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Are Human Needs Fulfilled In Treatment Adherence In Hemodialysis? A Crossover between Social Work and Neurology

M J Cabral Sacadura[1], H N Almeida[2]*

[1]Social Work Department, Catholic University of Portugal and University of Coimbra, Portugal

[2]Departments of Psychology and Education Sciences, CEIS20, University of Coimbra, Portugal

***Corresponding author:**

M J Cabral Sacadura

Catholic University of Portugal and University of Coimbra, Coimbra, Portugal.
E-mail: mjsacadura@gmail.com

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ABSTRACT

Objectives: From a starting point based on a conceptual framework of human needs, adherence to treatment and neurological impairments in end-stage renal disease (ESRD), this article attempt to answer to the question: are human needs fulfilled in adherence to treatment regimen in ESRD? In particular, we want to identify the main human needs in the adherence and non-adherence behavior (absences to a life-sustaining dialysis treatment). **Methods:** Integrated in a larger PhD Social Work investigation in progress in Portugal, the present exploratory study, concerns a specific qualitative sample of a total of 10 cases recruited from eleven dialysis units in Portugal between October-December 2021. Two groups were made. Three or more absences to dialyses sessions in the year of 2019 were considered non-adherence behavior. The main inclusion criteria were references of patients with neurology impairments and diversity in ages, social status, race, school degree, time on dialyses, geographic dispersion, and dimension of the dialyses units. **Results:** We have identified some human needs related to biopsychosocial needs in non-adherence group as well as neurological impairments that can interfere with daily routine related to adherence to treatment regimen. Condition-related factors, health care team and system-related factors of adherence were only found in the non-adherent group. **Conclusions:** The theory of human needs from the systemic theory of social work is relevant to get a better ecological and holistic view in order to improve human needs satisfaction among patients in hemodialysis. From a service user´s perspective, analyzing the absences to treatments requires crossing emotional and familial factors with social and ecological conditions.

Keywords: Social Work, Human Needs, Chronic Kidney Disease, Treatment Adherence, Dialysis, Neurology

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INTRODUCTION

In 2040, chronic kidney disease (CKD) will become the fifth leading cause of death (Foreman et al., 2018). It is an increasing public health issue, and its prevalence is estimated to be 8–16% worldwide (Jha, V. et al, 2013). The kidney accomplishes fundamental and essential functions to our human existence (Ponce, 2020). They remove wastes, toxins, and excess fluid. They also help control of blood pressure, stimulate production of red blood cells, keep your bones healthy, and regulate blood chemicals that are essential to life. (Centers for Disease Control and Prevention, 2015). Abnormalities in kidney structure or function requires to start a renal replacement therapy that leads to dialysis, or to a kidney transplantation. Dialysis is a replacement technique, in a partial way, of some kidney functions and the two common forms of dialysis therapy are hemodialysis (HD) and peritoneal dialysis (PD). Hemodialysis is the preferred modality of treatment of end-stage renal disease (ESRD) (Rakshitha, B.V *et al.* 2019), a life-sustaining treatment. People on dialysis, can face many needs and challenges, because they are confronted with the necessity of following a demanding therapeutic plan, attending scheduled dialyses sessions, medication, nutritional and lifestyle changes. Adherence is the primary determinant of the treatment effectiveness (WHO, 2003) because poor adherence diminishes the expected clinical benefit. In the context of ESRD there is a prevalent concern about the non-adherent behavior. Complications can arise as well as increased morbidity and death. Al Salmi et al. (2018) in their study indicated that "missed treatments were positively associated with all cause of mortality (…) cardiovascular mortality, sudden death/cardiac arrest, hospitalization, serum phosphorus level > 5.5 mg/dL, parathyroid hormone level > 300 pg/mL, hemoglobin level < 10 g/dL, higher kidney disease burden, and worse general and mental health."

Patients suffering from ESRD have a slew of comorbidities that raise the risk of cognitive impairment (CI) and dementia (D), and those risks increase as the severity of CKD increases to.

Juncos, L., Chandrashekar, K. & Juncos, L.I. (2017, p. 515) emphasize the importance of CI/D in CKD/ESRD patients, "it impairs quality of life, and carries with it, a greater risk of hospitalization, disability, dialysis withdrawal, and mortality". Complications and outcomes of cognitive dysfunction/ dementia in patients with renal disease can lead to lower levels of adherence.

The current research is situated at the crossroads of the following theoretical map: Human Needs from Werner Obrecht (Trenkwalder-Egger, in André, 2022), dimensions of adherence defined by the World Health Organization (2003) and Neurology in ESRD (Juncos, L., Chandrashekar, K. & Juncos, L.I., 2017). It's a proposal to give some visibility to the human needs that can be underlying the dimensions of non-adherent patients that miss dialyses sessions. The main issues that will be exposed in this article concern: the CKD and human needs for a better wellbeing; the therapeutic adherence versus personal and ecological determinants; an exploratory study comparing two groups of adherent and non- adherent patients who are attended at different hemodialysis clinics.

Table 1. Intersection framework of Human Needs, Dimensions of Adherence and Neurology in ESRD

Human Needs Werner Obrecht (Trenk-walder-Egger, in André, 2022)	**Dimensions of Adherence** (WHO 2003)	**Neurology in ESRD** (Juncos, L., Chandrashekar, K. & Juncos, L.I., 2017)
I. Biological II. Biopsychological III. Biopsychosocial	I. Patient-related factors II. Social and economic factors III. Condition-related factors IV. Health care team and system-related factors V. Therapy-related factors	I. Brain functions II. Impairments Cognitive Memory Sleep disturbance

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CKD and human needs for a better wellbeing

In many scientific fields of knowledge, where social work is also included, it is possible to find different approaches and perspectives to explain the bases behind needs. The concept of need in science research is not a consensual one, but for social work it is a key and central concept. Mönnink (2017, p.440) a senior lecturer at Hanze University of Applied Sciences, emphasizes that the taxonomy of universal needs is based on neuroscientific and social science research, thus referring to the crossover with the biological background of human needs. The author emphasizes that human needs are the experienced wishes on a biopsychosocial terrain, which lead to optimal quality of life, when meeting adequate satisfiers. The biopsychosocial terrain refers to the strong connection not only between our physical and psychological conditions but also with our social environment.

"All human beings have practically the same biology, psychological and social needs" (Walz, in André, 2022, p.45).

It is not possible to write about human needs without referencing the humanistic psychologist Abraham Maslow (1908 -1970) and his progressive model of needs. He developed a hierarchy of needs, with five levels: physiological needs, security and protection, esteem, and self-realization. In his opinion to achieve higher needs, a person must first satisfy his or her most basic needs. "For example, the need to satisfy the human motivation for love/belonging can only be fulfilled when safety and psychological needs are satisfied" (Maslow, 1943, in Schneider, 2013, p.7). This idea is currently out of date, yet it is universally known in the field of motivation.

Len Doyal and Ian Gough (1991, p.73), who come from distinct academic backgrounds - philosophy and political economy - developed a different theory of needs and argue that "health and autonomy are the core demands which humans need to satisfy in order to prevent the serious harm of fundamentally degraded involvement in their form of life". People must accomplish far more than just live. They must be in quite decent physical condition. Manual, mental, and emotional abilities are required to execute a variety of practical tasks in daily life, and poor physical health frequently interferes. These theorists presented the distinction between needs, wants, and desires. The term 'need' is also used, directly or implicitly, to refer to a set of goals that are thought to be unclassifiable.

Another theory came from one of the founders of neuropsychotherapy, Klaus Grawe (1943-2005) that combined the knowledge of the brain with psychology to understand the very neural substrates that are at the basis of human behavior. "Neuroscience complements psychology and looks deeper and from a different angle into these perceptions. We can now see that many behaviors are not processed differently but that the processing that drives certain reactions and behaviors is similar." (Ghadiri, A., Habermacher, A. & Peters, T,2012, p.70).

Grawe emphasizes that the brain in all healthy humans develops in a similar manner, with the same brain structures controlling the same functions. The connections are predetermined; how they are used will vary by individual, and the intensity with which they are used will determine how they grow in relation to one another. This foundation of human behavior is the desire that drives our contentment, well-being, and fulfillment. To meet these basic needs, each person will design his or her own strategy—looking for happy experiences while avoiding unfavorable ones.

Grawe and Epstein (idem, p.72) defined four basic needs: the need for attachment, the need for orientation and control, the need for self-esteem, protection and development, the need for pleasure and avoidance of pain. For Grawe "needs that are present among all humans, and their violation or enduring nonfulfillment leads to impairments in mental health and well-being." (idem, p.72). On a daily basis, humans will seek to meet these four basic needs, consciously or unconsciously. As a result, we will limit and shape our actions and interactions with the environment to conform to our own unique motivational schema based on the satisfaction and fulfillment (or protection) of our basic wants. These four needs are inextricably linked and satisfying one will have an impact on the others. Each basic need stimulates various neural pathways and activates different parts of the brain.

From the Zurique School of Social Work, Werner Obrecht (Trenkwalder-Egger, in André, 2022, p.64) a swedish theorist, developed a theory of needs from the systemic theories of social work in the 90´s of the 20th. For Obrecht there aren´t predetermined hierarchies of needs. He believes that all human beings have fundamental needs and social problems arise because of the incapacity of satisfying those needs, arguing that permanent dependency in the satisfaction of needs causes people's vulnerability. (cf. Trankwalder, in André, 2022, p.64).

Obrecht defines human need as an "internal condition regulating an organism's state of wellbeing". The internal state of an organism is its intrinsic value, which maintains a

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specific range of properties and conditions, without which the organism cannot thrive (idem, 47). This theory provides the framework for deeper understanding of human biological, biopsychological and biopsychosocial-cultural needs (Schneider, 2013, p.7).

Obrecht's central argument is that if our basic wants are not addressed within a given amount of time, we will develop personal and/or social problems. The term "elasticity" is used by Obrecht to describe the amount of time it takes to meet or compensate a certain need.

"The tension of a need depends on the elasticity of that specific need. For example, our biological need for water is of low elasticity, which means that if we are unable to satisfy our need for water within two to three days our survival is severely threatened, and our entire organism will collapse" (Schneider, 2013, p.7).

Fulfilling biopsychosocial demands, such as the need to belong, is, on the other hand, not life threatening, but rather a strong necessity for human well-being. As a result, a person can live for years without her or his basic needs being satisfied.

Applying these concepts to our study about adherence factors in ESRD. There are interdisciplinary teams in dialyses unit to care and to promote the well-being of patients, and social work is one of such professions that participate in this mission. Social Work is a scientific profession-based practice (Schneider, 2022, p.99) and an interdisciplinary field that identifies, describes, assesses, and works for the explanation of the causal links underlying social problems. It tries to meet human needs in a human rights´ framework. In the field of dialysis, social workers are the professionals that developed an ecological and holistic approach, making a social assessment to identify and address those needs. Based on systemic theories, some social workers should be scientists argue that there are human fundamental needs to be fulfilled, and social problems result from the incapacity of satisfying those needs because of social structures. Hall (2018) appoints that being aware and monitoring social needs which are not fulfilled, is an important step to optimize the care of people in risk and they need to be followed in the same way as hypertension, proteinuria, and anemia in ESRD.

Therapeutic adherence versus personal and ecological determinants

The World Health Organization (WHO) characterizes adherence "as the extent to which a person 's behavior (taking medications, following a recommended diet, and /or executing life – style changes) corresponds with the agreed recommendations of health care provider". (2003, p.3).

The opposite of this conceptual definition is the non-adherent behavior. In order to better understand the underlying reasons for this behavior, WHO (2003) defined five dimensions:

- "Patient-related factors - resources, knowledge, attitudes, beliefs, perceptions, and expectations of the patient.
- Social and economic factors – include various sociodemographic and economic variables "(poor socioeconomic status, poverty, illiteracy, low level of education, unemployment, lack of effective social support networks, unstable living conditions)
- Health care team and system-related factors - include, "poor medication distribution systems, lack of knowledge and training for health care providers on managing chronic diseases, lack of incentives and feedback on performance, weak capacity of the system to educate patients and provide follow-up, lack of knowledge on adherence and of effective interventions for improving it.
- Condition-related factors - particular illness-related demands faced by the patient (severity of symptoms, level of disability (physical, psychological, social and vocational), rate of progression and severity of the disease.
- Therapy-related factors - those related to the complexity of the medical regimen, duration of treatment, previous treatment failures, frequent changes in treatment, the immediacy of beneficial effects, side-effects." (pp.27-29).

Adherence to treatment in Hemodialysis and the consequences of non-adherence

In the context of dialysis, adherence combines the presence in regular dialyses sessions and taking regular medications with the recommendations of health care providers, like following a recommend diet and executing lifestyle changes.

Why is it so important to follow these determinants and factors in ESRD? Because lack of adherence can cause serious health complications. Tolkof-Rubin (in Chironda G, & Bhengu B., 2016) emphasizes that poor adherence to hemodialysis increases the risk of complications in CKD patients. The author points some complications: increased all-cause and cardiovascular

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mortality, chronic anemia, brain dysfunction, acute kidney injury, cognitive decline congestive heart failure, decreased function of white blood cells, excessive bleeding, infections, weakness of bones and pulmonary complications.

There is a prevalent concern about non-adherence in dialyses units, and studies indicate that non-adherence to the specified treatment schedule is linked to increased morbidity and death. It also proven that between 30% and 70% of patients do not follow fluid restrictions. In what concerns the dietary regimen, the potassium intake ranged from 2% to 24% of patients. Non-adherence to drugs is another serious worry among hemodialysis patients for researches show that 19% to 99% do not take their prescriptions as prescribed. And the percentage of hemodialysis patients who skipped dialysis sessions ranged from 7% to 32%. (Chironda G. & Bhengu B., 2016).

"Why patients miss dialysis remains incompletely understood (…) a large comprehensive analysis of adherence barriers to dialysis care and their impact on patient outcomes is currently elusive". (Chan, K., Thadhani, R. & Maddux, F., 2014, p.2642). Several studies have linked depression, demographic factors, and lack of motivation to missed dialysis treatments.

Neurologic disorders in patients with CKD and ESRD

Sedaghat, S. et al. (2014) refers that patient with CKD are more likely to develop cerebrovascular illness and dementia. Depending on age and demographic investigated, stroke rates in people with CKD are 1.9–7.6 times greater than in subjects without renal disease. And that, practically in every stage of CKD is linked to an elevated risk of CI/D, and the risk rises with the severity of CKD.

Juncos, L., Chandrashekar, K. & Juncos, L.I. (2017) emphasize evidence that shows a link between kidney dysfunction and cognitive decline, which is mediated by vascular mechanisms. The proper functioning of the kidney is critical for the regulation of total blood volume and vascular tone. As a result, deficiencies in renal function might lead to an irregular distribution of blood flow to organs that rely on a continuous and adequate flow of blood, such as the brain.

The brain may be especially vulnerable, not only because it is sensitive to changes in the internal milieu (increased nitrogenous waste products, oxidative stress, and inflammation), but also because renal damage modifies neurotransmitter concentrations and breaks the blood–brain barrier.

"For every 10 ml/min/1.73m2 drop in eGFR, the risk of developing CI/D increases by 11%, and the risk of declining memory, language, skills, executive functioning, and global cognition increases by 15–25%." (Juncos, L., Chandrashekar, K. & Juncos, L.I., 2017, p.518).

Depression, non-adherence, and a lower quality of life (Shrestha, M. J., et al. 2017) are all linked to reduced cognitive performance. It could lead to poor self-care, decreased decision-making, and higher healthcare consumption. In HD patients, CI has also been linked to an increased risk of death. (Juncos, L., et al, 2017, p.523).

MATERIAL AND METHODS

This qualitative exploratory study is integrated in a larger PhD social work research project in progress in Portugal. From the larger research survey an intentionally non-representative sample of 10 cases was selected. The main inclusion criteria for this study were references of patients with neurology impairments and diversity in a broad range of ages, social status, race, school degree, time on dialyses, geographical dispersion and dimension of dialyses units. Two groups were made. Three or more absences to dialyses sessions in the year of 2019 were considered non-adherence behavior. Some answers from the larger research survey were brought to this analysis. The questions were about the reasons to miss dialyses sessions, wellbeing interferences in the integration of dialysis treatment in daily routine and neurological impairments reported by patients.

Sociodemographic characterization

Concerning the clinic center dimension, the participants were integrated in units between more than 100 patients and more than 250 patients. It is possible to see prevalence of non-adherent participants in units with more than 200 patients. The ages of the participants were between 27 and 62 years old. Two groups were made by gender one of six women and the other one with four men. In what concerns school degree, one of the non-adherents has no formal education, the other one has few qualifications, and the other ones have the frequency of high school. In the group of patients who were adherent we can find one who has low qualifications, three who attended high school and one who has a graduation degree. In what concerns labor market, in the group of non-adherents, four are retired, and one is still working; in the group of adherents, four of them still work and one is retired. In the total of ten

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participants, eight of them have social benefits. The household size is of two people but one adherent and one non-adherent live alone. In the group of non-adherents four of them had intervention and support from social work, and in the group of adherents four of them also had social support.

Referring to dialyses sessions, in the group of non-adherents, three of them were in the morning shift of Monday, Wednesday and Thursday, one in the morning shift of Tuesday, Thursday and Saturday and one in the midafternoon of Monday, Wednesday and Thursday schedule. All the non-adherents came to treatment by ambulance (shared transport) except for one adherent who comes by car and another one sometimes who uses ambulance or other public transportation. In what relates to physical autonomy, two non-adherents need some help from other person for their daily routine, whereas all the others are independent.

According to clinical records, participants have some comorbidities such as peripheral vascular disease, cerebrovascular disease, diabetes without complications and diabetes with organ damage. In the 10 cases only one participant reports no neurological symptoms and he doesn´t have any morbidity related to cerebrovascular disease, peripheral vascular disease, and diabetes. The main symptoms expressed by the participants were sleep disturbance, forgetfulness, and memory loss. Other references are strong headache, stress, and irritability.

Data analyses

When asked about interferences of forgetfulness in their daily routine, the participants gave similar answers about the symptoms: "I know that memory lapses occur, I´m very bad recording names, when someone tells me something I feel I have a cognitive failure"(I1); "sometimes I repeat the same things and I not aware of that or when I´m more tired my husband tells me, you have already said that a couple of times" (I2); "I´m have afraid when making house payments, the other day I switched the cards by mistake and made a payment with my mother's ATM card"(I3); "I´m talking and all of a sudden I feel that I got lost, I have always been forgetful, but now I forget words, I cannot remember"(I5).

One of the non-adherent participants refers that she needs her husband´s help and support in what concerns forgetfulness of medical orientations (medications, medical appointments). One of the adherents also said that she needs her mother´s support to organize that kind of information.

Talking about sleep disturbance the participants say that it seriously interferes with their daily routine. This complaint is referred by four non-adherent participants and in two adherent participants. Comments like, "I couldn't sleep and so I smoked pot to sleep, now I only smoke cigarettes because of the transplant list" (I1); "without medication I can´t sleep" (I3); "The first night after my treatment I find it difficult to sleep, I get disturbed and I don't manage to calm down, it is difficult." (I5).

Sleep plays a crucial role in memory stabilization and integration, yet many people get insufficient sleep. "The proposed importance of sleep for memory processes has been supported by many studies showing detrimental effects of total sleep deprivation on the learning and retrieval of new information." (Cousins, J. & Fernández, G., 2019, p.27).

Adherence dimensions

The dimensions of adherence are present in both groups. The most significative in both groups are those related to indicators of social and economic factors and patients-related factors. In the group of non-adherents it is possible to identify other factors, that are not represented in the adherent group, such as those related to the physical condition, health care team and system-related factors. The social factors presented are specially related to low income. The more prevalent ones in non-adherent are low incomes, poor socioeconomic status, poverty, low level of education and illiteracy. In the adherent group people also refers low incomes, but it is the lack of autonomy in their daily life that strikes them as most important.

Human needs and wellbeing

According to Obrecht´s human needs theory, it is possible to identify some indicators connected with the bio, psychological and biopsychosocial needs, and a predominance in both groups. Those needs that have more expression in the non-adherent group are: according to sociodemographic data and users´ experience it is possible to see different human needs at a personal, social, and environmental level. At the personal level, we can refer physical disability, emotional disorders, sadness, demotivation, anxieties, tiredness, severity of symptoms (strong pain) and gastrointestinal indisposition, comorbidities, loneliness, and lack of autonomy in daily life. At the social level, we could also identify low incomes, poor socioeconomic status, poverty, low level of education, or illiteracy, lack of effective social support from family or social network, reduced

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friends' group, lack of support in neighborhood relations, or social isolation. At the environmental level, it was possible to identify poor housing conditions, unstable living conditions, difficult access to health services, absence of occupational activities and weak integration in the community. When asked about the reasons for missing the dialyses sessions, the excuses focus on various reasons: falling asleep, tiredness, felling severe pain, bad night's sleep and falling asleep after work, being unmotivated with the treatments, not feeling like going. There are also other reasons such as work issues, family burdens, difficulties with dialysis unit context and means of transport.

The main factors that have more expression in the adherent group are: at the personal level, motivation, emotional management, resilience; at the social level, family support, a good income, support in neighborhood relations; at the environmental level, it was possible to identify adequate housing conditions, adequate living conditions, access to health services, social security, regular occupational activities and integration in the community, with a subjective feeling of wellbeing.

CONCLUSION

The theory of human needs is controversial and it's far from consensual. Human needs cannot be observed, only satisfaction and dissatisfaction behaviors can be observed. It is possible to identify different human needs in both groups, so all human beings have universal needs to be fulfilled but with different skills and different resources. At present time, because of the small sample it is only possible to say that both personal and social issues have an influence on the non-adherence behavior. Biopsychosocial factors came in first place and became prevalent in both groups. According to the dimensions of adherence factors we found patient-related factors and social and economic factors present in the two groups. The condition-related factors, health care team and system-related factors are only presented in the non-adherent participants. From some participant´s statements it is possible to see that neurological complications interfere with their daily routine and their individual capabilities and competences are fundamental to change living conditions. In order to improve the conditions of adherence a closer relationship among social workers, physicians, and families is required to control emotional and familiar factors by creating better social and ecological conditions. More research in a multilevel model needs to be developed.

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