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Original Article

Kidney transplantation: experience of men in hemodialysis entered on the waiting list

Transplante renal: vivência de homens em hemodiálise inscritos na lista de espera

Trasplante de riñón: experiencia de hombres en hemodiálisis inscritos en lista de espera

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Objective: to know the experiences of men with chronic renal failure under hemodialysis treatment entered on the kidney transplant waiting list. **Method:** qualitative study based on the principles of the National Policy for Integral Attention to Men's Health and Masculinity, conducted with 11 participants in a hemodialysis service, through serial semi-structured interviews and inductive data analysis. **Results:** the following categories emerged: Gaps between the health policies and the reality of the male population and Challenges and possibilities of change in the life process. **Conclusion:** although many of these men see hemodialysis as synonym of imprisonment, others understand it as the possibility of maintaining survival and this help them waiting for the kidney transplant.
Descriptors: Renal Insufficiency, Chronic; Renal Dialysis; Kidney Transplantation; Men's Health; Nursing.

Objetivo: conhecer as vivências de homens com insuficiência renal crônica em tratamento hemodialítico inscritos na lista de espera do transplante renal. **Método:** estudo qualitativo, fundamentado nos referenciais da Política Nacional de Atenção Integral à Saúde do Homem e da Masculinidade, desenvolvido com onze participantes em um serviço de hemodiálise, por meio de entrevistas semiestruturadas seriadas e análise indutiva dos dados. **Resultados:** as categorias criadas foram: As lacunas entre as políticas de saúde e a realidade da população masculina e Desafios e possibilidades de mudanças no processo da vida. **Conclusão:** embora a hemodiálise seja vista por muitos destes homens como sinônimo de aprisionamento, para outros significa a possibilidade de manutenção da sobrevivência e é o que lhes garante esperar pelo transplante renal.
Descritores: Insuficiência Renal Crônica; Diálise Renal; Transplante de Rim; Saúde do Homem; Enfermagem.

Objetivo: conocer experiencias de hombres con insuficiencia renal crónica bajo tratamiento de hemodiálisis inscritos en lista de espera del trasplante renal. **Método:** estudio cualitativo, basado en los principios de la Política Nacional de Atención Integral a la Salud del Hombres y de la Masculinidad, desarrollado con once participantes en un servicio de hemodiálisis **Resultados:** a través de entrevistas semiestructuradas y análisis inductivo de los datos en serie. Las categorías creadas fueron: Brechas entre las políticas de salud y la realidad de la población masculina y Retos y posibilidades en el proceso de cambios en el proceso de la vida. **Conclusión:** aunque la hemodiálisis sea vista por muchos de estos hombres como sinónimo de encarcelamiento, para otros, significa la posibilidad de mantener la supervivencia y ofrecerles esperanza para el trasplante de riñón.
Descriptores: Insuficiencia Renal Crónica; Diálisis Renal; Trasplante de Riñón; Salud del Hombre; Enfermería.

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Introduction

Chronic renal failure has been one of the health system priorities, given the growing number of people with chronic renal failure waiting for a transplant. Recent data reveal that there are 17,969 active candidates in Brazil on the kidney transplant waiting list[1].

Kidney transplantation constitutes a great progress in health, as it provides years with better quality of life for people with chronic renal failure[2]. The Order No. 1,168/2004 establishing a National Care Policy for Chronic Kidney Disease Patients to Nephrology Services[3] secures the universality, equity, comprehensiveness, social control, and access to various forms of renal replacement therapy: peritoneal dialysis, dialysis, and transplantation. Nevertheless, the wait for an organ reflects in all dimensions of human life, namely physical, psychological, social, and spiritual[4].

A bibliographical survey on the subject identified that men represent 57.7% of people on hemodialysis[5] and yet, there are few studies approaching this subject among men. Faced with this finding and approaching the references of the National Policy for Integral Attention to Men's Health[6] and Masculinities[7], concerns arose in relation to the experience of men waiting for a kidney transplant because, as nurses committed to comprehensive care, we need to know the singularities of patients in renal replacement therapy, since they cover more than physical dimensions.

Given these concerns, this study aimed to know the experiences of men with chronic renal failure on hemodialysis registered on the kidney transplant waiting list, which may provide support for nursing professionals to improve the quality of care to these people.

Method

This is a descriptive study of qualitative approach conducted with eleven (11) men with chronic renal failure on hemodialysis included on the kidney transplantation waiting list. The theoretical frameworks of the National Policy for Integral Attention to Men's Health and Masculinities were adopted. This policy draws attention to the fact that the male population enters the health system through specialized care, resulting in the aggravation of injury. Many of these injuries could be prevented if men conducted regular measures of primary care. As for Masculinities, hegemonic masculinity refers to an ideal cultural model of man that, though unattainable, has a controlling effect on the behavior of others[7].

To select the participants, the following inclusion criteria were established: male, over 18 years of age, with a diagnosis of chronic renal failure, on regular hemodialysis, registered on the kidney transplant waiting list, and with clear communication skills. In addition, we excluded those who were hospitalized during the data collection.

Data collection occurred from February to May 2014, in a Hemodialysis Service of a philanthropic general hospital in Minas Gerais, Brazil, through an individual pre-interview with potential participants, in which we explained the objectives of the study and verified their interest in participating in the research. After confirming the interest, we scheduled an interview for data collection with the participants, which occurred at their homes in date and time previously chosen by them.

For data collection, the semi-structured interview technique was used, recorded in MP3 electronic device, with participants' consent, and that consisted of the following question: What does it mean to you to wait on the kidney transplant list?

Each interview lasted 40 minutes on average, being immediately transcribed by the main author. We finished the data collection when the answers of study participants began to repeat themselves frequently.

After transcription, we used inductive content analysis in accordance with proposed frameworks obeying the data sorting stages, gathering all the material obtained in the data collection step, in order to achieve an overall picture of the content. For data classification, we established the essence of the main ideas and common points to then define the categories. In the final analysis stage, the researchers accessed all the empirical data as a starting and arrival point in the apprehension and interpretation of experiences[8].

Seeking to ensure the ethical principles, the Research Ethics Committee of the Universidade Federal de Alfenas approved the study under favorable opinion No. 525,962.

All participants were informed about the study objective and the guarantee of anonymity, volunteered to participate, and signed the Free and Informed Consent Form. The researcher gave them fictitious names.

Results

The 11 men participating in this study were in the age group between 18 and 63 years, with four of them aged between 18 and 30 years. Six had incomplete primary education, five had monthly family income between one and two minimum wages (minimum wage at approximately US$306.00), seven received sick pay, six lived with a partner, and Catholicism was the predominant religion.

It was found that the length of stay on hemodialysis ranged from 9 months to 14 years, with six participants in treatment for more than four years. Nonetheless, the time on the transplant waiting list ranged from 10 days to 12 years, where five participants had more than 4 years of waiting. The main underlying diseases were systemic hypertension and diabetes mellitus.

From data analysis, the following categories emerged: Gaps between Health Policies and the reality of the male population and Challenges and possibilities of change in the life process.

Gaps between Health Policies and the reality of the male population

The analysis of the empirical material enabled to identify that even when in pain, men continue delaying the diagnosis and treatment, assigning relevance to work: *because I have worked my whole life, so I did not know, I had no idea what was going on. There was a time they told me to get a doctor's statements to work, they said I had a high-pressure problem, I did not feel anything. I was working normally, sometimes I felt a little pain on the side, I thought it was a regular thing or some back pain; I kept working, I did not care; then the pain grew stronger, then I took some medicine to relieve the pain and it was all right, I kept working* (Pedro).

This situation may be associated with gender and masculinity issues, where the man plays the role of family provider: *My illness started with a very high pressure, I was measuring the pressure and it was twenty by ten, then my wife said: You need to check this! You need to check this! But I have to work, I have to raise my children, my wife thought the same as me, that as long as I manage to work I keep going, I could not stay idle, because my children were all very young at the time; so I kept working and heavy-duty, working as bricklayer helper* (Henrique).

On the other hand, the statement below may indicate the lack of problem-solving in primary health care in relation to men: *I went to the pharmacy and measured my blood pressure, it was high; the first time, he* [the doctor] *gave me the medicine, I took only the medicine, controlled pressure with the medicine, you know? However, it was always high; I had god health, only pressure problem, you know? I performed heavy duty and had no problem* (Daniel).

For this reason, men postpone the treatment and there is the need for immediate institution of renal replacement therapy, according to the following statements: *I lived a very normal life until last year, when I went to the hospital, the doctors asked for urea and creatinine examination because I was very swollen, you know? That was when came an eleven*

percent creatinine and a hundred and some urea; and I kept getting worse, very short of breath; until the day came when I went to surgery, I had a catheter in the neck and started my first hemodialysis session (Rafael). *My illness started like this: I slept at nights and woke up with a swollen eye, I thought it was from sleeping, and it kept going; until one day I passed out, I went to the hospital, the doctor admitted me and said: you have a kidney disease and you will have to undergo hemodialysis! Since I knew nothing, I thought it was all normal, but I did not know how sad hemodialysis was, how hard it is, that was when the problem started* (Marcelo).

Challenges and possibilities of change in the life process

When experiencing the illness and learning about hemodialysis, men accept the need and the importance of treatment for the maintenance of life: *But at first I did not like undergoing hemodialysis, I cried a lot, I did no feel so good; but now I accept it more; I thank God for this hemodialysis, otherwise we'd all be dead. I would have died, my brother would also have died, and all patients would have passed away* (Renato).

Although they seem resigned, the following statements highlight the restrictions imposed on them by the treatment: *Hemodialysis takes away the good stuff, you cannot travel; it takes your freedom. I am very hyperactive, I do not like to idle, and I have practically to stay idle, I cannot work, cannot go back to study, do what I want, so I have to calm down, you know.* (Raphael). *My illness is like this, three times a week in the morning shift, I leave home five in the morning and arrive at 12h30, it is only routine, you know. I have no time for anything, there is no way to do anything, you cannot plan anything new, so you have to live according to the hemodialysis, it is not easy to get hemodialysis out, you know, so you have to stay in that routine, of hemodialysis* [in the city] *and at home. It is hard; this is a prison for us* (Daniel).

To cope with the treatment imposed, they look for references in the health team, as evidenced: *Nurses are all nice, they treat us well, you know, it does not matter if it is there or in the street, it is not a hemodialysis there, it is a family, they treat us very well, everything is cool for me, so it is a family there* (Fernando).

Men believe that renal transplantation is the only option for changes in the life process. *God will help me to receive the transplant, you know; because the best hope that is in the person is to have faith that you will get the transplant; not only undergoing dialysis, in hemodialysis you have no way of doing anything, but after transplant it is another life, you can hang out. The hope is to receive the transplant in order to live a normal life* (Marcelo).

Although taken by expectations for the chance to break free of the limitations imposed by hemodialysis, they also reveal the apprehension caused by not knowing when they will be called upon to receive the transplant: *This is what gives me strength, to believe that I will receive the transplant and then everything will be alright, I will go back to study, to work. This is what makes me believe and wait, not that I have other choices. Then you start to live it until it works out. People also help to overcome a little, family, girlfriend* (Gabriel).

In order to receive a kidney transplantation, people must have all exams updated, the name entered on the waiting list, and the selection. Even fulfilling these requirements, transplantation may not occur. *I have been there once, when they called me for the transplant, then I stayed there until midnight, then there was another guy, who was in worst situation, a little weaker, so the doctor said to me: There is no problem, the next time it will be you; but it has been a while though* (Pedro).

Discovering a matched related donor appears as a great opportunity to get rid of the long waiting list. Nonetheless, in some cases men felt frustrated with the questions of the matched related donor. *They told me once that if the family wanted to donate they could; then my father made an examination and he was compatible, but his fear was stronger than donating the organ, so it did not work out! My brother was going to donate, but he had kidney problems, he is also on hemodialysis* (Renato).

When registering on the waiting list men hope that everything goes well: *When I get the transplant, I want to go back to my normal life, playing sports, being able to go to college, move forward, like everyone else. Now I am waiting to be called, but I have faith that it will be quickly and so I keep going, until the day of*

transplantation, which God willing, it will not be long (Rafael, 10 days registered on the kidney transplant waiting list). Nevertheless, over the months, not occurring the transplant, these feelings become frustration and disappointment: *I will be honest, I practically have delivered it into the hand of God, and let God's will be done, if it does not work out, God knows what he does. I have been wanting to receive the transplant, who does not want to get well, to get out of hemodialysis?, but if it does not work out, I better stay the way I am, my hands are tied, there is nothing I can do* (Pedro, 12 years registered on the kidney transplant waiting list).

Given this reality, men remain on hemodialysis, using resources that constitute networks of spiritual, family and social support, while waiting for a kidney transplant.

The reports revealed that family involvement is utterly important in the treatment of men with chronic renal failure, since it plays the protection and integration functions among its members: *My family helps me by giving me strength. Everyone plays with me, tell me to stay calm, and do not freak out, because people get nervous. God also helps us, we pick up the Bible and read, and it is great. Friends also help us, my friends who come here* (Miguel).

The value attributed by men to spiritual support was also identified: *I will tell you something, I have great faith in God and believe too much in the Divine Eternal Father. This gives me a lot of strength, every Sunday I go to church. God gives me a lot of strength, the more I pray, the more strength he gives me, so it is the only thing that comforts us, first God up there, Our Lady of Aparecida, I have great faith, you know, I have a living faith. You must have a lot of faith, otherwise you cannot stand it* (Henrique).

Discussion

The National Policy for Integral Attention to Men's Health, created in 2008, aims to qualify the care to men's health in the perspective of comprehensive care for this population and the encouragement of self-care actions, and recognizes that "health is a primary right of social citizenship of all Brazilian men"[6:3]. However, even today, the inclusion of men in primary health care services is far from being achieved, since many still consider these places as female environments[6,9].

This reality may relate to sociocultural constructions based on the beliefs and values of "being a man". In this perspective, a sign of body pain can be considered as a weakness to their male biological condition and so, men choose to ignore it. For them, health is the absence of pain, as well as physical willingness, which indicates no evidence of disease and strengths their masculinity. It is also worth highlighting the fact that men feel invulnerable, exposing themselves to risk situations to reaffirm their masculinity. The demand for primary health care can be recognized as an activity inherent to females, which added to the distinction between genders, becomes little recognized and valued by men[6,9].

The reason mentioned by men for the low demand for health services is the difficulty of reconciling work with the opening hours of the unit[6-10]. In our view, it adds to an incipient training of human resources in Primary Health Care services for the specific care for men in the perspective of comprehensive care.

Furthermore, the fact that chronic renal failure is a disease of insidious onset, diagnosed when the person already presents typical clinical symptoms such as swelling of the eyes, feet and legs, anemia, fatigue, weakness, back pain, lack of appetite, and nausea. These symptoms are often associated with systemic hypertension or diabetes mellitus[11].

The importance men give to work is a barrier to the search for assistance in the health services, even when showing clinical signs of disease. In our opinion, the early detection of systemic hypertension or diabetes mellitus as well as the beginning of treatment could help change the course of the disease, but many men postpone the search for the health system. Additionally, the "delay" can be permeated

with the fear of facing the reality of illness or the idea that men should only seek health care in emergency cases[12].

Under the influence of sociocultural constructions, men are assigned the role of being strong and work to support the family. They attribute relevance to labor over health care. For men, particularly those with low social status, the responsibility to support the family occupies a special place, which can often be a barrier to access the health services[6], however it is also a way to strengthen their role of men in the working class, because it is assigned to them the worker role to support the family[7].

The lack of problem-solving of primary health care in relation to men represents a gap in public policies, which may influence the search for care. We believe that the commitment of the professionals of these services with the principles of the Unified Health System is extremely important, principles such as universality, with preventive actions and reduction of injuries, and the principle of integrity, taking into account the needs of persons or groups of people[13]. For cultural reasons men tend to seek assistance at the pharmacy, because in the past it was the resource available at the time. Nowadays it is the closest resource that does not require line or schedule and meets the men's problem-solving perspective. We also emphasize that Primary Health Care is more than prescribing drugs and that the actions to be developed for the control of systemic hypertension involve health education, welcoming, listening skills, and bonding.

It is worth highlighting that minimizing the indicative signs and symptoms of the need to seek health services makes men postpone even more the search for treatment. Thus, health problems that could be solved in Primary Care, which today is the gateway to users in the Unified Health System, end up becoming more complex and requiring high-complexity care, such as a kidney transplant[14].

Data from the first category indicate the existence of gaps between the National Policy for Integral Attention to Men's Health and the reality of the male population. Moreover, health education seems to have an incipient action, because if the health care programs were actually implemented by most professionals, many men would probably be free of chronic renal failure, hemodialysis, and transplant waiting lists.

Corroborating this fact, the lack of human resources able to care for the target audience of men, lack of materials to meet these customers, and the opening hours of health services, since in most services the opening hours are incompatible with the working day of men. Additionally, the delay in performing diagnostic tests for consultations with specialists and surgical procedures when men are referred to secondary or tertiary care services oppose to the male demands for quickness and problem-solving[15].

Nevertheless, waiting in the kidney transplant list represents a possibility of change in the process of life permeated by several challenges.

Because of the silent nature and gradual development of chronic renal failure, the diagnosis often occurs in late stage[16]. Early diagnosis is essential for conservative measures to restore kidney function, thus avoiding being taken into renal replacement therapy[17].

Most people with chronic renal failure comes to the health service through urgent or emergency care, when serious complications of the disease are already installed[18]. The late discovery may result from fragile health education activities carried out by health professionals to users of services in relation to prevention, the importance of preserving renal function, the care required for the urinary tract, and the risks that urinary disorders may conceal[11]. Furthermore, the entry of users into health services by secondary care shows that assistance to the main risk factors for chronic kidney disease, such as diabetes mellitus and systemic hypertension, does not suffice[17,19].

Our data support that men enter health services through secondary and tertiary care, because in most cases the diagnosis of chronic renal failure is unveiled during hospital admissions where subjects undergo dialysis. Such events may compromise the various dimensions of human beings, namely physical, psychological, social, and spiritual, and generate multifaceted feelings affecting their masculinity. However, we apprehended that during treatment men might accept it as they acquire knowledge about the chronic disease and the hemodialysis treatment for the maintenance of life.

The discourses of men highlight the restrictions imposed by hemodialysis and once again, the lack of work[20]. Hemodialysis requires people to adapt to a new lifestyle, changes in eating habits and fluid intake, and restriction in labor activity, which leads men to a smaller participation in the household budget, hence affecting their masculinity. This reality undermines not only the person but also their families, so that the disease influences not only the personal, but also the family and social dimensions[18].

This way, due to the dependence caused by the illness, many people lose their family and social references, and may seek these references, for example, in the health team[21].

In addition to the limitations imposed by the treatment, men still need to adapt to the routine of hemodialysis, leaving their home and comfort three times a week to go to the city where the treatment takes place, since only four study participants lived in the city with hemodialysis service available.

One of the main difficulties faced by people with chronic renal failure is the time spent in hemodialysis sessions, which prevents patients from performing other activities because of the displacement for long periods of time[22].

Impositions and restrictions experienced by people in relation to hemodialysis lead them to believe that kidney transplantation is the best solution for their health problem[4,20]. Therefore, many of these participants faced the treatment as something temporary and reported the desire to receive the transplant, as an opportunity to resume their activities that have been set aside.

After starting hemodialysis therapy, there are several challenges to be faced, including conducting a series of clinical, laboratory, and imaging tests, known as pre-transplant tests. These tests aim to check the health status and evaluate the conditions to receive a kidney transplant[17].

Another challenge is to be selected to perform the transplantation and it does not occur. People under 18 have been given priority to receive donor organs of the same age group.

The chance to skip the long waiting list for a kidney is to have a matched related donor, however, at this moment, there might be several questions from family members and the donation does not materialize. A kidney transplant from a relative involves a number of concerns on the part of the donor who faces the possibility of future risk of losing the other kidney. There are concerns with regard to altered body image and difficulty in interpersonal relationships by lack of knowledge on the procedure they will undergo. At this moment, the psychological support is essential for both the patient and the family.

While they wait for the kidney transplant, men reveal feelings that adjust according to the waiting time for a kidney. Initially, they glimpse the possibility of change in the life process, but over the years on dialysis, hopelessness, frustration and disappointment arise, hence the importance of spiritual, family and social support networks, while waiting for a kidney transplant.

We reiterate that the family is the main source of support and encouragement. The reports demonstrated that family participation is of paramount importance in the treatment[23].

In this context, health professionals, especially nurses, should conduct educational activities that encourage people to continue the dialysis treatment,

helping them to have a good relationship with their family and friends, respecting their limitations[24]. They should also promote the awareness of these patients so that any process that involves transplantation have a satisfactory outcome[4].

Spiritual support is utterly important for coping with the illness and the wait for a transplant. Over the statements, the value attributed by men to spiritual support was verified.

In general, religion influences the quality of life of people with chronic kidney failure, accounting for source of comfort and hope, encouraging them and causing general wellbeing, thus contributing to the acceptance and coping with their chronic condition[25].

Faith and hope give new meaning, so thoughts, once of deprivation because of hemodialysis, have now gained a new sense of freedom, associated with post-transplant life, with improved quality and away from hemodialysis[4].

We emphasize the need for the competence of health professionals, especially nurses, to welcome people with chronic renal failure, encouraging them to follow through with the hemodialysis treatment while waiting for the kidney transplantation. Therefore, one should know their expectations, anxieties and limitations in order to provide holistic nursing care, in other words, see the human being in its entirety.

Final Considerations

This study enabled to apprehend that men face different challenges and opportunities for the maintenance of their lives in hemodialysis while waiting for a kidney transplant. The sad news of the diagnosis of chronic renal failure, a situation often unusual, ends up destroying the idea of men as being invulnerable.

After the diagnosis of chronic renal failure, men begin to deal with various challenges arising from the illness, the limitations and difficulties in hemodialysis such as the displacement from home to the health service, the frequency of therapy, the duration and impact that therapy causes in personal, family, and social life.

Although many of these men see hemodialysis as a synonym of imprisonment, others see the possibility for maintaining survival. For these reasons, men glimpse in renal transplantation the chance to free themselves from the constraints caused by hemodialysis. Thus, the study participants remain on hemodialysis using resources that constitute spiritual, family and social support networks, while waiting for the day they will be selected to receive the kidney transplant that will provide them the full reestablishment of health and life.

Nonetheless, we reiterate the importance of implementing the public policies on health care for the promotion of healthy lifestyles and the prevention of systemic hypertension and diabetes mellitus, as well as a work committed with people, so that primary care performs its role in health promotion, early diagnosis, prevention of complications, and recovery of health, thus reducing health risks to the male population, and especially by preventing that people come to the health service through urgent and emergency care.

The fact that this research occurred in one of the Hemodialysis Services in the city, covering only a small share of men in the municipality who await transplantation, might represent a limitation for this study.

Collaborations

Souza AM contributed to the work design, data collection, data analysis and interpretation, and drafting of the article. Filipini CB, Rosado SR, Dázio EMR, Fava SMCL and Lima RS contributed to the work design, data analysis and interpretation, drafting of the article, and final approval of the version to be published.

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