ISSN: 1676-4285

OBJN Online Brazilian Journal of Nursing
ENGLISH
Federal Fluminense University
AURORA DE AFONSO COSTA NURSING SCHOOL
uff
Original Articles

The care of elderly patients receiving pre-dialysis treatment: a descriptive study

Caren da Silva Jacobi[1], Margrid Beuter[1], Nara Marilene Oliveira Girardon-Perlini[1], Arlete Maria Brentanno Timm[1], Jamile Laís Bruinsma[1], Claudelí Mistura[2]

1 Santa Maria Federal University
2 Cruz Alta University

ABSTRACT

Aim: to describe the views of relatives regarding the care services provided for their elderly relatives receiving pre-dialysis treatment. **Method:** this was a qualitative-descriptive study, with participants including eight elderly individuals and their families who attended a uremia outpatient clinic. Data collection occurred between March and July 2013 at families' homes and the study used genograms and circular question interviews. To analyze the data, this study used topic content analysis. **Results:** besides the regular demands of aging, families need to add pre-dialysis treatment to their elderly relatives' routines. The possibility of dialysis forces relatives to change their roles and search for other possible solutions to the illness. **Discussion:** families search for alternatives within both the realm of common sense and in the spiritual world in order to meet the demands of their elderly relatives' illness. **Conclusion:** family care for the elderly is fundamental in the fight against renal disease and the dialog between relatives and health professionals can improve care performance.

Descriptors: Family; Therapeutics; Chronic Renal Insufficiency; Elder.

bi CS, Beuter M, Girardon-Perlini NMO, Timm AMB, Bruinsma JL, Mistura C. The care of elderly patients receiving pre-dialysis treatment: a descriptive study. Online braz j nurs [internet] 2016 Dec [cited year month day]; 15 (4):713-723. Available from: http://www.objnursing.uff.br/index.php/nursing/article/view/5437

INTRODUCTION

Families have changed. The definition now used by nurses notes that a family is a group in which its members declare themselves a part, irrespective of their genetic bonds[1]. The family unit has altered due to social changes, thus affecting its concept and structure. Usually, these transformations impact the family core, making it more fragile and vulnerable. Based on this, the family must be included in the context of social and public health policies that aim to improve family members' quality of life as, outside of the family itself, individuals belong to a certain social-family group[2]. Within the structural changes to families is the aging of family members and a reduction in fertility rates, which may reduce the size of the family core in the future.

The process of aging generates changes that can increase the possibility of chronic disease in the elderly. Changes to a family member's state of health can make the entire family unit positively change their behavior in efforts to help control the illness, improve the elderly relative's chance of survival, and help the family face the challenges to come[4].

Among the changes that result from aging is a reduction in the size of an individual's kidneys, the loss of nephrons, and a reduction of blood supply, which, combined, lead to an attenuation of glomerular filtration rate[5]. These transformations, when associated with arterial hypertension illnesses and/or uncontrolled diabetes mellitus, will develop into a chronic renal disease (CRD). CRD is characterized by renal seizure and the progressive loss of endocrinal, tubular, and glomerular functions of the kidneys, sometimes without any symptoms. As the disease progresses, renal functioning becomes limited, developing into chronic renal insufficiency (CRI)[6]. CRI can produce changes in the everyday life of families as, depending on the clinical conditions of the elderly relative, the new routine must allow family members to provide the necessary care for their ill relative while performing their regular roles and activities.

The control of CRI in its initial stage can be set as pre-dialysis or conservative treatment, in which both aim to slow down the development of the illness and prepare the patient and family for dialysis, when necessary. Pre-dialysis therapy encompasses drug and diet treatments to control arterial hypertension or diabetes mellitus, to reduce the chances of anemia, and provide rigorous control of calcium and phosphorus[5]. The therapy also involves the management of dyslipidemia, protein intake, and smoking habits along with frequent laboratorial consultations and examinations[6].

In pre-dialysis treatment, it is important to consider the high prevalence of co-morbidities that usually affect the elderly population and the physical and psychological issues that may occur during old age. Based on such changes, families need to actively participate in the process of the care of their elderly relatives. The presence of a family member who requires care directly or indirectly affects the components of a family unit[1].

Care originates from the condition of fragility, either in terms of the body or the affectionate, social, or spiritual spectrum in which a human being requires support. To care for someone is to participate in that individual's state of health and the process of caring is a search to reestablish the individual's original state through available technical and human resources. Care is an act of responsibility in helping and supporting suffering individuals and in responding to the needs of another person[7].

Health professionals, in particular those in the nursing field, need to recognize the context of family care for the elderly so they can provide subsidies to families that do not feel prepared to care for their elderly relatives who are receiving

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pre-dialysis treatment. Due to this issue, studies that analyze this scenario are of considerable importance. Furthermore, a search in the literature about elderly individuals in pre-dialysis treatment demonstrated a gap in the information regarding the topic[8].

Based on such considerations, the following research question was designed: how does the family see its participation in the care of their elderly relative receiving pre-dialysis treatment? The goal of this research was to describe families' perceptions regarding the care of elderly relatives receiving pre-dialysis treatment.

METHOD

This is a descriptive study using a qualitative approach, performed with the families of eight elderly individuals receiving pre-dialysis treatment who are supported by a uremia outpatient clinic at a college hospital located in the south of Brazil. The study had a total sample of 21 participants. Data collection took place from March to July 2013 through the use of genograms and interviews performed by the main researcher in the families' homes.

Genograms help researchers understand the structure and context of the generational standards of a family through graphical representation[9]. In this study, genograms allowed the researcher to learn more about the participants, allowing the researcher to begin an initial dialog before the interview. For the second stage, in order to deepen the questions posed, the researcher raised several circular questions[1], which initially focused on the following topics: changes, involvement, and organization needed in taking care of an elderly relative; challenges in the treatment; living with an elderly individual with CRI; and perspectives about the care provided. Based on the answers of the initial questions, other circular questions were designed, including the cycle of questions and answers for use among the participating relatives[1]. For the data collection, the study used a previously designed script to collect family members' characteristics, such as: distance between the family member's residence and the elderly relative's residence; monthly income; age; schooling; degree of kinship; and time spent caring for the elderly relative. The interviews took an average of one hour and ended when the researcher felt there was a saturation of data, characterized by the repetition of discourse[10].

The selection of participants was carried out via the observation of scheduled appointments at the clinic during the period of data collection. After the selection of the elderly individuals, the families were invited to participate in the research. If the telephone number information was outdated or missing in the patient's medical records, the relative was contacted on the day s/he was accompanying his/her relative to the clinic. The criteria of inclusion for the families were: the presence of a family member of an elderly individual receiving pre-dialysis treatment and a family composed of at least two members besides the elderly individual undergoing treatment. The selection of the family members to be interviewed was based on a conversation with the elderly individual, who identified the members involved in his/her care. After identifying possible participants, two families refused to participate. The number of family members interviewed varied between two to three individuals. It is important to highlight that the elderly individual was not considered a member, as s/he was not going to be observed in this research.

The data acquired were analyzed using Minayo's thematic content analysis according to the operative proposal, in which there are two levels of interpretation. The first level searches

for the determinants or, in other words, the understanding of socio-historical and political context to which the participants belong. These determinants were observed during the design of the genograms and during the visualization of the contexts during the home interviews. The second level tries to capture the specific meaning, which is operated by the ordering and classification of data. The ordering consists of the transcription of interviews and the organization of empirical data in the research *corpus*. The classification of data involves a horizontal and exhaustive reading of the texts, followed by a transversal reading, the final analysis, and the production of a report[10].

In order to retain the anonymity of the participants who were interviewed, the researchers used a coding system based on each participant's bond with their elderly relative and the sequence of interviews. This study is research for a Master's dissertation, which was approved by the Committee of Ethics in Research at Santa Maria Federal University, under the Certificate of Presentation for Ethical Appreciation protocol #09996912.5.0000.5346 and Committee's Opinion #145.565, issued in November 2012, following the ethical precepts under Resolution #196/96 throughout the complete research process[11].

RESULTS

Regarding the participant families' characteristics, three lived in districts near to or even in the same district as their elderly relatives—in two of these families, the elderly relative lived with his/her spouse and the other lived by himself; four families lived in the same terrain as the elderly relative but in separated housing units; and one of the families lived with their elderly relative. The age of the participants varied between 14 and 83 years old. The degrees of kinship based on the elderly relatives were: eight sons/daughters; three nieces; three spouses; two granddaughters; two brothers/sisters-in-law; one son-in-law and one daughter-in-law; and one partner. Income ranged from one to seven minimum wages, and education levels ranged from the incomplete middle school level to a full undergraduate degree. The average period of care of the elderly relative receiving pre-dialysis treatment was 5.6 years.

In this study, families witnessed their elderly relatives' aging in terms of common physiological changes that occur during the process. These modifications can be amplified when an elderly person has a chronic-degenerative disease. Therefore, relatives must deal with the illness, which can be provoked by many causes, and it can be a cumulative process:

> We know that, as the years pass by, some illnesses occur. He is taking some drugs for the "shakiness." Once he went to change a light bulb and fell from the chair. And the other day he went to the hospital to have a cataract removed. I know he is depressed, this "thing in the kidneys" moved him. We did not expect that, but we get used to those events. One day I told him to take a walk; he fell and got hurt. After this thing in the kidneys he does not do things by himself anymore. (Wife 3)

> She receives treatment for her heart, her kidneys, she goes to the psychiatrist, and now maybe receives hemodialysis treatment, so everything is building up. (Husband 8)

> He is forgetful and he misses doctors' appointments. The ultrasound was to

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> be done on day two; he arrived here on day 10 and wanted to do the ultrasound. (Niece 7)

Regarding the elderly individuals' illness, the study observed the presence of multiple pathologies that can generate functional and cognitive limitations. As a consequence of these pathologies, the elderly individuals depend on relatives to perform regular daily life activities and for support in controlling co-morbidities. CRI places further demands on families who, besides dealing with the changes that occur in their elderly relatives that occur due to aging, also have to deal with the renal illness of their older family member. After identifying that the care needs of elderly relatives are cumulative, the families commented on the fear of the possibility of their elderly relatives' total dependency on them:

> Before he used to go [to the rural zone] to cut some grass, walk along the bushes, and go for walks by the river. Now, he does only a little of this and he is already tired. Mother used to help him shower. I think that, for him, to be this way—needing the help of a daughter—is not good because some things only a mother can do and he gets ashamed. (Daughter 3)

> We are worried because he was always an independent person. He used to do everything by himself. I am afraid one day he may fall from bed and he may not survive the injuries. (Son 4)

The participants demonstrated that elderly relatives' physical limitations require care. Based on this situation, the person who requires care lacks the ability to perform the most basic daily needs, such as bodily hygiene, and, to meet these needs, it is often necessary to invade the privacy of the elderly individual, generating discomfort for both the care receiver and the caregiver, who needs to overcome these limitations to provide care in the case the elder becomes more dependable. The concern of the caregivers is also related to the possibility that the elder feels invalidated by the illness.

The families also reported that the present health condition of their elderly relatives was a consequence of a series of long-term behavior patterns, which may mean that they are predisposed to emergency illnesses and any attendant complications:

> Mother used to self-medicate a lot. When she was in pain she used to go to the pharmacy to buy antibiotics because, back in the day, the people behind the counter did not ask for a prescription. (Son 5)

> A person who was drunk all day and all night is supposed to have some sort of suffering in this area—the kidneys and the liver—and maybe there is something related to the smoking too. (Brother-in-law 6)

> It is not something new; he did not take care of himself. His diabetes is because of his excesses. When he received the diagnosis, he took care of himself. Whenever his exams showed improvement he would throw a party, barbecue, and everything would return and until today he did not stop. He drinks beer once in a while. He is very stubborn about his diet; he eats what he wants but during the week I prepare food for him. What I do is remove fried food and reduce his salt intake. I take

> control; I force him to eat and I say "There is nothing else here, you have to eat this." (Partner 4)

Families did not know the origins of CRI but they associated the issue with the unhealthy attitudes and habits formed throughout their elderly relatives' lives. The families considered that these practices slowly harmed their relatives' bodies, thus leading to their present health status. The families were trying to be vigilant regarding the actions they considered a risk to the health of their elderly relatives, as such risks can escalate and damage those individuals' fragile health.

The possibility of dialysis is increased after a CRI diagnosis, even if the physicians have not indicated this procedure as part of the treatment. The families had built their own ideas about dialysis based on the testimonies of people who were already undergoing this treatment:

> I have a friend who is 61 and who has started the dialysis. I saw him and … my god! The person gets stiffed, it looks like he is hard as a stone. But it is like people say: "It will help him to survive." I see how dialysis is a beast! (Son-in-law 1).

> I know people undergoing dialysis. He [the elderly relative] also knows. There is one person we knew who was undergoing treatment and died. She had to drink little water, eat small portions, and take medication. Everything must be controlled and restricted! (Daughter 4)

> I said that maybe she would feel better doing dialysis. My boyfriend had to have dialysis once and he said he felt relief afterwards. So, I think she may feel better, in a better mood. He said that and she was calmer because people come to her and say: "Oh, so you will be going on dialysis? Poor you!" (Granddaughter 8)

The families' search for testimonies of positive or negative experiences of dialysis is a way to forecast both their own and their elderly relatives' futures and a method for thinking about the necessities of care that the next set of treatment will require.

Based on the illness that is affecting the elder relative at the moment, there are changes in the attributions for each family member in providing care. Family members had tried to develop the best procedure to maintain the satisfaction and well-being of their elderly relatives during the process of aging:

> If she wants me to not work anymore, so that I can stay at home, I'll do it for her to have some time to go to the gym. Or maybe another thing I can do to make her feel better is this: it will not work to take things way from her because if she has to die, she'll die. With my grandma, I took fatty food away from her diet and she used to get mad at me and in the end it did not work because she died anyway, so dietary restrictions made no difference. (Daughter 5)

> I get upset when she smokes and if it was up to me me she would not smoke any more. That's why she asks other people to buy her cigarettes and hides them from me. But my son, who is also a physician, asks me why I'm worried about seeing his grandmother smoking at the age of 85, if she is going

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> to die anyway. He usually says, "Would you prefer to see her die happy or unhappy?" (Daughter 1)

The families noted that they faced a dilemma when providing care for their elderly relatives. The dilemma was based on either the desire to have the elderly individual around, co--existing with all the limitations that pre-dialysis treatment imposes or the wish to not deprive the elderly relative of his/her will, taking into consideration issues such as quality of life, remaining time alive, and the inevitability of death.

Despite CRI being an irreversible state, the families looked for alternatives that can improve the renal functioning of the ill family member. In doing so, they believed they had a shared understanding with people in their social networks, which culturally influenced the health care practices they used with their elderly relatives:

> I learned all I could about diabetes and kidneys. When I learned something new, I went over to try it. A friend of mine taught me that when he fasts he has to drink a mix of pineapple and Coke shaken in the blender and he's been having that lately. (Wife 3)

> If you come and say to him: "Have this and you'll feel better," he will take it, it doesn't matter what you give him. (Son 4)

> He had an exam and it showed that his kidney was withered, and the doctor showed that it had to be removed. But between the exam and the operation he went through a spiritual surgery and afterwards it was not necessary to remove the kidney. I think we need to believe and do everything they tell me. (Daughter 3)

The family members demonstrated self--confidence in the information and practices they had learned, which some considered effective, as demonstrated by their elderly relatives' lab exam results. Another alternative used by the families was spiritual belief as a means to believe in a cure and confirm the cure.

Faith in the possibility of a cure through alternative therapies besides regular medication was presented as an option in the effort to improve the health of the elderly relatives undergoing pre-dialysis treatment.

DISCUSSION

Aging can reduce elderly individuals' functional capacity and can lead to the coexistence of chronic diseases, which in turn can lead to dependency or loss of autonomy[12]. Elderly individuals with more than one diagnosed chronic disease have a higher chance of being incapacitated and developing deficiencies as the pathologies develop[13]. Thus, considering that CRI is one of the illnesses that affect the elderly, it requires a more complex care procedure as this care must be complementary, not in opposition to, the treatment they receive for other existing diseases.

Chronic multi-morbidities of the elderly demand an organization of health systems due to the high costs of accumulated treatments and the need to plan long-term care procedures in order to minimize decreases in quality of life and social impact[14]. It has been noted that the present tendency is to have families care for their elderly but the responsibility to provide healthcare for the elderly also lies with the health services, which must support and follow up the demands of the elderly and their families. Within this perspective, education in health can be an important strategy to help families that

care for elderly relatives with multiple chronic co-morbidities[15] A educação em saúde permite que as pessoas realizem seu papel de maneira individual e coletiva na promoção e restauração da saúde, sendo que sua efetivação, por meio do ensino pelos profissionais de saúde deve envolver a família, a fim de incluir nos hábitos já pré-estabelecidos, comportamentos eficazes para manter saúde.

The families' testimonies revealed a preoccupation with their elderly relatives' inability to perform their regular everyday routines, which is a sign of a fear of future physical dependency and concern about the reduction of self-esteem due to health conditions. Faced with the possibility of supporting their relatives in basic care, such as bodily hygiene, family members reflected upon the possibility of their elderly relatives feeling embarrassed when undressed, thus leading to a discomfort for both patient and carer. This is inevitable based on the perspective of a total state of dependency. In this sense, one study[16] mentioned that, to perform bodily hygiene care and other similar procedures, the family member develops abilities in line with an increase in the relative's need for care and creates strategies to deal with the situation to make it less uncomfortable.

The presence of a chronic disease made the families question how their elderly relatives had developed the pathology, associating the present condition of illness with their relatives' unhealthy habits throughout their life; these habits, however, may not be the cause of the disease. Hence, the families have tried to impose some care, aiming to reestablish the well-being of the elderly relatives, which somehow works to protect the elderly relatives' health condition.

The diagnosis of renal disease in the elderly is complex and can be made too late due to the fact that physicians consider a reduced renal filtration rate normal for elderly individuals. The diagnosis can also be made prematurely by labeling the elderly as sick, causing unnecessary worry[17].

Pre-dialysis treatment includes the preparation of the elderly individual and his/her family for the start of dialysis when it is required to prolong the patient's life. Facing this possibility, the families noted that they had tried to find information from people who were already undergoing hemodialysis because this is the treatment the ill most often require when there is a need for substitutive renal therapy. The disease and renal treatment change several life habits, such as food and drink intake, sexual relations, and work. The disease and treatment also decrease patients' cognitive, emotional, and functional performance[18]. At the same time, a CRI diagnosis and the need for dialysis treatment can generate physic and physical suffering for the patients undergoing the procedure and the harsh modifications in everyday life affect the elderly individuals who have to undergo hemodialysis daily and experience the possibility of death[19].

Against this, the families noted that they feared that their elderly relatives must initiate this type of treatment, as they consider hemodialysis an aggressive treatment that is associated with a higher mortality rate. The dependency on a machine and health professionals who work in the renal service, in addition to the large amount of medication required, creates a phenotype of fragility for the patients undergoing dialysis. This is a multidimensional construction that contributes to a functional decline in proportion to patients' age, increasing the risk of hospitalization, disability, and death[18]. When the elderly undergo dialysis, the image is even more fragile, generating a feeling of commiseration by others, which can be a demotivating factor for the elderly patients receiving treatment for CRI.

The families highlighted that they felt they

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were caught in a conflict: whether to assist their relative during pre-dialysis treatment, which implies limitations in the leisure activities of the relative, or fulfill their relative's wishes during this stage of their life. This conflict was observed in this study via the control of appropriate diet elements and the control of smoking habits, both considered necessary measures for effective pre-dialysis treatment[6]. In this case, it is the nursing professionals who are responsible for discussing care and they must respect the decisions of the family unit and the elderly patient.

The testimonies of the families demonstrated a search for resources to improve the health conditions of elderly relatives, such as spirituality and popular remedies, which can be seen as a way of dealing with elderly relatives' illness and to help use faith in improving the health of their family members. These resources include common sense knowledge and spiritual beliefs, together with medical treatment, and they indicate that sociocultural practices are complementary to the therapeutic practices used by the families. It was demonstrated that these practices cannot be ignored by health professionals[20].

It is important to mention that these resources have been used with the intention of improving the clinical state of elderly relatives; there is no scientifically proven effectiveness. However, the search for a solution can be interpreted as a mobilization of the family unit toward the confrontation of their relative's illness, keeping the family active and propositional.

Based on the evidence, it is important to consider the alternative actions taken by the families as potentiating their relationships and that they use these actions as a way to continue to build a sense of belief in the improvement and stabilization of their relatives' renal disease. In order to respect culture, people's understanding, and technical-scientific knowledge, it is necessary to continue a dialog with the elderly and their families regarding the care being provided, and it is necessary to remain aware of the application of different types of knowledge[15].

Nurses must observe the care practices of family members and intervene if a procedure might harm the health of an elderly patient. Therefore, education in health performed by these professionals is a relevant strategy in the effort to obtain positive results within the process of care provided by the families of elderly relatives undergoing pre-dialysis treatment.

CONCLUSION

The perceptions of the families regarding the care provided to their elderly relatives undergoing pre-dialysis treatment showed that this procedure is complex. This is because the family unit must deal with the changes related to aging and other co-morbidities as well as the changes imposed by the treatment.

Despite the demands of care placed on the relatives, these family members had a positive view about their provision of care for their elderly relatives, and they tried hard in their search for further information about dialysis and they planned ahead for how they would deal with the situation.

The families were also worried about the issue of happiness, the quality of care their elderly relatives received, and their relatives' satisfaction with their life during treatment. The family is responsible to filter the desires of the elder, allowing him/her to fulfill or not some of them. Then, the nurse's role is to respect each family's opinions, as the family is the main care unit of elderly patients. isso representa a união e movimento da família e amigos em prol do mesmo objetivo.

Love and a desire to see their relatives in better health has made families search for resources and information about the treatment, using common sense strategies and finding in spiritual faith support for dealing with their relatives' diagnosis of CRI. Even if actions commonly considered therapeutic do not improve the health status of elderly relatives, it is the nurse's role to respect the sociocultural practices of the family, as these performances represent their agreement with each another and movement toward improving the health of their elderly relative.

Based on the findings, health professionals should pay close attention to the family unit during the pre-dialysis treatment of elderly patients. It is important to offer support to families in order to help them care for their elderly relatives, to stop the progression of CRI, and to maintain the autonomy of elderly patients in pre-dialysis as much as possible.

The performance of this study using a qualitative approach has allowed us to understand the subjective experiences of families that live with elderly relatives with CRI; however, this procedure limits the generalization of the research, as each family implements a unique way of providing care.

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Participation of the authors of the research:

Elaboration of the research project, research performance, and development of report and research articles: Caren da Silva Jacobi

Tutoring and participation in the design of research project, research performance, and development of report and research articles: Margrid Beuter, Nara Marilene Oliveira Girardon-Perlini.

Participation in the elaboration of the research article: Arlete Maria Brentanno Timm, Jamile Laís Bruinsma, Claudelí Mistura.

All authors participated in the phases of this publication in one or more of the following steps, in According to the recommendations of the International Committee of Medical Journal Editors (ICMJE, 2013): (a) substantial involvement in the planning or preparation of the manuscript or in the collection, analysis or interpretation of data; (b) preparation of the manuscript or conducting critical revision of intellectual content; (c) approval of the versión submitted of this manuscript. All authors declare for the appropriate purposes that the responsibilities related to all aspects of the manuscript submitted to OBJN are yours. They ensure that issues related to the accuracy or integrity of any part of the article were properly investigated and resolved. Therefore, they exempt the OBJN of any participation whatsoever in any imbroglios concerning the content under consideration. All authors declare that they have no conflict of interest of financial or personal nature concerning this manuscript which may influence the writing and/or interpretation of the findings. This statement has been digitally signed by all authors as recommended by the ICMJE, whose model is available in http://www.objnursing.uff.br/normas/DUDE_eng_13-06-2013.pdf

Received: 12/20/2015
Revised: 09/18/2016
Approved: 09/20/2016