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Veröffentlichungsversion / Published Version

Zeitschriftenartikel / journal article

Empfohlene Zitierung / Suggested Citation:

Salimena, A. M. d. O., Souza, M. O., Melo, M. C. S. C. d., & Ferreira, M. R. (2016). Daily life of a woman undergoing hemodialysis. *Revista de Pesquisa: Cuidado é Fundamental Online*, 8(3), 4636-4643. <https://doi.org/10.9789/2175-5361.2016.v8i3.4636-4643>

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O cotidiano da mulher em hemodiálise

Daily life of a woman undergoing hemodialysis

El cotidiano de la mujer en hemodiálisis

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How to quote this article:

Salimena AMO; Souza MO; de Melo MCSC; et al. Daily life of a woman undergoing hemodialysis. Rev Fund Care Online. 2016 jul/set; 8(3):4636-4643. DOI: <http://dx.doi.org/10.9789/2175-5361.2016.v8i3.4636-4643>

RESUMO

Objetivo: compreender o cotidiano da mulher em hemodiálise. **Método:** estudo qualitativo realizado com 9 mulheres por meio de entrevistas em fevereiro e março de 2013 no setor de hemodiálise de um hospital da Zona da Mata Mineira. **Resultado:** a análise compreensiva desvelou 3 unidades de significado: ser portadora de doença renal crônica e enfrentar a hemodiálise, a hemodiálise e suas reações, o cotidiano da mulher em tratamento por hemodiálise. Foram percebidos sentimentos de medo e rejeição. Todavia, a religião e a família se mostraram importantes na aceitação e esperança durante o tratamento. **Conclusão:** destaca-se a importância do papel do enfermeiro no serviço de terapia renal substitutiva. Esse profissional atua como educador, promove o autocuidado e auxilia as pacientes a encontrar novas maneiras de viver de acordo com seus próprios limites.

Descritores: insuficiência renal; hemodiálise; cuidados de enfermagem.

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ABSTRACT

Objective: understanding the daily life of a woman undergoing hemodialysis. **Method:** qualitative study conducted with 9 women by means of interviews in February and March 2013 in the hemodialysis unit of a hospital in Zona da Mata (Minas Gerais), Brazil. **Results:** the comprehensive analysis unveiled 3 units of meaning: having a chronic kidney disease and facing hemodialysis, hemodialysis and its reactions, the daily life of a woman treated with hemodialysis. Feelings of fear and rejection were noticed. However, religion and family proved to be important for acceptance and hope during treatment. **Conclusion:** we highlight the importance of the nurse's role in the substitutive renal therapy service. This professional works as an educator, promoting self-care and assisting the female patients to find new ways to live according to their own limitations.

Descriptors: renal insufficiency; hemodialysis; nursing care.

RESUMEN

Objetivo: comprender el cotidiano de la mujer en hemodiálisis. **Método:** estudio cualitativo realizado con 9 mujeres por medio de entrevistas en febrero y marzo de 2013 en la unidad de hemodiálisis de un hospital en la Zona da Mata (Minas Gerais), Brasil. **Resultados:** el análisis desveló 3 unidades de significado: estar con una enfermedad renal crónica y someterse a hemodiálisis, la hemodiálisis y sus reacciones, el cotidiano de una mujer tratada con hemodiálisis. Se percibieron sentimientos de miedo y rechazo. Sin embargo, la religión y la familia han demostrado ser importantes para la aceptación y la esperanza durante el tratamiento. **Conclusión:** se destaca la importancia del papel del enfermero en el servicio de terapia renal sustitutiva. Este profesional actúa como educador, promueve el autocuidado y ayuda a las pacientes a encontrar nuevas maneras de vivir de acuerdo con sus propias limitaciones.

Descriptoros: insuficiencia renal; hemodiálisis; atención de enfermería.

INTRODUCTION

Chronic kidney disease is characterized by a progressive decline in the glomerular filtration rate, which consequently influences on the maintenance of body homeostasis, since kidneys are responsible for this balance. Therefore, there's the impairment of regulatory, excretory, and endocrine functions involving the other organs in our body.^{1,2} The substitutive renal therapy becomes necessary in the advanced stages of the disease, where there is "functional kidney failure when the glomerular filtration rate [...] becomes very low, less than 15 mL/min".³ Hemodialysis is responsible for sudden changes in patient's life, due to limitations caused by the treatment.

Dependence on the hemodialysis machine is given by an average of 3 times a week, being 4 hours per day, which in addition to the physical limitations derived from the disease often result in incapacity for work.⁴ This may culminate, besides frustration with the fact of not being able to work, in financial constraints, due to the decreased family income and in more changes in the lifestyle of this patient.⁵ With advancing disease, attendance to personal commitments and treatment settings becomes limited due to physical

difficulties. Such factors also extend dependence on family, because of the necessity for support regarding the comings and goings.⁴

After hemodialysis sessions, many patients suffer from physiological changes, such as fatigue, malaise, low blood pressure, and cramps, thus, they need some rest.⁶ In addition to physical problems, we observe emotional distress due to decreased autonomy and increased dependence on other people - which are translated into feelings of sadness, anger, lack of confidence, frustration, and concern about the future.⁵ Psychological weakness and low self-esteem may arise, because patients with chronic kidney disease tend to suffer from premature aging, skin discoloration, loss of weight, and edema. Another abrupt change in the life of this population originates in food and water restrictions, which are seriously needed to optimize treatment and improve quality of life and life expectancy for these patients.³

The nurse, as a member of the health team, works as a link between patient, family, and the other members of the health team, and she/he should engage in a relationship with the patient that allows a comprehensive and individualized care.⁷ This commitment makes it possible for the professional to act focusing on the patient's emotional dimension, helping her/him to overcome difficulties related to self-image and encouraging her/him to social reintegration, pointing out alternatives that stimulate her/him to adapt to her/his current situation.

Through the various changes taking place in the daily life of patients who initiate hemodialysis, women's care stands out. The female patients must be high lighted because they often play a double or even triple role, taking responsibility for a professional occupation, household chores, and also looking after children. Thus, activities in their daily life are hindered because of all difficulties posed by the disease.⁸

Thus, this study aimed to understand the daily life of a woman undergoing hemodialysis, considering that her routine is changed from the beginning of treatment, with numerous physical, social, dietary and work-related, restrictions, in addition to the psychological changes permeating this stage in a woman's life.

METHODS

Qualitative research has proved to be the appropriate option to favor the manifestation of participants regarding their experiences related to the theme and enable the analysis of private and subjective issues for understanding meanings.⁹ The regulatory provisions of Resolution CNS 196/96¹⁰ were observed and the study was approved by the Research Ethics Committee of the Federal University of Juiz de Fora (UFJF), under the Opinion 188,802.

The research scenario was the hemodialysis unit of a hospital in Zona da Mata (Minas Gerais), Brazil, where there is a significant number of women affected by chronic renal failure undergoing hemodialysis. A previous visit was

made to the institution, in order to introduce the research to professionals and determine the most convenient schedules for meetings with women.

The respondents were 9 women being treated by hemodialysis, all over 18 years old, without distinction of race, color, marital status, educational level, and religious belief. The interviews took place within women's dialysis period, in February and March 2013, guided by the following questions: "How did you feel about discovering to have a chronic kidney disease?"; "What was it like when hemodialysis treatment began?"; "How did hemodialysis change your daily life?". The testimonies were recorded by means of a digital media device (MP3) and later transcribed by the interviewer. We also observed and recorded in a field diary gestures, expressions, and looks, because nonverbal language is a rich source of research.¹¹

After transcribing all interviews, we proceeded to reading, which enabled the identification of key ideas and relevant structures - unveiling changes in the daily life of a woman undergoing hemodialysis. Finally, we performed a comprehensive analysis, according to the steps proposed by Martins and Bicudo.¹²

RESULTS AND DISCUSSION

The women's age ranged between 34 and 64 years, 5 of them were married and 4 single. Out of the 9 women, 3 said to be black, 3 brown, and 3 white. Regarding the educational level, 2 reported to have studied up to 4th grade, 3 had incomplete elementary education, 3 had complete high school, and 1 had complete higher education. As for religion, the majority reported being Catholic. The time under substitutive renal therapy ranged from 2 weeks to 18 years. Among those women under treatment for less time, 2 are still working. Three units of meaning emerged from the comprehensive analysis: having a chronic kidney disease and facing hemodialysis, hemodialysis and its reactions, the daily life of a woman treated with hemodialysis.

Having a chronic kidney disease and facing hemodialysis

Chronic kidney disease arises from various causes, mainly hypertension and diabetes mellitus.² Some individuals are regarded as being at a higher risk for chronic kidney disease: hypertensive individuals, with frequency of 75% among patients at any age; diabetic individuals and those having a cardiovascular disease, being that both must be monitored for detecting renal injury. Age must be analyzed due to elderly susceptibility to impairment of renal function secondary to chronic diseases, and the chronic kidney disease also represents a risk for cardiovascular disease that was showed in a recent study to be independently associated with glomerular filtration rate and chronic kidney disease. The family aspect is also relevant for the higher prevalence

of hypertension, diabetes mellitus, proteinuria, and kidney disease among relatives of patients with chronic kidney disease. Hypertension and diabetes affect a large part of the population that often has no symptoms and, therefore, it is not treated. So, these diseases will affect, among other organs, the kidneys.¹

[...] blood pressure was too high... he told me to go seeing it... treating kidneys. (R2)

I am diabetic since I was 16... 14 years ago I discovered that I had a kidney disease and now it is getting close to the point of hemodialysis. (R4)

I was diabetic... I lost too much protein through urine, I began to swell, then, I treated it without hemodialysis for 5 years. (R6)

We also noticed as the etiology of kidney disease the hereditary diseases, such as, for instance, polycystic kidney and congenital malformations.²

[...] my brother was going to have a transplant, then I wanted to donate a kidney and when I did the tests they showed that I had the same problem as him... it is polycystic kidney. (R3)

[...] I took the exam and it showed that my bladder... was born smooth, without those small veins, then, because of it, there are many infections... due to this... I have lost my kidneys. (R1)

Another cause noticed for loss of kidney function was renal tuberculosis that, in the urinary system, occurs through lymphatic and hematogenous dissemination - with the bacillus remaining in the renal cortex. There is impairment of renal calyces, pelvis, ureters, and bladder. The disease progresses silently, and its main manifestations are dysuria, pollakiuria, and hematuria.¹³

[...] when I got sick I was working, then, I felt really bad, I went to the doctor... then I was admitted to the hospital... I had tuberculosis and it went down to my kidney. (R7)

Some respondents expressed their ignorance about the causes that led to the loss of kidney function:

[...] it was three years before I started doing dialysis. (R5)

[...] I was treating (the disease)... there was no solution. (R8)

[...] I started urinating blood... at that time, they did not explain what hemodialysis was, indeed... I thought I had

to go to the hospital for treatment, but I hoped to be better one day... (R9)

It is of paramount importance that the health team schedules educational strategies to inform the patient about her diseases, the clinical manifestations, the adoption of a healthy lifestyle, and the effects of treatment.¹⁴ Many patients are unaware of the causes that led to the onset of renal failure, as well as the appropriate habits to prevent a further progression of the disease. Therefore, health professionals, especially nurses, must always seek to inform and explain about the pathology as a strategy to promote self-care.¹⁵

The certainty of starting treatment with hemodialysis is permeated by feelings of hopelessness, lack of confidence, and fear. Because “the diagnosis of chronic kidney disease has a strong impact on individuals and their family members, with possibilities to affect the person’s social life and cause physical and emotional harm.”¹⁴⁻¹⁶ Such an experience, in many cases, is among the most difficult moments, since the individual faces the unknown, suffering and death:

[...] He said: you will have to undergo hemodialysis... I thought that he was wrong... I got out of there feeling no ground under my feet... So, I got home desperate, locked myself in the bedroom, punched the door in my wardrobe as much as I could... (R1)

[...] If I have to do it I would rather die... (R2)

It was very sad... it seems like we are ready, but we are not. (R3)

I was scared... I was shocked... I never thought I could get to the point that it is now... Did not I comply with my diet or did not I receive proper advice?... (R4)

[...] everything was complicated, for my body and my soul, you know... (R5)

[...] it was hard... it was a big impact... I really wanted to work, but God did not allow it... (R7)

[...] it was difficult, you know... we have to totally change our life... I was slowly adapting. (R8)

[...] at first, it was very difficult... I had no close family, you know, so, it was very hard... at first, I did not accept... I wondered why it happened to me... (R9)

At this stage, it’s noticed that patients go through a period of rejection/acceptance, defining various types of reactions and ways of acting in face of the onset of treatment by dialysis.¹⁷ Besides the feelings of fear, anguish, and sadness due to the onset of treatment, they have to live with the idea of interrupting their professional activities, with the certainty that there is no cure, and that they’ll have to deal with an undeniable change in their daily life, since the comings and goings to the hospital will be a recurrent fact in their life.¹⁸

Religiosity is a strong supporting point, because besides constituting a source of hope, it helps in understanding and accepting what was hitherto denied.

[...] I was very afraid... but I put everything in God’s hands... now, I am accepting it, but before... I did not accept it... God will give me strength, he gives me courage... (R2)

[...] having to do this was not easy, indeed... it will be whatever God wants it to be, but I did not think it would be so fast after she told me... I was really upset... it is sad, but I can still live for some time... (R6)

In this context, emerges “the importance of believing in a higher being as a source of hope and strength to face the difficult situations involving resignation to facts, which cannot be modified”⁷ Religion and faith constitute a way of relieving internal conflicts, accepting the situation experienced at the time and also positivism regarding expectations about the future.

Hemodialysis and its reactions

The onset of treatment by hemodialysis is a difficult period, in a totally new environment, and it requires time so that the patient can adapt to the new reality. Early sessions are permeated by lack of confidence, fear of pain, fear of feeling bad during sessions and also by the fact of dealing with an unknown location. Getting to the dialysis room and making contact to those machines, where we see blood filtration through the capillary tubes, can arouse distress in a newly admitted woman.¹⁹

At this moment, the presence of an embracing and humanized professional team is crucial. The nurse must support the female patient, providing her with the needed support at this difficult time. It is important to reassure her, explaining the entire procedure, answering to her questions, and seeking to create a bond of trust with her, who will feel safer. The ideal is being attentive, providing a calm environment, and engaging in dialogue without hurry.

[...] she took me to the hemodialysis room, showed me the stretchers, showed me the fistulas of each patient, how it works and everything... she did not want me to look... she put some sound there, for me to choose and everything... I have not felt bad, I just felt some weakness... (R1)

[...] I thought it was different, you know... I thought it was much worse... it is not what I thought it was... but I had no appetite... I thought is that hemodialysis, too? Is it an appetite suppressor, does this take our hunger away? Does this quench the thirst, does this take it all? (R2)

[...] he had asked me to address the fistula... use a catheter and undergo hemodialysis... (R3)

[...] I was very well received... very well received... but we do not want that for us. (R4)

[...] it was complicated... our health becomes very poor, we have to engage in a routine of medicines, diet... (R5)

[...] I was there in the morning, some days I was there in the afternoon, because there was no vacancy, no chair, machine... I felt bad... in the beginning, I vomited a lot. (R6)

[...] it was very difficult. I cried, because at the time I had a little child, I was afraid of dying... thanks God I felt good, it was just... coughing and tiredness... (R7)

[...] good because it helped me a lot... (R8)

[...] I went to the clinic crying and came back in tears, blood pressure fell, too, the machines were not good... we called it 'tancão', it sucked us every day... (R9)

The nurses must be prepared to advise the female patient and her family, using clear and understandable language.²⁰ Thus, it becomes possible to adequately inform about the procedure and indispensable methods regarding food, water intake, and the catheter or arteriovenous fistula. This educational activity conducted by the professional as a whole will contribute to the quality of life of this woman.⁸ The health team must be mobilized to support the patient, since in her adaptation phase revolt and anxiety are characteristics observed due to the physiological and psychological changes consistent with this moment.

The professional from the health team must also help the patient to have a positive self-image, discover new ways to live according to his limitations and adopt a lifestyle that allows him to take responsibility for his treatment and his life, after all, being an active individual in the society where he lives.^{6,192}

Another difficult situation to which this clientele is subject involves the reactions that occur during and after hemodialysis sessions. There are complaints of hypotension, weakness, cramps, nausea, being hypotension the main reaction. "Clients undergoing hemodialysis report fatigue, weakness, lack of appetite, dizziness, nausea after this procedure."²¹ From this perspective, also, "hypotension is undoubtedly a major complication of treatment by hemodialysis, occurring in up to 20% of sessions."⁶ The following testimonies are expressions corroborating it:

[...] the day when I undergo hemodialysis is a bit difficult... because blood pressure sometimes goes up, sometimes it goes down... a very common thing insomnia at the day we undergo hemodialysis... (R1)

[...] I leave, you know... well weak. So, in the days when I undergo hemodialysis, I am almost... bedridden... When I leave here, I am destroyed, then, I come home and I have to stay at least 1 hour lying... (R5)

[...] we get weak... I leave here destroyed... we get better after about 2, 3 hours... (R6)

[...] I come home... and I rest... after leaving here, sometimes blood pressure is rather low, you know. (R7)

As a way to minimize such reactions, it is important that the health professional is aware of the onset of these complications, in order to promptly act after discovering it and avoid more suffering for that woman. The team must be able to advise the female patient about these possible complications so that she also contributes towards caring and helping to monitor any changes.

Daily life of a woman treated with hemodialysis

Hemodialysis is a therapeutic procedure that completely changes a patient's life, because besides the acceptance of having a chronic disease that despite treatment is irreversible, hemodialysis completely affects the routine and life of those who are undergoing it.^{1,2} In a study conducted in 2011, patients reported as difficulties observed in chronic renal failure changes in lifestyle and the impossibility of doing activities they like, because of physical inability to fulfill daily activities - negatively reflecting on social life.²²

On the other hand, it was noticed that, despite being a treatment which requires sacrifices from the female patient, it is also seen as a benefit when compared to the lower quality of life before such treatment began. That it because "hemodialysis extends the patient's life, it relieves suffering and even prevents further disabilities."⁷ Thus, the respondents expressed:

The more I pulled my legs to walk, I could not and there a terrible shortness of breath would take place. (R1)

I had a lot of medicines, medication... now it is much better, this helped me a lot. (R8)

The daily activities of this woman are compromised, due to the amount of hours she is required to dedicate to treatment. There is a need for 12 hours per week, on average, of exclusive hemodialysis, and the female patient is obliged to let other people fulfill her activities.

Today I may say that I do not have the same willingness I had before... it is an exhausting treatment... we have no vacation... three times a week we have to come, even if it

is raining, we may be feeling ill, having a stomach ache, but we have to come here... (R1)

The reality of chronic disease brings along a new life for the patient, who has her daily activities compromised and faces changes due to physical weakness, leading most patients to become dependent on their family members.^{7,23}

[...] I liked going into the street, going to the market... I was more independent. I miss it... doing my things, going to do my exams alone... I am more dependent... at first, I did nothing... now, I have started preparing my own food... I started doing my things... there is something that changed a lot... I love staying there in the rural area, but now it has to change. My rural area is too far, it has no recourses, indeed... (R3)

This greatly affects the family... it changes the routine of our family, because we depend on transportation... it is not an easy treatment... it is a treatment for a lifetime, you know, until the day we have to go. (R5)

[...] my husband has been able to bring me. But it poses many difficulties... (R6)

Dependency is a remarkable factor in the female patients' life, especially at the times of coming and going from hemodialysis since they leave the health unit weakened, often feeling nauseas and hypotension. They also start needing help to fulfill activities outside her home, such as going to the doctor, going to the bank, going shopping and going for a simple walk.

Another adaptation needed regards change in eating habits, such as decreased intake of salt and water restriction, which represent stressors in their life.^{17,24}

[...] I have to stay here for 4 hours... I could be home, I am here... we have to keep monitoring... feeding, water, which we cannot drink much, we have to keep taking it in little drops. Water is more difficult to control. (R8)

A balanced diet is the key to the success of their treatment, as well as fluid restriction, and the latter is among the most difficult restrictions to the patient. Water, so common and banal for us, represents a precious good, often impossible to be obtained. The female patient is aware that drinking more water than the allowed amount will cause complications during the next dialysis session, such as nausea, due to the increased weight to be removed.²⁴

Along with food and water restrictions there is also physical restriction due to arteriovenous fistula or catheter in the neck, which hinders fulfilling some of her daily and professional activities.²⁰ Physical restraint is one of the causes

that prevents a woman to keep working, along with the fact of undergoing treatment three times a week, a fact that forces her to be absent from work for repeated days:

[...] it seems that now I am understanding what I could be doing better... checking more urea, creatinine... phosphorus... these days that I wanted to be at my workplace it is not possible... (R4)

[...] there are some limitations... I had to stop after the machine. I had to retire... it is very weakening, we have a life... completely different from that we had before, we have to change our whole thinking, our entire routine... so, we live day by day, one session per day... It changes everything, it changes our professional life, emotional life, our daily life, our routine, it changes everything... there is the obligation of having to come here three times a week, staying here for 4 hours... We have to control the intake of phosphorus, calcium, potassium, so, we have to be watching over ourselves... this is a prison without bars, we are under arrest, without being under arrest... (R5)

From then on I could not work, I could not do anything... I was on the waiting list for transplantation, now I do not want it no more... Every day I thank God... I am fine... I can still clean my house, I can still walk... over the 4 hours I remain here I am under arrest, you know, I could be solving many things... we are going on, but it poses problems, it interferes very much... I come here alone... I walk alone, with God. (R7)

Work is something important in the life of every human being, because it is both a means of survival and an opportunity for satisfaction and pleasure, when we are pursuing the occupation we like.^{19,25} So, labor restriction can lead to major social and psychological problems when there are feelings of inadequacy, helplessness, and idleness. Another concern that arises is the fear of becoming a burden to their relatives regarding the financial aspect, something which constitutes another factor aggravating the psychological context.^{25,26}

The treatment by dialysis causes limitations in leisure and it may result in boredom and decreased quality of life among patients, who face restrictions regarding travels and tours due to the commitment that hemodialysis poses to them. Quality of life is compromised, because they abdicate pleasures such as traveling and visiting their family in face of the insecurity caused by concerns related to the fistula and the possibility of undergoing hemodialysis in a different health center - that is, with a health team they do not know.¹⁷ This alternative is evidenced in the following testimony:

We cannot go out... we cannot travel, there are responsibilities, there are three days, they are Monday,

Wednesday, and Friday... I go there on Friday, after leaving here. On Sunday I have to be back. Then, my niece says: Ask, aunt, to come here! Because you can take it to another town, but I am afraid of infection, you see? But I visit my sister, if I have to go out, then, I go out, but it is just like this, you see? (R6)

The family plays an important role in patient's coping with chronic kidney disease and in keeping her treatment, because by offering love and support, it provides her with feelings of protection and confidence - which will constitute stimuli to alleviate suffering and to go on with treatment. The family works by strengthening the woman's psychological balance and, as a consequence, the emotional pain is reduced. "It is important for the female patient to live along with family members and friends that provide her with strength and courage to go on with treatment, face the fear and suffering arising from it"²⁷ This corroborates other studies by claiming that: "As for family participation, it is known to be crucial, since it takes functions related to the protection and socialization of its members."²⁸ In this sense, women expressed:

Support has been very important to me, both from my family, my friends, and everything. (R3)

Everyone in my family is very supportive, but... my family is not from here... everyone provides support, but they are far away... it is difficult. (R4)

It is also noticed that there are those women who surrender, seeing only the good side of treatment - which is the maintenance of life with better quality. These patients adopt hemodialysis as part of their daily life and learn to live along with it:

[...] I live a normal life... I have my house, I have my stuff, I live alone, I work... Today I take it without any problem... because I know that, then, if this is the way I have to live, I need to accept it... I come home, I sleep, I wake up, as usual, as if I had to go working, you see?... I do not stop doing anything due to hemodialysis, indeed, but I also do not miss a session to do another thing... I move, I walk... I do gym... everything depends on control, you know... everything is within limits. (R9)

The patients who accept and recognize the importance of treatment have a better quality of life and they often identify hemodialysis as the only chance to stay alive, something which makes them able to gradually adapt to the new life that is imposed on them, as a means of survival.²⁹ The search for better quality of life among women with chronic

kidney disease is a challenge for everyone involved in this process - the patient herself, her family, and the health team, everyone in pursuit of a common goal: a successful treatment by hemodialysis.

CONCLUSION

It was observed that, by being aware of the need to start treatment by hemodialysis, women face a period permeated by suffering and fear arising from uncertainty about the future and death. They go through a phase of rejection/acceptance during which they seek support from family, God, and also health professionals.

The nurse was highlighted as crucial in a hemodialysis service, because in addition to the responsibility of managing the service and the need for a specific technical and scientific knowledge in the area, emotional balance is a must. The professional should be always prepared to be a reference, aiming at the individuality of each patient in order to act not only regarding physical care, but to also provide a comprehensive care that focuses on the various human dimensions.

The educational aspect and the creation of a bond showed to be relevant in professional practice related to the patient's adherence to the therapy - in this was the nurse must act answering to questions, and promoting self-care. Other significant foci of actions highlighted were the assistance towards creating a positive self-image for the patient, the of discovering new ways of living with the new limitations the patient has to face, and the stimulation for the pursuit of leisure and social interaction that allow this woman - patient- to see herself as active, free from lament and negative feelings.

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Received on: 26/03/2014

Required for review: No

Approved on: 03/09/2014

Published on: 15/07/2016

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