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The Hope of Patients Undergoing Hemodialysis and Peritoneal Dialysis

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Abstract

Hope facilitates the adaptation of disability to health care. In the context of chronic kidney disease, hope is a relevant factor, as it encourages patients to adhere to treatments that include invasive procedures, change their lifestyle, and remain, even if weakened, in a painful and delicate treatment. Currently, there are three main therapies for the advanced stage of chronic kidney disease: hemodialysis (HD), peritoneal dialysis (PD), and kidney transplantation. The last is the ideal treatment, but not all patients can be transplanted, for different reasons. Thus, most individuals in a situation of renal failure undergo hemodialysis or peritoneal dialysis. Kidney failure is an unpleasant and difficult disease to accept. In general, a chronic renal patient on dialysis can live in anguish, fear, and insecurity about their subsequent quality of life. Thus, you can abandon your everyday life desires as well as your dreams of enjoying more favorable conditions in the future. The Herth Hope Scale aims to quantify hope in individuals in clinical situations. Therefore, this chapter will deal with the level of hope of dialysis patients, proposing a comparison between those who undergo hemodialysis and peritoneal dialysis.

Keywords: hope, chronic kidney disease, nursing, renal dialysis, kidney transplantation

1. Introduction

Hope is a construct that helps to adapt to the treatment of various diseases [1]. It is a multidimensional, universal, and dynamic concept, being described as a cognitive process through which individuals actively pursue their goals, in an effort to move from the current situation toward new, more favorable conditions in the future [2].

This multidimensional concept allows the feeling of hope to permeate different disciplines. Because it has many approaches, it reveals itself as a transversal phenomenon, with multiple meanings, covering different areas of knowledge [3]. It is an individualized and subjective feeling, lived in a unique and personal way.

In the health area, hope is a concept that has gained increasing importance, especially for nurses who have a fundamental role in health promotion, as they are professionals who are in a privileged position to favor this feeling for those who receive their care [4].

In the context of chronic kidney disease (CKD), hope is a relevant factor, as it is what leads the patient to undergo relentless invasive procedures to change their lifestyle and to remain, even if weakened, in painful and delicate treatment [5].

According to data from the “Brazilian Chronic Dialysis Survey,” in 2019, there were about 139,691,000 patients with dialysis in Brazil [6]. These patients face severe limitations, especially physical and emotional, imposed by hemodialysis and/or peritoneal dialysis [7, 8].

The growing interest in the concept of hope in professional health areas reflects the commitment and concern to reinforce this aspect with patients, in order to contribute to training to deal with situations of crisis and suffering [9].

Thus, given the alarming statistics and so many challenges faced by chronic kidney patients, whether in the physical, mental, social, or spiritual sphere, it is important to analyze the level of hope of patients with chronic kidney disease, due to its relevance in the patient’s adaptation to treatment.

2. Hope in the health area

Hope is a multidimensional, universal, and dynamic concept. It can be described as a cognitive process through which people actively pursue their goals, in an effort to move out of a current situation, toward new, more favorable conditions in the future [2]. It is a construct that facilitates the adaptation of individuals to different health treatments [1]. In view of this, as it is associated with this concept, hope does not belong to a single discipline, it manifests itself as a transversal phenomenon, with multiple meanings, covering different areas of knowledge [3].

In the field of health, hope has become of paramount importance, gaining more and more relevance and strength. Thus, in the field of nursing, nurses occupy a privileged position to encourage this feeling with patients who receive their care [4]. Therefore, it is necessary that these professionals understand that hope allows their patients’ personal, clinical, and social adaptive efforts to be successful, in order to enable a possible intervention through actions, aiming to help their patients to adapt to a life reconstructed and modified [1].

In this context, in the face of kidney diseases, hope is a relevant factor [5]. CKD is an unpleasant and difficult disease to accept. Patients with CKD are individuals who face severe limitations, especially physical and emotional, imposed by hemodialysis and/or peritoneal dialysis, at the risk of living in anguish, fear, and deep uncertainty about their future, giving up their daily desires for life, and their dreams of having a pleasant future [7, 8, 10].

In summary, it can be said that the limitations resulting from kidney diseases produce negative effects on the energy and vitality levels of patients, as they establish restrictions related to common daily activities, causing severe changes in productive and personal life, which can lead to a functional disability of the individual [7, 11]. Given the above, identifying the level of hope of CKD patients can contribute to better coping with the treatment and the limitations/restrictions it imposes, preparing them to deal resiliently with the pain of the moment and the uncertainties of the future [5, 12].

2.1 The feeling of hope

Studies have shown that the induction of the state of hope expands the human being’s field of attention, develop positive emotions, intuition, and creativity [13] that favor the release of hormones that alter the body system, favoring positive thoughts and emotions [14].

Therefore, positive emotions promote mental and physical health, as these feelings reinforce resilience in the face of adversity, increase happiness, and favor psychological growth [13].

Hope is a part of positive emotions, along with love, joy, forgiveness, compassion, faith, reverence, enthusiasm, contentment, satisfaction, a sense of control, and gratitude. Hope is a feeling that leads to emotions, capable of providing well-being and improving the quality of life of individuals, especially those undergoing treatment for chronic and/or severe diseases [15]. Positive emotions connect us with our experience of the divine; however, we conceive of it. In this way, spirituality works as a kind of amalgamation of positive emotions [16].

In this line of argument, it can be said that hope is not a mere cognitive defense mechanism, but a positive emotion. According to Vaillant, [16] the feeling of hope allows us to deal with reality in a lucid way and look death directly in the eyes and accept the reality of incurable diseases. Paradoxically, the greater the suffering, the greater the power of honest hope, as the individual embraces the truth.

The opposite of hope is hopelessness (or despair), which is reflected in our organism through negative emotions that cause metabolic and cardiac excitement, activated by the sympathetic autonomic nervous system, triggering reactions such as fight or flight. Negative emotions, such as fear and anger, limit the individual's attention, causing him/her to become entangled in unnecessary detail without seeing the context. So, suffering is hope destroyed, and it causes pain, loss of self-control, and despair. However, if the end of hope turns pain into suffering, the return of hope makes suffering a tolerable pain. Suffering is the loss of autonomy, and hope is your restoration of personal power and self-confidence [16].

Similarly, the opposite of trust is distrust, and the opposite of hope is despair. Without trust, we are cautious and even paranoid. Hopeless, we are completely depressed. Hopelessness and clinical depression are the same thing and can be fatal. Soon, hope will be born out of an involuntary need to function effectively in the face of threatening situations. It is a source of comforting emotion and reminds us that tomorrow can always be better. Hope and despair are feelings, and true hope has its roots in the heart, music, and cognitive awareness [16].

Hope is born from the dialectic of feelings of indignation and anger. The indignation lies in the refusal to live in a situation of misery (or inequity) that prevents human beings from going beyond, from being more. Anger and indignation are motivating feelings of denial and make the individual look for changes in an undesirable situation. Ultimately, hope is a feeling capable of transforming reality, of making human beings always seek their best [17].

Added to this, hope must be distinguished from desire, since the latter is associated with words and the left side of the brain. On the other hand, hope is made up of images and relates to the right side of the brain. Desiring something is effortless. Hope, in fact, takes a lot of effort and shapes real life. It reflects our ability to imagine a positive and realistic future. Hope is then emotional, energizing, and it gives strength. Desire, in turn, is a passive, cognitive feeling and can be debilitating [16].

Furthermore, in the context of health, hope leads the patient to take the focus off the pain. Hope is the result of our first experience with zeal, it comes from the visceral feeling, not from a cognitive knowledge that we are important and that we will win someday [16].

2.2 The hope of the chronic kidney patient

In the context of kidney diseases, available treatments such as hemodialysis (HD), peritoneal dialysis (PD), and kidney transplantation have profound implications,

both physical and emotional [18]. It is known that renal replacement therapies (RRT) have increased the survival of patients with chronic kidney disease (CKD), but it is important to emphasize that they generate negative impacts on these people's lives [19].

Soon, nursing care, which in its essence seeks integrality of action, defined by a singular objective according to the particular need of each individual, considers human needs, in the physical, emotional, mental, and spiritual dimensions, aiming to promote the feeling of hope [20].

In the clinical management of CKD, the nursing team knows the importance of maintaining the feeling of hope, as the treatment generates frustration and limitations, due to various restrictions, such as maintaining a specific diet associated with water restrictions and changes in body appearance in the reason for the presence of the catheter for vascular access or the arteriovenous fistula. Thus, the patient lives daily with an incurable disease, associated with a long-lasting painful treatment, with possible complications, generating even greater limitations and changes of great impact [21].

Dialysis has negative effects on individuals' energy and vitality levels. The various restrictions related to daily activities and the severe changes in productive and personal life can lead to functional disability [7, 11, 18].

Chronic kidney patients face a drastic transformation in their daily lives, experiencing various limitations such as painful treatment, controlled diet, changes in family life, changes in professional and social life [22]. In this sense, the new life condition of these individuals affects not only their physical condition but also their social, family, economic, psychological, and spiritual dimensions, due to the prolonged period of exposure to long and stressful situations, inherent to the therapeutic procedures of the renal syndrome [23].

It is a fact that dialysis therapy is essential, as there is no way to be different, as intervention is necessary. In this way, it symbolizes the breadth of their suffering, as it affects the patients' lives as a way of imprisoning their entire existential potential, in the face of a difficult, inflexible reality, full of necessary restrictions. However, a good level of hope echoes in their heart, the possibility of transplantation reminds them of a "light at the end of the tunnel," given the inspiration of having a "normal life," far from the limitations imposed by dialysis [20].

The psychosocial impact of a chronic disease, such as the end-stage of kidney injury, is intense and deserves attention as a stressor, as feelings of anger with the treatment and loss of stimulus to maintain balance are common, leading patients to miss the dialysis sessions, not respecting water restrictions, drinking alcoholic beverages, and even using drugs [11].

Kidney disease is unpleasant and difficult to accept. Chronic renal dialysis patients run the risk of living in anguish, fear, and deep uncertainty about the future, with a great possibility of abandoning their daily life pleasures, as well as their dreams of having a blessed future [10]. Thus, there may be the triggering of doubts about their life expectancy, in addition to fear and other negative feelings [23]. In this sense, suicidal thoughts, poor perception of health, and the lack of hope to improve their quality of life are common feelings throughout the process [22].

Therefore, it is expected that the patient will present feelings of hopelessness, given the huge impact that CKD causes, both in the individual's personal and professional life. In this situation, maintaining hope is a valuable process in the coping process [21].

The individuals with CKD in the disease process may lose autonomy, with a consequent reduction of hope in the continuity of their own life, since different forms of lifestyle interfere, which can interrupt or hinder their insertion in the

means of production in society, dramatically affecting their daily life. Thus, the patients become dependent on constant and permanent care from the health service and a machine [24].

The illness process of the kidney patient is intensely experienced, associated with various manifestations of personal behavior, from the discovery of the disease to the possibility of kidney transplantation. Kidney transplantation is desired by most patients. The term “new kidney” represents a healthy kidney, hope for resuming life, independence from the machine, and the “cure” related to faith. Attachment to belief is mentioned by patients, as it brings comfort and hope, strengthening and promoting the well-being of CKD waiting for a new kidney [25].

The patient awaiting kidney transplantation experiences negative and positive feelings. Negative feelings consist of insecurity, uncertainty, lack of autonomy, dependence, fear, lack of clarity, high perspective, difficulty in coping, inner conflict, hopelessness, and nonconformity. The positive ones, on the other hand, constitute the hope of happiness, will to live, well-being, overcoming difficulties, desire to maintain life, and search for quality of life [20].

The transplant is expected in the time in which the patient’s experience is lived, a time full of meanings. It is a time to be-wait. Time in which you learn to be attentive and prepared, to fulfill the meeting with an uncertain future that awaits you. An uncertain future that will arrive unexpectedly and unannounced, meaning the end of the suffering that has been experienced since the moment of CKD diagnosis. Therefore, the option for transplantation is the hope of improving quality of life [26].

Generally, transplant recipients are aware of the finitude of the kidney. The duration of the organ is a continuous issue that permeates the lives of transplant patients, as some factors can influence its duration, such as the body’s defense against foreign agents and the emergence of new diseases. The challenge for transplant recipients is to ensure that the graft lasts as long as possible [26].

The transplant requires a lot of care, such as the use of various medications, and there are risks of complications, including death, if the donated kidney is rejected by the recipient’s body [1, 27].

In a survey conducted in a hemodialysis clinic of a public hospital in Brasília, it can be seen the patients registered on the kidney transplantation waiting list (mostly young and of working age) had lower levels of hope than those who weren’t, which suggests that patients who are not registered on the transplantation waiting list feel safe and adapted to hemodialysis [28].

Another research pointed out that although transplantation can be seen as a way of “liberation,” patients know that it does not reflect the possibility of total rescue of the aspects of life left behind. In this sense, transplantation does not mean the total and definitive resolution of the “problems,” since these individuals experienced an undesirable survival of quality of life, resulting from restrictions caused by CKD, as a sudden change in their daily lives, full of limitations, merciless treatment and with an inevitable thought of death. Thus, transplantation is seen as something new, with multiple meanings, limited by fear and disbelief [20].

In view of the COVID-19 pandemic scenario, potential deceased donors and actual kidney, heart, and cornea donors were significantly reduced. In addition to the SARS-CoV-2 being an impediment to organ donation, with the government measures of social isolation, the number of accidents decreased, thus impacting the brain deaths of possible donors [29].

Another aspect that contributes to the multiplicity of meanings is the awareness that the organ can fail at any time, feelings of anxiety and sadness, and the fear of losing the transplant and the consequence of returning to dialysis therapy. However, transplantation also promises to release the bonds imposed by the disease

and treatment, allowing these individuals to make new plans and activities that the disease forced them to interrupt [26].

In summary, in the transplant phase, patients believe in success, due to the fact that it provides them with a lifestyle close to the “normality” experienced before the diagnosis of the disease. Kidney transplantation is associated with the life of a healthy individual, linked to the sense of being reborn and starting a new life. The new birth allows them to escape the space where they were confined by pain, suffering, and anguish [26].

Despite the ambiguity of feelings about the result of kidney transplantation, it is noted that transplantation fosters the feeling of hope of some individuals, who see in it an opportunity for a new life, with more freedom and quality. At the same time, it is a therapy that still causes fears and uncertainties regarding the success and duration of the procedure [27].

In this context, faith can be a source of hope, as it helps to deal with uncertainties in the transplant process, offering comfort and tranquility, being one of the most used coping strategies while waiting for the donation. Receiving a kidney donation is a way to free yourself [26].

Therefore, hope is beneficial to the health of these individuals, as it contributes to the empowerment of patients when dealing with crisis situations, aiming at maintaining the quality of life, setting goals, and promoting health [21].

There is no doubt that the events are reenacted, by encouraging the adherence of positive feelings, such as hope, for example, in order to enable the chronic renal patient on dialysis to face the disease optimistically, helping them to reestablish their health, so that they continue fighting for their survival. The hope in health recovery makes the patients travel long distances in search of the arduous treatment for their disease, such as the tireless invasive procedures, changes in their lifestyle, their routine, and even if weakened, they remain in treatment [5].

Without a doubt, hope can help them to position themselves in a positive way in the face of different situations in life.

Some scientific instruments aim to quantify hope in individuals in clinical situations, such as the Herth Hope Scale (EEH), developed by Herth (1992), originally called the Herth Hope Index [30].

The EEH is a scale that has 12 affirmative items. The grading of its items occurs using a four-point Likert-type scale: 4 indicates “completely agree” and 1 indicates “completely disagree.” There are two – items 3 and 6 – that have inverted scores. The total score ranges from 12 to 48, and the higher the score, the higher the level of hope. It is a scale considered brief (it takes, on average, 10 minutes to complete) and easy to understand [9, 21].

The items on the EEH scale are composed of the following statements: (1) I am optimistic about life; (2) I have short-term and long-term plans; (3) I feel very lonely; (4) I can see possibilities in the midst of difficulties; (5) I have a faith that comforts me; (6) I am afraid of my future; (7) I can remember happy and pleasurable times; (8) I feel very strong; (9) I feel able to give and receive affection/love; (10) I know where I want to go; (11) I believe in the value of each day; (12) I feel that my life has value and usefulness.

The Herth Hope Scale is of great importance, as it is a validated instrument for the use of patients in clinical situations (chronic, oncological and/or palliative care patients, and family caregivers) and the planning of interventions in the scope of nursing services. Reliability was verified through internal consistency analysis represented by Cronbach's alpha coefficient of 0.834, which demonstrates a high reliability of the instrument [30].

In a research on the applicability of EEH in patients with chronic kidney disease, the result was obtained that despite all the limitations imposed by the treatment

and by the disease itself, the studied population had a high level of hope. In these patients, it was observed that the item with the highest HSE score was that which refers to faith as a measure of comfort (item 5, "I have a faith that comforts me"). Therefore, it was possible to deduce that faith contributes to maintaining a high level of hope [28].

The same research compared the level of hope between patients undergoing hemodialysis and those undergoing peritoneal dialysis, there was no statistically significant difference, since both groups maintain a high level of hope, even with routine differences related to treatment [28].

The fact that motivated the comparison was the perspective that patients on peritoneal dialysis have a higher level of hope than those on hemodialysis, due to the fact that they dialyze at home and depend less on the modality. A study on the domain of self-care indicates that patients on peritoneal dialysis are favored because there is less loss in activities of daily living and more free time, causing minimal changes in their routine [31].

2.3 Treatment and nursing

The nursing team must plan care strategies for patients with CKD, with a view to increasing the patient's hope, seeking to minimize the aspects that impede adherence to treatment. A systematic review pointed out, through the analyzed studies, some strategies that should be implemented to survey the patient's needs, such as: listening to the patient/relatives, establishing an empathetic relationship and developing communication skills, maintaining a sense of humor, and encouraging positive memories; strengthen social/family support; strengthen spiritual support; explore patients' feelings; foster emotional and motivational strategies; discuss information about the disease; set realistic goals and encourage the person to look beyond the disease [32].

A study identified that young people have greater difficulty in adhering to treatment, due to issues involving immaturity and resistance to the restrictions imposed by the disease and hemodialysis itself. However, the nurses successfully managed the resistances encountered, favoring the acceptance of the disease and treatment, maintaining the spiritual connection and emotional balance at high through conversations with the young people, seeking during the appointments and clarifying doubts, fears, and insecurities [33].

By providing comprehensive care and due to prolonged contact with the patient, nurses are able to create an interpersonal relationship, which favors a therapeutic bond. In this way, the observation capacity is expanded, detecting verbal and non-verbal expressions indicative of relevant and contextual situations, which may or may not interact with the patient [20].

Nurses are essential agents for promoting hope. Thus, moments of conversation and interaction with patients are opportunities that encourage this feeling, according to the needs of each one. Although they also have their own personal, family, spiritual, and/or financial dilemmas and problems, nurses are professionals capable of positively interfering in the level of hope of patients with chronic kidney disease on dialysis, since, in their interventions, with light technologies, they deal with essential themes such as faith, beliefs, and religion [33].

Nursing teams must implement interventions aimed at promoting and maintaining hope strategies, favoring the planning of comprehensive care that aims to improve the quality of life of patients with CKD [33].

Therefore, it is important that the nursing team is aware of the complications of the disease, anxiety, and possible stresses that involve this condition. Thus, promoting and encouraging care, also through health education, is essential, with a view to reduce low self-esteem related to the evolution of treatment [34].

3. Conclusion

Despite all the limitations imposed by the disease, these patients still manage to maintain a good level of hope, supported by faith, religion, and a good support network.

Hope is a feeling that facilitates the adaptation to treatment and helps patients to support the limitations imposed by the disease. Thus, nursing is the profession that is closest to the patient in their hemodialysis routine, therefore, they must implement interventions aimed at promoting and maintaining hope strategies, favoring the planning of comprehensive care, aiming at a good quality of life.

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