

# The leadership of youth with chronic kidney disease and the gift in the construction of health service

O protagonismo de jovens com doença renal crônica e a dádiva na construção da atenção à saúde

## **Daniele Borges de Mello**

Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, Criança e Adolescente Fernandes Figueira. Rio de Janeiro, RJ, Brazil.  
E-mail: daniele.mello2012@gmail.com

## **Martha Cristina Nunes Moreira**

Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, Criança e Adolescente Fernandes Figueira. Rio de Janeiro, RJ, Brazil.  
E-mail: marthacnmoreira@gmail.com

## **Abstract**

This research discusses the chronic illness process in young people in the context of social exchanges based on the gift theory. The objective is to analyze the meanings of being a young person with chronic kidney disease in the universe of social exchanges of care goods. The research, which is of a qualitative nature, was carried out in one health care unit specialized in dealing with young people with chronic kidney disease in the city of Rio de Janeiro. Eleven young people - aged between 12 and 20 years - and 4 health care professionals, involved in the care of this group, participated in this study. The referential methodological and theoretic system was guided by Schütz's Comprehensive Sociology that allows the exploration of the social relationship based on the experience of the subject. The results reveal the importance of the symbolic exchange between the young person and the health care service in the constitution and full experience of being young, as well as the relevance of the young person's perspective in the construction of the care system and the health care providers' practice. With this study, the importance of enlarging young persons' role was obvious and, stimulated by the health care, we tried to recognize this group as a potential agent of its own health, as well as of other subjects that are also included in the context of a chronic disease. **Keywords:** Juvenile Protagonism; Kidney Chronic Disease; Gift Theory.

## **Correspondence**

Avenida Rui Barbosa, 716. Rio de Janeiro, RJ, Brasil. CEP 22250-020.

## Resumo

Esta pesquisa discute o adoecimento crônico na juventude no contexto das trocas sociais baseadas na teoria da dádiva. Esta pesquisa discute o adoecimento crônico na juventude no contexto das trocas sociais baseadas na teoria da dádiva. De natureza qualitativa, a pesquisa foi realizada em um serviço de saúde especializado no atendimento aos jovens com doença renal crônica na cidade do Rio de Janeiro. Participaram do estudo 11 usuários com idades entre 12 e 20 anos e quatro profissionais de saúde envolvidos no cuidado a esse grupo. Como referencial teórico-metodológico nos guiamos pela Sociologia Compreensiva de Schütz, que permite explorar as relações sociais a partir da experiência do sujeito. Os resultados apontam para a importância da troca simbólica entre o jovem e o serviço na constituição e vivência plena da juventude, e a relevância da perspectiva do jovem na construção do cuidado e da prática profissional dos cuidadores. A partir desse estudo, ficou evidente a importância de refletirmos sobre a ampliação do protagonismo juvenil desses jovens e, estimulados pelo serviço de saúde, tentarmos reconhecer esse grupo como potencial agente de sua própria saúde, bem como de outros sujeitos que compartilham o universo da doença crônica.

**Palavras-chave:** Protagonismo Juvenil; Doença Renal Crônica; Teoria da Dádiva.

## Introduction

Chronic Kidney Disease (CKD) is regarded as a global public health problem that is significantly growing. Diabetes mellitus and arterial hypertension are the most common risk factors associated with the disease, which are two conditions that stand out in the sphere of chronic global diseases. It is estimated that, in the United States, the number of individuals undergoing renal replacement therapy (RRT) – also known as dialysis – will exceed two million by 2030 (Araújo et al., 2014). In Brazil, to have an idea, in 2013, the percentage of individuals affected by hypertension was 21.4%, which represents 31.3 million people in the country that have one of the risk factors associated with developing CKD (IBGE, 2013). With specific regards to chronic kidney disease, data from the latest census of the Brazilian Society of Nephrology (SBN - *Sociedade Brasileira de Nefrologia*), performed in 2013, showed that there were 50,961 patients on dialysis in Brazil at that time. The age range for 5.6% of the patients is 13 to 18 years. Despite this number not initially seeming to be a significant number, it is necessary to emphasize that this percentage is increasing gradually. For example, in 2011 the SBN recorded figures showing 1.2% of young people on dialysis, which revealed two important aspects: improved data collection regarding the young population and the fact that the CKD is affecting more people in this age group<sup>1</sup>.

The definition of CKD, advocated by the Kidney Disease Outcome Quality Initiative (KDOQI), is based on three components: (1) an anatomical or structural component (evidence of renal damage); (2) a functional component (based on the glomerular filtration rate - GFR) and (3) a temporal component. According to this conception, an individual is defined as a CKD sufferer, regardless of the cause, when they have a GFR of < 60 mL/min/1.73 m<sup>2</sup> or GFR of > 60 mL/min/1.73 m<sup>2</sup> associated with at least one marker of renal damage (for example, protein-

<sup>1</sup> SBN - SOCIEDADE BRASILEIRA DE NEFROLOGIA. *Censo 2013*. Available at: <<http://www.sbn.org.br/>>. Accessed: May 17, 2015.

uria) for a period of three months or more (Bastos; Kirsztajn, 2011). It is worth mentioning that CKD is a silent disease and most of the time asymptomatic, which makes its early diagnosis difficult. When symptoms of this condition appear, renal function is usually already compromised. Thus, CKD affects different dimensions of human beings - physical, psychological, social and economic -, which are worsened when referring to the young population, who depend on specific care and require effective family support in the choosing and adherence to treatment (Ramos; Queiroz; Jorge, 2008).

CKD also affects the routine of the sufferer's life and requires that strategies are developed to deal with the chronic dimension of the disease. Therefore, there have been several studies that focused on the experience of this chronic illness from the perspective of children and adolescents (Moreira; Macedo, 2003; Ramos; Queiroz; Jorge, 2008; William et al., 2009; Moreira; Macedo, 2009; Protudjer et al., 2009; Vieira; Dupas; Ferreira, 2009; Mello; Moreira, 2010; Carvalho, 2012; Moreira; Souza; Corsaro, 2015). To enrich and broaden discussions in this field of knowledge, this article focuses on the participation of young people in the process of living with and managing CKD, investigating how relationships are established between the disease and health professionals, who are identified in this study as key actors in both the treatment of CKD and in the recognition of young people as protagonists of their conditions. The term "juvenile protagonism" has been discussed within the framework of public policies geared towards the young population (Boghossian; Minayo, 2009). The Brazilian Comprehensive Health Care Policy for Adolescents and Young People (PNAISAJ - *Política Nacional de Atenção à Saúde de Adolescentes e Jovens*) (BRAZIL, 2008) defines juvenile protagonism as the active participation of young individuals in social processes that govern their lives. Costa (2000) sees juvenile protagonism as an educational process that encourages the establishment of a democratic relationship between young people and adults based on solidarity. Protagonism can also be understood as a way to guide young people towards exercising their citizenship (Meirelles; Ruzany, 2008).

Based on the perspective of social exchanges illustrated by a gift (Mauss, 2003), this research is interested in analyzing the relationship among young people, assuming the position of protagonist of their life and experience with chronic kidney disease and the health service that cares for them, which is represented by professionals who establish links of care with these patients.

## Theoretical framework

The foundation of this study is the gift theory (Mauss, 2003) and the concept of healing goods (Martins, 2003). Marcel Mauss (1872-1950), a French sociologist and anthropologist, studied traditional societies, which were referred to as primitive, to identify and understand how social relationships worked, in particular exchange rituals. In his findings, Mauss notes that exchanges and contracts were sealed with gifts in many of the civilizations he studied. The links established through these transactions were permeated by the obligation of giving, receiving and retributing, which were theoretically voluntary.

Martins (2003) brings the gift concept to the field of health by proposing the circulation of a system of symbolic exchanges among healers and patients. The paradigm of gift associated with the medical field would be expressed by the exchange of goods (gifts provided by the caregiver) offered during caregivers' interaction with their patients. Healing goods consist of elements of a material and symbolic nature that engender the system of constituent interactions of the relationships between health professionals and sick individuals. In the material dimension of healing goods are, for example, drugs, examinations, professional technique and medical consultations. Whereas the symbolic field includes the affective dimension, such as attention, trust and security, which is transmitted to the patient during the circulation of the medical gift.

Upon translating the gift of healing goods into a state of care given to young people suffering from chronic illness, we took the liberty of considering healing goods as care goods (Moreira, 2005), since any chronic condition resulting from illness

demands continuous care. We are not more interested in the elements made available by the health service directed towards the patient being healed; conversely, our interest mainly lies in the gifts that represent the social interaction established by the network of care offered to these young people. Our main focus is essentially on the nature of the gifts circulating within the care environment and how the bonds between caregivers and young people are established.

## Methodology

This article is part of a master's thesis focused on analyzing what it means to be a young individual with chronic kidney disease, based on a context of exchanging care goods (Mello, 2011). The article was approved by the Ethics Committee under registration No. 2629/2010 in 6/7/2010.

This study takes a qualitative approach and is based on the Comprehensive Sociology by Schütz (1979). According to this perspective, the understanding is that reality is not something objective or outside the human subject, but rather it is built in and through relationships, with emphasis on experience and on socially constructed meaning. This assumption guided the theoretical analysis of the data in the interface with the Maussian perspective regarding the construction of the social link, in which the exchanges and the experience of the triple meanings of giving/receiving/retributing place the subject before the challenge, in the case of health care related to long-term diseases, of recognizing differences in the exchanges and unveiling them, in addition to a cost/benefit relationship that is essentially symbolic.

In our opinion, it is essential to clarify that the gift theory provided us with an interpretative model to understand and define what a social link is and its establishment as a symbolic exchange, as care goods and the links it creates in this health care environment. In other words, as Martins (2005) reminds us, gift theory has been “rescued as an contemporary relevant interpretative model to think about the foundations of solidarity and alliance in the contemporary society” (p. 45). The fact that

we associate this interpretative model, a definer of categories and concepts - social link, exchange of care goods - means that it is not in conflict with the need to complement its dialogue with Schütz's approach. In this case, we resorted to this author, regarding the qualitative design of the research, as it is a perspective that allows us to assume and qualify the dimension of intersubjectivity as being positive, in the context of the interaction built depending on something whose value is incalculable: health care. It is essential to consider the intent of the actors involved in this context. Schütz helps us further performing a dialogue with the field of chronic illness regarding the area of renal disease in young people. In this sense, we subscribe to the symbolic exchanges, the established links, the solidarity in action, and also the understanding of the intersubjective dimension of health professionals and young people meeting one another, which is mediated by the sharing of insights, experiences and knowledge. From a long-term illness perspective, relationships end up being established over time, in which the dimension of the “we” might be relevant. The possibility of intentionality is therefore apparent, in which the meeting is constructed, contributing to qualify, in the field of knowledge production, the intersubjectivity in a positive way, not rectified in the individual, reaching the collective and enabling the qualification of the singular in universal terms of experience and meanings. Thus, our objective is to contextualize the exchanging of care goods and other material goods in the environment of the health unit, which starts from the interaction between the various subjects who establish relationships with the goal of creating health care for young people.

The field chosen for performing this research was a public clinic with adolescents as its focus, which is a place where young people undergoing CKD treatment can be found. The subjects involved in the study made up two specific groups. The first group was composed of young people with chronic kidney disease, aged between 12 and 20 years, who at the time were users of an outpatient nephrology service at a public hospital. The criteria used for choosing this particular age group was based on

the profile of the care service. We highlight that throughout the subject selection period we were not concerned with the length of time these subjects had spent at the service, which was because our interest was focused on the situational experience of the group. The young participants were randomly chosen in the outpatient clinic during the 4-month observation period in the field. The second core of people is integrated with employees from the aforementioned clinic who directly work to care for these patients. The chosen field was an university hospital that includes several researchers and that therefore has great turnover of professionals. Thus, to ensure the effective participation of the actors involved in the general and lasting care provided to these patients, we requested that participants in the first group indicate professionals whose care giving roles were considered permanent. Eleven young people and four health professionals participated in the study, which totaled 15 subjects. The identity of the institution and the subjects were kept confidential by using fictitious names.

## Results and discussion

The results of this study are based on research performed regarding young people's relationship with the health service designed for them. The study demonstrates how the service establishes these relationships with its public, as well as how the symbolic exchange among them occurs based on the gift concept (Mauss, 2003). We highlighted the three aspects of giving/receiving/retributing in addition to healing goods (Martins, 2003), which enhance care goods, starting from the assumption that our patients require prolonged, total and permanent care. To conduct an in-depth analysis of the interactions that exist between young people and the service, we organized this category in two blocks. The first block refers to the youth perspective regarding the content received through the service, and how they can retribute them. The second block opens the dimension of the service that is represented by various health

professionals who maintain direct contact with this particular group.

### Perspective of the young people regarding the exchanging of care goods with the service

Regarding the young people's perspective, they receive treatment that meets their needs, which is highlighted by Michele, 14 years old, when referring to the content provided by the service:

*Normally, it is good here. I think the **treatment is the best thing** (Michele, 14 years old).*

According to the statement of this young girl, treatment is considered one of the most important aspects in the symbolic exchange with the health service. It is also important to highlight the emphasis given to the "treatment" as an empirical category that carries valuable aspects in connection to a long-term illness (Canesqui, 2013), such as chronic kidney disease. The exchange in this environment is mediated by time, extended care, recurring visits to the service and the construction of personal references, which may contribute to these adolescents assuming a vocabulary, and dominating their environment and relationships.

Other young people highlight the quality of the relationship that they established with the service, highlighting content such as freedom, security and health:

*I think it is good. I think it is a **cool relationship**. It gives me a lot of **freedom** (Roberta, 15 years old).*

*Well, I think they offer me **security** (Cláudio, 18 years old).*

In line with Maussian reading, it is worth highlighting the appropriation and updating of the idea of exchanging care goods in the context of health care, which, from this discussion, we can refer to as symbolic goods valued in the context of chronic juvenile illness: freedom, the "cool" relationship and security. In other words, the paradox between what is valued by young people and something that

insinuates itself as effort in treating a long-term illness: a no-choice commitment due to a disease that requires constant attention.

The notion of reference constructed concerning the service is present in the discourse of the young people, which mainly denotes the confidence that the service inspires in them. The young people do not only receive treatment and hospitality; the service, which is represented by the link established with the medical professionals, is considered by them as a safe haven which contains resources prepared to meet their needs whenever required. Therefore, in their eyes, the medical professionals seem to play the role of counselors and health advisors, influencing how the disease is managed and covering other significant aspects of life, such as developing self-confidence and self-care. One example of this is the case of Marcos, who used diapers up to the age of 12 years due to the urinary incontinence resulting from kidney failure. Upon arriving in the health service, he was immediately instructed to perform a catheterization, which changed his relationship with the disease and with himself. Today, Marcos performs this procedure about twice a day by himself. Not having to use diapers makes Marcos a genuine teenager who is, albeit gradually, gaining his independence and autonomy. Based on this experience, the contribution of the service in the process of gaining and exercising juvenile protagonism is highlighted.

One point that deserves attention is the quality of this differentiated care that is offered. The young people highlighted the effort made by the professionals in the interests of improving their clinical condition and helping them on their path to well-being, as pointed out in the following examples:

*I would say that they try to **offer as much as possible**. So, I can say that it is really possible for you to feel good, right?* (Jussara, 18 years old).

*I think they want a better life for me. Because they are always **giving me the best treatment possible*** (João, 19 years old).

Some young people stressed the change in their condition and attributed this transformation to the service. In subsequent statements they talk about the results of their treatment, which, due to its success, has a high rate of adherence by the young people:

*Oh, **I get a lot**. Because if not for them, I would not be better. At least now I feel much better. This is what I get from them* (Lúcia, 13 years old).

*I am just getting **better and better**. One step at a time. And that is it. The service is very good. They have **helped me a great deal*** (Marcos, 17 years old).

Here the importance that young people attach to the treatment is highlighted. In a broader view, it is clear that, for them to adhere to a treatment that they consider to be of quality, communication between the health team and the young people is important and assumes a key role in this process, as is pointed out by Oliveira and Gomes (2004).

An interesting factor that is worth mentioning is regarding the symbolic elements that are also offered by the service. Ana, 16 years old, highlights the friendships that she established with the professionals over the course of her treatment, and Pedro, 13 years old, stresses the reason why he appreciates the care so much:

*Many **good things**. Oh, because we... in this place also receive **friendship** from the doctors* (Ana, 16 years old).

*The **doctors** are also kind of **relaxed**. So, that kind of boring atmosphere does not exist* (Pedro, 13 years old).

The professionals try and speak in the same way as the young people so that they can identify themselves with the young people and make sure that they understand the guidelines regarding care along with disease management. The young people also mentioned another as-

pect regarding the affection they receive, as shown by Jussara:

*That's because... it's like this. They are affectionate. They treat me well* (Jussara, 18 years old).

The reports above show that the professional practices that encompass the affective and technical skills are crucial in the physical, emotional and social development of these young people. These findings are in line with other studies, such as the research performed by Ramos, Queiroz and Jorge (2008) regarding the adolescent perspective on their health care, in which they identified the presence of affective elements, especially the confidence built by establishing a link between the young sick people and their caregivers. According to these authors, young people value the technical care offered, but also stress the importance of their communication with the professionals at the service, which results in strengthening bonds of friendship.

When asked about what they offer in exchange for the service, the young people showed that they understood their illness to be an opportunity for doctors and other health professionals to deepen their knowledge. They consider themselves an instrument that enables the professionals to improve their knowledge, as they illustrate in some of the statements:

*For the service, I think I give... I give them more experience. I am here. So, this and that happens. The **experience** they gained from working with me. Since I was a child, they would know step by step everything about me and such* (Marcos, 17 years old).

*This is an **opportunity** for doctors so they can learn, right? The more **diseases**, the more **life*** (Michele, 14 years old).

Based on these young people's points of view, the medical professionals acquire more experience from their experience; they consider their trajectories in the service relevant, as the professional improvement of their caregivers is also involved. Thus, it is clear that the patients offer more than

only practical experience, as people with chronic kidney disease represent opportunities for study and knowledge acquisition. It should be mentioned that this knowledge is not only limited to specific aspects linked to the disease. Michele's statement shows that young people provide knowledge of life, i.e., they give advanced knowledge that can encompass both the development of clinical as well as emotional skills. Highlighted here is the role that young people play in the construction of this differentiated care. In the young people's view, their state of illness provide improvement regarding knowledge of chronic kidney disease - they consider themselves to be agents of information. It is not the disease itself that is the catalyst for relationships between these social actors, but the experience within it. It is the behavior of the young people and the way in which they manage the illness that they are faced with that guides the clinical practice, as well as directs the health service to contemplate the demands of this specific follow-up.

Some young people highlight their adherence to treatment, self-care and acknowledgement of routine consultations as resources that can retribute the content provided by the service. Lúcia, 13 years old, believes that complying with medical recommendations, such as taking the correct medicines, for example, is a way of retributing:

*I retribute in this way, by helping myself. Helping myself, right? I take my meds at home, don't I? I think this is what I can do to repay them* (Lúcia, 13 years old).

Her statement shows that following medical guidelines contributes to comprehensive and quality care being achieved. When the discussion on the elements which circulate in the exchange between young people and the service, the highlight is the importance of self-care in the relationship with health professionals, since this does not only contribute to the advancement of the treatment but it also means that the young people develop in a role as a promoter of independence and freedom in the face of his illness. According to the gift perspective (Mauss, 2003), a subject who receives gifts has an

obligation to accept them and retribute. Analogously, the young people primarily accept their illness and extended dimension in which it presents itself, and subsequently the care provided from this experience of illness are guided and made possible by health professionals. It is important to highlight the relevance of experience and the acceptance of the young people in relation to their disease, which refers to the phenomenological perspective of Schütz (1979), which values the collective dimension of individual experiences. Regarding the symbolic exchange of young sick people with the health service, the subject offers his/her experience with the disease as a form of compulsory retribution, thereby providing the possibility for caregivers to deepen their studies. In this sense, self-care also seems to be a retributing element, since it facilitates adherence to treatment and improves the clinical outlook of the patient, which is devised in a positive way by the healthcare professional. Continuing in this sense, William et al. (2009), in a study that addressed the concept of normalization among young people with chronic illness, showed that when the adolescent can handle their own health care, they acquire greater autonomy and, consequently, their quality of life is promoted, allowing them to coexist with their illness in a more peaceful way.

### **The professionals' perspective regarding the exchange of care goods with the young people**

From the perspective of the medical professionals, the young people's retribution is based on a return of the treatment offered. They assume an echoing position of the proposed therapy administered by the responsible caregivers. Dr. Guilherme, a nephrologist who works directly with young people, says:

*I think they offer things. Because of what they bring. They **enrich us**. And in some ways this is **feedback**, right? It is **constant** (Guilherme, nephrologist).*

The statement given by this professional stresses the importance of the young people's role

in the care process. The issue of feedback seems to be an important element that is retributed by the young people, since it contributes to the professional improvement of caregivers. According to the statements given by the professionals who were interviewed, young people offer many opportunities to acquire knowledge, especially concerning the learning that is related to diseases:

*I think that **young people always offer a lot to the service**. In regards to that state when you are always **refreshing and learning new things**. It is important to know about the diseases. Because the diseases change over time. As does their behavior (Júlia, nurse technician and social worker).*

From a Maussian perspective, feedback can be understood as a gift that takes on a dual role, which involves both the element being retributed by the young people, when receiving their compulsory treatment, as well as in the element offered by doctors in the form of care.

Regarding the dimension of the professionals, the quality of the learning experience offered by the young people is not only restricted to aspects related to the illness itself. According to professionals, young people represent examples of overcoming the limits imposed by the disease. That is, the retribution of the adolescents sits mainly in the return of the care offered. Young people take on a role of knowledge promoters as they offer constant and valuable feedback to the clinical practice of their caregivers. Based on the research results of our study, we can affirm that the practice of these professionals is perfectly in line with the precepts advocated by the Brazilian National Policy for Comprehensive Health Care for Adolescent and Young People (PNAISAJ) (BRAZIL, 2007), which defends the comprehensive care for young people's health and respects all the dimensions of illness, be they physical, emotional, social or cultural, with it being a primordial condition for the promotion of a quality care for this population group.

These teachings also influence the very daily practice of these caregivers, as is pointed out in following statement:



This excerpt points to a possible equivalence of relationships between caregivers and patients, to the extent that the statement of this professional leverages an active young position, which is represented by the possibility to teach caregivers. Regarding the empowerment of young people as central actors in the management of their disease, Ruzany (2008) points out the main aspects for constructing comprehensive care for adolescents, which highlights the importance of establishing a horizontal relationship between health professionals and adolescent health care users. Thus, the service seems to fulfill the role of a health promoter geared towards enhancing the active participation of young people. We also emphasize the reciprocity of the perspectives concerning the Maussian dimension - reciprocity recognized as the basis of the gift concept -, through which the gift is manifested and governs social relationships.

In relation to the elements offered by the service, the responses given by the health professionals who work at the clinic are in line with the views of the young people. The service looks to provide efficient treatment performed by suitably qualified staff who are competent technically and are able to build affection-based relationships with their patients, as is reported by Dr. Joana:

*I think that **we offer our knowledge and our affection.** This is what I think. As well as our willingness to help them.*

The gift also provides the possibility that the young people will have greater recognition for the professional actions of the caregivers, due to the circulation of the gift of affectivity and knowledge, which are two important elements in the process of establishing a social bond. Knowledge results both from the treatment offered and the retribution from the young people who live with the CKD. The professional builds most trust in their professional techniques employed in care, and with the improvement of their clinical condition, young people then start to recognize the service as a reference, which thereby establishes the bond. Dr. Guilherme, nephrologist, believes that young people find this reference in the treatment of their chronic condition. It is worth noting that the term “freedom”

was also mentioned in relation to the relationship between the service and the young people:

*I think the **service is very satisfactory**, you know? These adolescents know that **they can come here** should any illness or doubt arise. They will always find professionals here, it could be a doctor, a psychologist, social worker or nutritionist who can see them (Dr. Guilherme, nephrologist).*

This report reinforces the aforementioned reference phenomenon highlighted by the young people regarding the service, which emphasizes the congruence of ideas among the research subjects. Both for the young people and the professional team, the service establishes relationships with this group that are mainly based on a feeling of confidence.

Another point relates to the availability that the service shows in its search for new ways of giving care, namely incorporating new methods (novelties):

*And I also think that the service is concerned with, let's say, **always looking to improve itself.** There are always people **looking for new ways to care or treat etc.** (Dr. Guilherme, nephrologist).*

Júlia, a nurse and social worker, confirms Dr. Guilherme's opinion concerning the idea of novelty. The service always seems ready to be innovative and experiment with new practices that are encouraged by technological advances. In addition, Júlia highlights the stimulation towards research, since the service is situated within a teaching hospital:

*For example, there are research projects here. It is a cutting-edge thing. Any new **resource that comes is offered** (Júlia, nurse technician and social worker).*

Regarding professional practice, there is an important factor that refers to the matter of not only restricting the clinical condition of the adolescent. Care earmarked for chronic renal patients is built along with the overall needs of the adolescent. That means that caregivers do not only take the visible clinical conditions into account, but they also in-

clude the patient's emotional, social, and cultural context as a basis for care. When administering a particular medication, caregivers give their attention to the physical, emotional and social effects that are caused by its use. The statement given by Dr. Guilherme exemplifies this phenomenon:

*I don't think that it is just about being pleased because you had a clinically satisfactory reply from the lab. While the **rest of him is terrible. He won't use that medicine.** He does not want to use it, and if you don't take that into account, you're going to insist with him that he has to use it. This doesn't solve anything. **He will remain sick otherwise.** Not a problem with the kidneys, but some other issue, do you understand?*

Therefore, health professionals provided evidence that their practice is based on primordial needs of the patient that are not only regarding the physical aspects, but also reaching the emotional and social universe of these individuals. The service always attends to changes in demand and offers compatible and flexible care. Dr. Joana cites an example that illustrates how the service adapts to the demands of the young people:

*We tried protocol 1, it is just that **she has a completely troubled family life and could not keep it up.** Because she is alone at home. And she didn't take the medication. The way that we had to ensure that she would get better, which she is now, was **this monthly injectable medication.** So, the protocols are adaptable.*

Due to the depth that defines the construction of the link between these young people and service, the affective investment and resource allocation in improving the clinical situation manifest themselves as essential items for consolidating and sustaining the symbolic exchanges that occur between these two groups. Martins (2002) states that social relationships emerge mainly under particular conditions of giving, trust and solidarity, feelings that circulate in this particular exchange system and that cannot be explained

from the perspective of individual interest and the state bureaucracy, but which finds a receptive environment with the gift paradox. The goods that are generated between these young people and the service are symbolic and transcend the market logic. Gift exchanging between these two groups provides a consolidation of a full and satisfactory care model and, moreover, represents the construction of a clinic of life.

The findings mentioned in this study refer us to the exchange that occurs between the health service and young people with chronic kidney disease, and the crux of interactions of certain goods that circulate within the sphere of comprehensive care.

## Final remarks

This research set out to analyze how it is to be young and suffer from chronic kidney disease in the social exchange universe of care goods, which is a context defined by explicit exchange of gifts in the world of giving care. Young people construct their identity, independence and existence through the establishment of affective links with the health service that welcome them.

Through the relationships established with health service professionals and with other social actors involved in their lives, the gift is not only between these contacts so that these young people are recognized while they are subjects. It can be affirmed that the service performs the role of protagonist of this group and that it is the young people who put themselves in that position. However, it is proposed that this protagonist role is extended in other directions that transcend the relationship between caregiver and patient. Chronically sick young people are fully able to participate and promote the involvement of other young people who, like themselves, have a relationship with the service. This study takes the recognition of these young people as the protagonist of their care into account, in addition, it suggests that the gift does not only permeate the relationships among these young people and the team of caregivers, but it also includes other social actors who are involved in this context.

It is very important that the chronic illness experienced by these young people can serve as a parameter for producing and implementing measures that can benefit the overall health of other young people who share the same clinical condition. It is hoped that when young people need to go to the service they can receive, in addition to the aforementioned and recognized care goods, the shared experience of other young individuals who have been through the same issues as them. Thus, value can be effectively attributed to the experience of a population of young people who have been touched by this chronic illness.

## References

- ARAÚJO, S. M. H. A. et al. Investigation of urinary abnormalities and risk factors for kidney disease in the World Kidney Day campaigns in the Northeast Brazil. *Revista da Associação Médica Brasileira*, São Paulo, v. 60, n. 5, p. 479-483, 2014.
- BASTOS, M. G.; KIRSZTAJN, G. M. DRC: diagnóstico precoce, encaminhamento imediato e a abordagem interdisciplinar em pacientes não submetidos à diálise. *Jornal Brasileiro de Nefrologia*, São Paulo, v. 33, n. 1, p. 93-108, 2011.
- BOGHOSSIAN, C. O.; MINAYO, M. C. S. Revisão sistemática sobre juventude e participação nos últimos 10 anos. *Saúde e Sociedade*, São Paulo, v. 18, n. 3, p. 411-423, 2009.
- BRASIL. Secretaria de Atenção à Saúde. Área de Saúde do Adolescente e do Jovem. *Política nacional de atenção integral à saúde de adolescentes e jovens*. Brasília, DF: Ministério da Saúde, 2007.
- CANESQUI, A. M. (Org.). *Adoecimentos e sofrimentos de longa duração*. São Paulo: Hucitec, 2013.
- CARVALHO, M. F.; MOREIRA, M. R. C.; NUNES, C. M. Estágios do pesar nos discursos de jovens em tratamento renal substitutivo. *Revista Enfermagem da UERJ*, Rio de Janeiro, v. 20, n. 2, p. 203-208, 2012.
- COSTA, A. C. G. *Protagonismo juvenil: adolescência, educação e participação democrática*. Salvador: Fundação Odebrecht, 2000.
- IBGE - INSTITUTO BRASILEIRO DE GEOGRAFIA E ESTATÍSTICA. *Pesquisa nacional de saúde 2013*. Rio de Janeiro: IBGE, 2013. Disponível em: <[www.ibge.gov.br/home/estatistica/populacao/pns/2013](http://www.ibge.gov.br/home/estatistica/populacao/pns/2013)>. Acesso em: 3 maio 2015.
- MARTINS, P. H. (Org.). *A dádiva entre os modernos: discussão sobre os fundamentos e as regras do social*. Petrópolis: Vozes, 2002.
- MARTINS, P. H. (Org.). *Contra a desumanização da medicina: crítica sociológica das práticas médicas modernas*. Petrópolis: Vozes, 2003.
- MARTINS, P. H. A sociologia de Marcel Mauss: dádiva, simbolismo e associação. *Revista Crítica de Ciências Sociais*, Coimbra, v. 73, p. 45-66, dez. 2005.
- MAUSS, M. *Sociologia e antropologia*. São Paulo: Cosac Naify, 2003.
- MEIRELLES, Z. V.; RUZANY, M. H. Promoção de saúde e protagonismo infantil. In: BRASIL. Secretaria de Atenção à Saúde. Área de Ações Programáticas Estratégicas. *Saúde do adolescente: competências e habilidades*. Brasília, DF: Ministério da Saúde, 2008. p. 35-39.
- MELLO, D. B. *Os significados de ser jovem com doença renal crônica no contexto das trocas de bens de cuidado*. 2011. Dissertação (Mestrado em Saúde da Mulher e da Criança) - Instituto Fernandes Figueira, Fundação Oswaldo Cruz, Rio de Janeiro, 2011.
- MELLO, D. B.; MOREIRA, M. C. N. A hospitalização e o adoecimento pela perspectiva de crianças e jovens portadores de fibrose cística e osteogênese imperfeita. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 15, n. 2, p. 453-461, 2010.
- MOREIRA, M. C. N. Contra a desumanização da medicina: crítica sociológica das práticas médicas modernas. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 10, n. 3, p. 780-781, 2005.

- MOREIRA, M. C. N.; MACEDO, A. D. A construção da subjetividade infantil a partir da vivência com o adoecimento: a questão do estigma. *Arquivos Brasileiros de Psicologia*, Rio de Janeiro, v. 55, n. 1, p. 31-41, 2003.
- MOREIRA, M. C. N.; MACEDO, A. D. O protagonismo da criança no cenário hospitalar: um ensaio sobre estratégias de sociabilidade. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 14, n. 2, p. 645-652, 2009.
- MOREIRA, M. C. N.; SOUZA, W. S.; CORSARO, W. A. Sociologia da infância. *Ciência & Saúde Coletiva*, Rio de Janeiro, v. 20, n. 1, p. 299-300, 2015.
- OLIVEIRA, V. Z.; GOMES, W. B. Comunicação médico-paciente e adesão ao tratamento em adolescentes portadores de doenças orgânicas crônicas. *Estudos de Psicologia*, Campinas, v. 9, n. 3, p. 459-69, 2004.
- PROTUDJER, J. L. et al. Normalization strategies of children with Asthma. *Qualitative Health Research*, Salt Lake City, v. 19, n. 1, p. 94-104, 2009.
- RAMOS, I. C.; QUEIROZ, M. V. O.; JORGE, M. S. B. Cuidado em situação de doença renal crônica: representações sociais elaboradas por adolescentes. *Revista Brasileira de Enfermagem*, Brasília, DF, v. 61, n. 2, p. 193-200, 2008.
- RUZANY, M. H. Atenção à saúde do adolescente: mudança de paradigma. In: BRASIL. Secretaria de Atenção à Saúde. Área de Ações Programáticas Estratégicas. *Saúde do adolescente: competências e habilidades*. Brasília, DF: Ministério da Saúde, 2008. p. 21-24.
- SCHÜTZ, A. *A fenomenologia e as relações sociais*. Rio de Janeiro: Zahar, 1979.
- VIEIRA, S. S.; DUPAS, G.; FERREIRA, N. M. L. A. Doença renal crônica: conhecendo a experiência da criança. *Escola Anna Nery Revista de Enfermagem*, Rio de Janeiro, v. 13, n. 1, p. 74-83, 2009.
- WILLIAMS, B. et al. I've never not had it so I don't really know what it's like not to: nondifference and biographical disruption among children and young people with cystic fibrosis. *Qualitative Health Research*, Salt Lake City, v. 19, p. 1443-1455, out. 2009.

---

#### Authors' contribution

Mello was responsible for producing the data in the field of research and writing the master's dissertation that preceded this article, which relied on methodological and theoretical guidance from Moreira. Writing this current version was the responsibility of both authors.

Received: 7/26/2014

Resubmitted: 5/4/2015

Approved: 5/27/2015

# ERRATUM

In the article “The leadership of youth with chronic kidney disease and the gift in the construction of health service” published in volume 25, number 1, 2016.

## **Daniele Borges de Mello**

Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, Criança e Adolescente Fernandes Figueira. Rio de Janeiro, RJ, Brazil.  
E-mail: daniele.mello2012@gmail.com

## **Martha Cristina Nunes Moreira**

Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, Criança e Adolescente Fernandes Figueira. Rio de Janeiro, RJ, Brazil.  
E-mail: marthacnmoreira@gmail.com

## **Luís Eduardo Batista**

Secretaria de Estado da Saúde de São Paulo. Instituto de Saúde. São Paulo, SP, Brazil.  
E-mail: lebatista@saude.sp.gov.br

Should read:

## **Daniele Borges de Mello**

Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, Criança e Adolescente Fernandes Figueira. Rio de Janeiro, RJ, Brazil.  
E-mail: daniele.mello2012@gmail.com

## **Martha Cristina Nunes Moreira**

Fundação Oswaldo Cruz. Instituto Nacional de Saúde da Mulher, Criança e Adolescente Fernandes Figueira. Rio de Janeiro, RJ, Brazil.  
E-mail: marthacnmoreira@gmail.com