy due to various factors, including those associated to amenorrhea and sterility, restricting this possibility. That is why some women understand the situation and accept the conditions imposed by the condition, such as the impossibility of carrying a child as a consequence of the risks associated to the mother and the infant.<sup>21</sup> Informant 7 was concerned about the possibility of the condition's heredity, choosing to abdicate procreating because of this risk.

Although there has been a change in current women's profile, like labor activities, in addition to home and assurance of rights, there is a responsibility culturally attributed to them, which is caring for the home, the children, the sick, the family, among others, which was evidenced in the speech of the study informants.

*Yes, I used to go out, worked mornings and afternoons [...]. I took care of my mother, and also my brother, I raised him, because my mother worked [...]. (Informant 5, 41 years old, 10 years on HT)*

*[...] I used to take care of the kids, tidy the house, did everything. I used to do everything before, I picked up the kids from school, took them [...], went with my mother to her job, I did everything that was normal. (Informant 2, 25 years old, 7 years on HT)*

It is understood that learning to care is passed on by generations, from mother to daughter, who teaches her daughters with the support of the grandmother. All female individuals are included in the family care process, which has a strong cultural influence, characterizing century-long practices and their own layman care. Thus, women have conquered an essential space to their social affirmation and their valorization before society through the roles they have been skillfully developing in the community, among

them the caretaker, which is culturally the most evidenced and learned.<sup>22</sup>

On this aspect, a study that reviewed the quality of life of patients with CKD showed that women reported more incapacity to perform daily activities, such as sweeping the floor, raising or carrying shopping bags, climbing steps, when compared to men. They also reported more depression, anxiety and less well-being.<sup>7</sup> Considering that these activities were usually performed and are characteristic to the gender, these limitations oppose the expectations on them.

The habits of consuming alcohol and smoking tobacco are also regulated by standards, with different social values along the years. In the recent past, the tobacco use was encouraged, with advertisements that linked it to positive things in people's lives, making it "fashionable". Currently, we notice the opposite, people are encouraged to have healthier habits, avoiding the abuse of alcohol and the use of tobacco.

*At first, I drank when I went to a party, had a beer, two, not too much, to get down, with my friends [...].*  
(Informant 8, 41 years old, two years on HT)

*Sometimes, I smoked a cigarette, not crack [...].*  
(Informant 7, 35 years old, five years on HD)

It is understood that several factors participate in the alcohol explanation chain in the context school environment, family, among others, such as relationship with friends.<sup>23</sup> These aspects may have influenced the participants to use the substances, once it is possible to notice, in their reports, which were the scenarios that stimulated the use socially.

Another issue, observed in this study, is the non-existence of symptoms like pain and presence of a "healthy" look, which leads to the concept of absence of disease, often delaying the diagnosis, because individuals, especially men, usually seek advice in the healthcare services only when not feeling well. The informants showed these concepts, which influence their lifestyle.

*[...] I wasn't "tiny", like skinny, a little more, a lot fatter [...].*  
(Informant 3, 35 years old, eight years on HT)

*It was normal [life before CKD]. I never felt any pain, or anything [silence].*  
(Informant 6, 40 years old, one year on HT)

*I used to play soccer, to go to gym, to go to parties and never felt anything. I could do everything normally [...].*  
(Informant 1, 37 years old, 18 years on HT)

We noticed that the male informants describe the absence of symptoms as "normality". This fact can be associated to their life frame, since for some individuals, being sick is synonym to feeling a change in the body, especially for men.

It is understood that CKD is a common, serious, treatable and preventable disease. In the earlier stages, it can be detected by simple laboratory exams, of low cost and the treatment of basic diseases can prevent or delay the evolution to later CKD stages, cardiovascular diseases and even death.<sup>24</sup>

Before this perspective, the relationships between masculinity and healthcare have been assessed based on gender, focusing on the men's difficulty to search for healthcare assistance. The way the services deal with their specific demands, orders social practices, like healthcare practices, conditioning the perception of the world and of thought.<sup>25</sup>

It is emphasized that humans are able to participate in any culture, learn any language and perform any task. However, it is the characteristic culture of where we are born and/or raised that determines what we must do, in addition to influencing the social mobility and hierarchic position in the social structure, decisions rules according to age, sex and other variables.<sup>26</sup>

Considering the information presented, CKD and hemodialysis cause physical and emotional transformations, in addition to social changes that bring limitations to the individual's life, so it is important that the nurse provides orientation in order to help adequate to the therapy adopted. Thus, one of the jobs of this professional is the adoption of educational activities that help the dialysis therapy adhesion and maintenance, contributing to maintain the individual's quality of life.<sup>27</sup>

## CONCLUSION

The onset of a chronic disease like CKD in a stage full of projects for the future, in which occurs the affirmation of personal identity, through changes associated with professional and marital stability, such as experienced by the young adult, destabilizes life.

Hence, this study showed that being dependent on a renal replacement therapy such as a hemodialysis can make the person emotionally vulnerable, because, in addition to living with the uncertainties of the period, he/she faces an incurable disease, with a treatment that causes changes in their lives, thus interrupting plans and daily activities.

In this context, promoting support is critical for the young adults to be able to face the demands provoked by CKD. However, we observed, in this study, that the influence of their culture can imply in the development of mechanisms to help coping with the disease. Thus, knowing what life was like before the disease can help develop strategies to cope with it.

On the other hand, it is perceived that the society's culture is still not ready to include individuals with chronic diseases, who depend on a continuous treatment in the social environment, once it is clear that the informants were not able to maintain job bonds and to have a partner. In this sense, the culture of exclusion of individuals considered

"non-productive" for a world that increasingly demands production and were perfection is cultivated.

Thus, we notice that the young adult's life before CKD was closely associated with the social expectations, noticing that work represented an essential aspect, although studies and the constitution of a family have also been mentioned. Also, they possibly did not achieve some goals in this stage experienced, because of the disease process, and may not have their plans fully carried out in the future.

Because the life stage experienced by the young adult is a period marked by events and accomplishments, with important choices and decisions, we emphasize the need of a humanized professional, friendly and understanding care.

Considering these aspects, we emphasize the importance of a cross-sectional healthcare team, with the purpose to contribute with coping with the CKD and the hemodialysis therapy, aiming at engaging the care to be adopted by the young adult and the benefits to his/her health.

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