

A Look to Nursing Care Perceived by Adolescents in a Hemodialysis Unit

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Abstract

Background: Adolescent's perception of nurse care imparted in the hemodialysis unit and the needs that they do not always express are an important starting point to optimize attention and care given by nurse professional; the goal is to reach the holistic focus characteristic of the discipline, and then generate scientific evidence that will help other health professionals, regarding given attention to patients in this step of their lives suffering chronic renal damage subjected to hemodialysis. **Objective:** To analyze the perception of adolescents with chronic kidney disease about nurse care in a hemodialysis unit. **Methods:** Qualitative and phenomenological study under the philosophic scope of Merleau Ponty, with a descriptive design; the information collection was through semi-structured interviews, field notes, and participants' observation from three adolescents' informers subjected to renal substitution by hemodialysis three times per week, in a high specialty medical unit in Mexico City. Selection of informers was by convenience and their previous authorization was requested by signed informed consent. The analysis of qualitative data was according to Rodríguez *et al.* **Results:** Four categories with seven subcategories emerged: Category 1, Adolescent's perception regarding nursing care on hemodialysis; Category 2, Care during hemodialysis process; Category 3, The world of hemodialysis; Category 4, Corporeity from adolescent's look. **Conclusion:** Nursing care to adolescents during hemodialysis must be accompanied by comprehension, communication, and knowledge of patients, regarding their needs perceived to know the way they live their chronic kidney illness, through their body, their world and the way they see themselves. The main characteristics of nurse care are communication and constant interaction with nurse-adolescent, this openness to an unknown world for them is seen as

a pleasant interaction, perceived as necessary and it helps them to feel good in their hemodialysis treatment.

Keywords

Adolescents, Care Perception, Hemodialysis

1. Introduction

The World Health Organization (WHO) places the Chronic Kidney Disease (CKD) as a forgotten pathology, such that no current precise information data exists; so, it recommends obtaining evidence showing statistical data regarding this illness [1]. WHO, in collaboration with the Latin American Society of Nephrology and Hypertension (SLANH), shows that about 10% of world population is affected by CKD, and both work in implementing strategies toward the increase of attachment to treatments of kidney substitution [2]. World prevalence is 13% of CKD, mainly of grade 3 in this pathology [3]. In Mexico, the CKD is the 7th cause of death in people 15 - 24 years of age, for those < 15 years old, 83 women and 97 men were reported dead, whereas 196 women and 284 men died in the range 15 - 24 years (INEGI, 2022) [4]. The Mexican Institute of Social Security (IMSS) reported that 69,267 beneficiaries received kidney substitution treatment, generating the cost of \$540,873 USD being 1641 kidney transplants from dead persons in 2018 [5]. Adolescents who experience this illness face emotions and continuous losses when informed of their diagnoses, which involves a radical change of life, roles and expectations, and keeps them in continuous self-suffering since they bear CKD that could lead to death, and they know it; once they are informed by health staff about their not curable disease, their dependency of an extracorporeal clearance machine that substitutes kidney excretion function, in order to prolong their life, generates an emotional impact due to the process of being candidates for kidney transplant coming from an alive donor, or from a dead body knowing to be in the long waiting list.

Adolescents once know that they will receive kidney transplant, and they will leave the renal substitution such as dialysis and hemodialysis, they manifest hope and joy; however, this expectancy falls apart due to a long waiting list and the complications of treatment. The patients that since infants knew treatments of kidney substitution, or that they were subject to kidney transplant but had tissue rejection, they went back to hemodialysis and being vulnerable during long time, they acquired great responsibility for CKD self-care at this early age. It is known that adolescents manifest emotional and physical changes, and they search for identity, so that the physical appearance is very important for them, as well as the social environment and friends [6]; according to their age and facing these needs, doubts appear regarding their illness, they search for answers of questions to health staff in charge of their care and clinical attention, *i.e.* the change in their life style,

reorganizing their family core, the economic resources, all of them important to keep in the nursing care. It is necessary to know these aspects of the nurse and the multidisciplinary team, for nurse evaluation; because some adolescents, during the mourn process, behave rebel and angry, when they are educated for healthy self-care, they deny their disease, debilitating the affective and effective communication between nurse-patient, or with any other member of the health multidisciplinary team.

Some factors are associated with the appearance of complications of the disease, such as lack of diet or pharmacologic attachment, no presence at the hemodialysis sessions (due to lack of economic resources), and no relative or tutor that brings them to the medical unit. Giving health education is not only to remind the self-care, but to take into account if it is possible to do it in their setting, if they have the economic resource to do it, or if there are other persons that help in their self-care; it is not only to comply with the procedures, since the professional work is more than that, to search more than the measurable and not forget that nurse care is holistic, to know the observed phenomena from distinct paradigms [7]. Humanism and holism must be present for those to be cared for, no matter if material or human resources are limited, the patient not only comes to receive renal substitutive treatment, their subjective aspects are also important; it should be considered that patients' feelings and emotions are vulnerable in this step of their lives, being in a transition process due to health loss and treated by a demanding condition, however, patient is responsible for its wellbeing no matter this condition [8]. Awareness that it has to spend two hours in the hemodialysis machine for extracorporeal clearance, three times per week and frequently traveling long distance to reach the hospital is a must. The duration of the procedure could be used to collect individual information, identifying the adolescent patients' needs, to generate evidence that supports plans to better implement nurse care, in addition to reaching favorable results in the hemodialysis area, increasing the quality and warmth that lead to optimal goals. Then, the aim of this investigation was to analyze adolescents with kidney disease' perception about the nurse care in a hemodialysis unit.

2. Method

This investigation was of qualitative type known as “any type of research that produces findings not reached by statistical procedures, nor by any other method of quantification” [9], it is used to know persons' experiences, and circumstances through emotions, behaviors, and feelings, as well as cultural and social phenomena. The method of study is phenomenological and descriptive, which allows to know the person in a subjective manner, considering feelings, emotions, and perceptions whose meaning derives from two greek words, *i.e.* phaintomenon or phenomenon, and logos or treatise, being the study of phenomena or facts [10]. This research was carried out in a highly specialized medical unit in Mexico City, where adolescents who were selected for this research attend. They receive renal

replacement treatment such as hemodialysis three times a week. The hemodialysis unit is located on the 8th floor and has 11 renal replacement machines, 8 of which are for scheduled treatment and 3 for patients with positive viral serology.

2.1. Inclusion Criteria

Informants were adolescents attending a hemodialysis unit to receive treatment in a high specialty medical unit, three times per week and being in this mode of kidney substitution more than five months, and they agreed through a signed informed consent to participate, in some cases a legal guardian also signed.

2.2. Information Collection

Data was collected through semi-structured interviews for each informant, field notes, and participant's observation. The questions triggered the interviews were evaluated by expert judges and also by a pilot test. Semi-structured interviews were done during February to April, 2021, in a third-level hospital in the pediatric nephrology unit in Mexico City.

2.3. Data Analysis

After the semi-structured interviews to informants, each interview was transcribed and shown to informants for acceptance and any changes they may have; later, the qualitative data analyses started, grouping similarities and differences up to reach data saturation, supported by the referential framework and by each of the informants' file. Data analysis was according to the proposal of Rodríguez *et al.*, with the following steps: Data reduction via categorization and coding of data, separating contents units, after classification and identification of the categorization elements, reaching the synthesis and grouping of meta-categories, availability and transformation of data, in this step, conceptual diagrams, formulation and verification of conclusions were done; this last step was completed through data triangulation and validation from informants, and later code verification by comparison [11] [12].

2.4. Ethics and Legal Aspects

The study was previously approved by the Ethics Committee of the high specialty medical unit, in which this investigation was conducted with authorization of the legal guardian and/or the adolescent. The study observed the Nuremberg code, Principle 1: Informed consent, by giving information about the research, its purpose, any possible risk and the beneficial results, as well as the role each adolescent had in it, and the legal guardian by authorizing the voluntary participation of the informant. The ethical principles of the Declaration of Helsinki on data privacy and confidentiality were applied, and the principle number 24 mentions that: "personal data given by participants must be protected by name substitution using a pseudonym", in the current study fruit names chosen by adolescents were used; as well as principle number 36: "authors of the study are committed to making

available the results of this investigation, in addition, to be responsible of the integrity and accuracy of the informs, all partners must accept the ethical rules of information delivery and the publication of positive or negative results". The authors are responsible to keep the results of this research [13]. The ethical principles of the Belmont report on protection of human beings under research were observed. Respect to persons: participants were treated with respect. Doing good: respect of their conditions to any damage that may appear, securing their physical and mental welfare by giving benefits for their role in this investigation, *i.e.* support groups according to their chronicity condition, and diminution of any damage. Justice: participants were treated with equal basis and rights [14]. Respect and anonymity were always maintained.

3. Results

The characteristics of the informants are shown in **Table 1**. Each informant's anonymity was maintained in order to assign them fruit names. One woman and two men, aged 12 and 15, participated in the study and, after qualitative analysis, four categories emerged with seven subcategories supported by their discourses and the frame of reference shown in **Table 2**.

Table 1. Informants' characteristics.

Participant	Gender	Age	Schooling	Time suffering CKD	Time of hemodialysis
Melon	Male	15 years	Secondary	4 years	3 years
Apple	Female	12 years	Secondary	2 years	5 months
Mango	Male	15 years	Secondary	2 years	5 months

Source: Adolescents with chronic kidney disease treated with hemodialysis, Mexico City, 2021.

Table 2. Emerging categories.

Category	Subcategory
1. Adolescent's perception regarding nurse care provided during hemodialysis	1.1) The adolescent's process during Hemodialysis
2. Care during hemodialysis process	2.1) Care provided by nurse staff according to the dichotomic view of the adolescent
	2.2) Attitudes and behaviors of nurse care
3. The hemodialysis world	3.1) The world seen from chronicity by the adolescent
	3.2) The world seen from adolescent's needs
4. Corporeity from adolescent's view	4.1) Advantages to his body with Hemodialysis
	4.2) Disadvantages to his body with hemodialysis

4. Discussion

According to Ingelfinger, the causes of CKD in children and adolescents are predominantly associated to congenital or hereditary alterations, while the occurrence of glomerulopathy is associated with chronic illness as a factor of lower incidence [15]. CKD impacts the psychology of those suffering it, they face physiological,

physical, and social challenges, such as radical modification in their life style and diet, as well as in family economy. CKD patients know and are familiar, since early ages, with substitutive treatments of kidney function such as dialysis and hemodialysis, and they are apparently adapted; however, this must not be taken as granted since health loss is overwhelming, and in every treatment there are complications. Being dependent of an external blood clearance machine, substituting the kidney function, is exhausting for the patient, for the relative care giver, and for the entire family. Care must be characterized by the user's comprehension regarding communication, then is fundamental to learn health practice, as observed in **Category 1**. Adolescent's perception regarding nurse care provided during hemodialysis, with **Subcategory 1.1**) The adolescent's process during hemodialysis. Perception, as mentioned by Espinal, allows the being to be illuminated, making sense to the environment, and translating the perception with our body; while for Merleau Ponty it is known as something experienced, the relationship between visible and invisible, that could be comprehended and perceived, what adolescents receive in the hemodialysis service [16]. Adolescent's comprehension before its treatment favors cooperation, attachment, and self-care; it is highlighted that adolescence is a physical and mental step in which many changes occur [6], being related in a different manner to those living without suffering a chronic disease, but placed under renal substitution treatment. These processes are completely under a hospital setting, its development is accompanied of continuous assistance that, at the beginning, is overwhelming for the user, as shown in the following speeches:

My first days I was afraid because I was never exposed to hemodialysis, in there the nurse staff calmed me down and told me nothing is going to happen to you, later they connected me the first day and nothing happened. (Melon)

At the beginning I was crying a lot, every time, but I am better now. (Apple)

They connect you, I do not know if they wash your blood or what, it is not clear to me. (Mango)

Treatment recurrence being accompanied allows that the user learn what is it all about, step by step, which leads to fear and anxiety emotions modification favoring tranquility and cooperation, facilitating the procedure [17]. It is known that nurse actuation associates more and more demands by the users, but we have to consider that caring is a way of accompaniment, that is harmonious, generates empathy in communication, and it is expected that this coexistence will result beneficial as mentioned by Osorio *et al.*, highlighting what Maturana said [18], care is a love for the other since humans are loving beings, and then it seeks a similar coexistence, such that nursing represents the holistic care and that what is not seen in the physiology sense, is perceived in a subjective way as observed in **Category 2**. Care during hemodialysis process, this process must have aspects of trust between care giver and user, that is related with **Subcategory 2.1**) Care provided by nurse staff according to the dichotomic view of the adolescent, the access to the care itself is the way the adolescent experiences, lives, and comprehends

care as mentioned by López Melero [19], such that care is related to the behavioral and rational aspects persons own, it is the sense that adolescents feel of the care provided by nurse professionals, which is coincident with the following speeches:

I like to enter hemodialysis, they care a lot about us, but sometimes they reprimand us, well it is for our wellbeing. (Melon)

They treat me ok, they allow me to ask questions, they hug me. (Apple)

Through care many assistance actions benefit the human needs demanded by users, mainly those that depend of a substitutive kidney treatment; which is coincident with **Subcategory 2.2)** Attitudes and behaviors of nurse care, such that an attitude generates a way to know a person, the manners to comprehend the other, as mentioned by Riquelme [20] citing Maturana, love must not be seeing as a quality aspect but on the contrary, it is a biological aspect that generates respect and coexistence behavior, as well as communication, evidenced as follows:

All nurses love me, they care about us. (Melon)

Everyone is good to me, especially the morning shift nurse, she is my favorite nurse, she treats me well giving me kisses and hugs. (Mango)

However, in the real world where events are lived, emotions emerge, and experiences are generated, as Firenze mentions [21], is very relevant to know that subjective part to understand the daily happenings inside him; for adolescents, the world they live in with chronicity in the hemodialysis service they depend to attend to get a better clinical status, in that context feelings arouse when inside the hemodialysis procedure, as observed in **Category 3.** The hemodialysis world, in this service adolescents know what happens in the clinic, it is more than a place that provides a kidney substitution treatment, it is a place where an opportunity to prolong life exists, such that Pommier [12], provides a context to consider how we are living in the world, generating experiences as observed in **Subcategory 3.1)** The world seen from chronicity by the adolescent, such that the world represents a very important and special part of the being (adolescent), which through entering every three days and in constant interaction, generates experiences [17], as shown in the following speeches:

Sometimes we have fun, we play, even if we are connected to the machine, we chat and have fun. (Apple)

My first days I was affraid because I was never been under hemodialysis before. (Melon)

In the world where we are relevant aspects emerge, that could be shared, as an example is the daily needs appearing based in our way we live, we perceive [21]; needs do not appear solely from anatomical of physiological traits, but also from behaviors that could be modified according to each individual's way of experience its world. This is related with **Subcategory 3.2)** The world seen from adolescent's needs. By knowing the way to get a better living manners, we desire to keep in the world that is grateful in experiences, as shown in the speech:

Normally I feel very tired, with a lot of sleep, and with hemodialysis I do not feel the same, it is quite different, I feel good to do other things. (Mango)

As Firenze mentioned, the body makes us to know the external world [21], it refers that the body gives sense, is a window to the exterior that generates a view about how we perceive ourselves, either objectively or subjectively, as shown by informants in **Category 4**. Corporeity from adolescent's view, the previous mention is congruent with **Subcategory 4.1**) Advantages to his body with hemodialysis, according to Merleau Ponty [21], the human body recognizes its corporeity, the body is the result of physical happenings, and it is translated to I am what my body is [22], coincident with the following speeches:

I would not change my hemodialysis by anything since, even is not as good, I need it. (Apple)

When I was in dialysis I did not eat, being under weight, but when I entered hemodialysis I started to gain and gain weight, that is why I like hemodialysis. (Mango)

And **Subcategory 4.2**) Disadvantages to his body with hemodialysis.

Hemodialysis makes us to swell, they connect us inside a big machine, with lines and they wash our blood and they subtract the water and that is it. (Melon)

Since they connected me to hemodialysis until now, they did not interned me. I understand that my kidneys do not work as they should function, and entering hemodialysis makes they work a little better. (Mango)

Compromising situations exist in the way to glimpse corporeity, then Firenze assumed that consciousness is separated from the corpus, the visible with the not visible, the self-perception, and the way the illness manifests in the adolescents' suffering bodies [21]. Through an adequate perception, the adolescent user comprehends the care nurse staff gives in the hemodialysis unit, intercommunication between nurse and adolescent makes a big difference in reaching the way the adolescents, through their bodies, experience CKD, their world, and the way they see themselves.

5. Conclusion

The proper perception in hemodialysis treatment favors attachment, cooperation, commitment, and self-care in the adolescent. Part of the responsibility of nurse professional is to reach a good communication with the patient that permits to know it and foment its care. Care must be accompanied by comprehension and knowledge of the patient, according to its needs based on its perception, this is obtained through communication channels, so that learning initiatives for a deep knowledge of the user, regarding the needs for its treatment, is a key task of nurse professionals.

Limitations of the Study

High mortality of these types of patients does not facilitate to collect more informants.

Authors' Contributions

All authors collaborated in the research. KPJMC and DCTP designed the protocol,

collected and analyzed data and wrote the manuscript. DCTP and DAHT revised and edited the manuscript for publication. All authors read and approved the final manuscript.

Conflicts of Interest

The authors declare no conflicts of interest regarding the publication of this paper.

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