CHRONIC RENAL INSUFFICIENCY: AN INTEGRATIVE REVIEW ON STUDIES WITH A QUALITATIVE APPROACH

INSUFICIÊNCIA RENAL CRÔNICA: UMA REVISÃO INTEGRATIVA ACERCA DOS ESTUDOS COM ABORDAGEM QUALITATIVA

INSUFICIENCIA RENAL CRÓNICA: UNA REVISIÓN INTEGRATIVA ACERCA DE LOS ESTUDIOS CON ABORDAJE CUALITATIVO

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ABSTRACT

Objective: to know the scientific production of studies with a qualitative approach on chronic renal failure. **Method:** integrative review, carried out in the electronic databases BDeF, LILACS and PubMed / MEDLINE, using the keywords "Renal Insufficiency" and "Qualitative Research". After the thematic analysis, the data were grouped and categorized. **Results:** the analysis of the 27 studies allowed us to discuss topics such as: Chronic renal failure - between diagnosis and treatment decision; The contextualization of care in chronic renal failure; The description of the relationship between health team, person with chronic renal failure and his family; The support network in the context of chronic renal failure. **Conclusion:** the studies allowed to know the approach of the experiences and the perspectives of the people in different stages of the renal failure in the therapeutic modalities. **Descriptors:** Health Care (Public Health); Nursing; Qualitative Research; Renal Insufficiency, Chronic; Health Services.

RESUMO

Objetivo: conhecer a produção científica de estudos com abordagem qualitativa sobre a insuficiência renal crônica. **Método:** revisão integrativa, realizada nas bases de dados eletrônicas BDeF, LILACS e PubMed/MEDLINE, utilizando-se as palavras-chave "Insuficiência Renal" e "Pesquisa Qualitativa". Após a análise temática, os dados foram agrupados e categorizados. **Resultados:** a análise dos 27 estudos permitiu discutir temas como: A insuficiência renal crônica - entre o diagnóstico e a decisão de tratamento; A contextualização do cuidado na insuficiência renal crônica; A descrição da relação entre a equipe de saúde, a pessoa com insuficiência renal crônica e sua família; A rede de apoio no contexto da insuficiência renal crônica. **Conclusão:** os estudos permitiram conhecer a abordagem das experiências e as perspectivas das pessoas em diferentes estágios da insuficiência renal nas modalidades terapêuticas. **Descritores:** Atenção à Saúde; Enfermagem; Pesquisa Qualitativa; Insuficiência Renal Crônica; Serviços de Saúde.

RESUMEN

Objetivo: conocer la producción científica de estudios con abordaje cualitativo sobre la insuficiencia renal crónica. **Método:** revisión integrativa, realizada en las bases de datos electrónicas BDeF, LILACS y PubMed / MEDLINE, utilizando las palabras clave "Insuficiencia Renal" y "Investigación Cualitativa". Después del análisis temático, los datos fueron agrupados y categorizados. **Resultados:** el análisis de los 27 estudios permitió discutir temas como: La insuficiencia renal crónica - entre el diagnóstico y la decisión de tratamiento; La contextualización del cuidado en la insuficiencia renal crónica; La descripción de la relación entre la equipo de salud, la persona con la insuficiencia renal crónica y su familia; La red de apoyo en el contexto de la insuficiencia renal crónica. **Conclusión:** los estudios permitieron conocer el abordaje de las experiencias y las perspectivas de las personas en diferentes etapas de la insuficiencia renal en las modalidades terapéuticas. **Descriptores:** Atención a la Salud; Enfermería; Investigación Cualitativa; Insuficiencia Renal Crónica; Servicios de Salud.

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INTRODUCTION

Chronic renal failure (CRF) affects approximately 13% of the adult population and is associated with high morbidity and mortality rates, as well as causing social and economic losses,¹ however, it remains underdiagnosed by health professionals, especially, in the early stages, when it can be asymptomatic, and its evolution to advanced stages implies loss of quality of life and an increased risk of early death.² Therefore, CRF has been the object of studies, in order to identify the negative outcomes related to this morbidity.

Data from the literature point out some key elements related to barriers in the treatment of CRF. Firstly, the lack of knowledge of the diagnostic criteria, in its initial stages, by general practitioners. Second, the difficulty of referral to the nephrologist. Thirdly, inadequate management of chronic renal failure, patients due to lack of access to health services and the inability of professionals to use the tools of care management for chronic health conditions.³

Early detection of CRF is still a flawed feature in most health services, including, in developed countries. Renal insufficiency is defined by the presence of alterations in the structure or functions of the kidneys, with or without alteration of glomerular filtration, for a period greater than three months. The annual screening for creatinine and microalbuminuria, capable of diagnosing CRF, is indicated for the risk groups represented by hypertensive, diabetic, elderly and people with a history of cardiovascular disease.¹

As a result of late specialist care, people with CRF face increased risk of mortality. Among the risks of mortality are polypharmacy, inadequate management of bone mineral disease, malnutrition, complications related to the use of temporary vascular access, longer hospitalization, reduced access to preemptive renal transplantation and, consequently, increased costs with health services.⁴

In addition to the above, there is still a gap regarding the attention to the effectiveness of the actions to the CRF, in addition to persisting misunderstandings about the perception of the actors involved in the topic. In this context, when considering that the qualitative surveys, in general, evaluate the life experiences of the people.

OBJECTIVE

- To know the scientific production of studies, with a qualitative approach, on chronic renal failure.

METHOD

Integrative review, in which, for its development, the following steps were followed: 1^a) Identification of the theme and selection of the research question; 2) Establishment of inclusion and exclusion criteria; 3^a) Identification of pre-selected and selected studies; 4^a) Categorization of selected studies; 5) Analysis and interpretation of results; and 6) Presentation of results.⁵

The study was conducted from June to July 2016, in the electronic databases: Medical Literature Analysis and Retrieval System Online (PubMed / MEDLINE); Latin American and Caribbean Literature in Health Sciences (LILACS); and Nursing Database (BDEnf). The search in the LILACS databases was performed using the advanced form, whereas, in PubMed / MEDLINE, "Mesh" was used as a research resource.

We looked for qualitative studies that addressed the issue of "health care for people with chronic renal failure" and answered the research question: "What is the health care for the person with chronic renal failure?". The keywords were "Renal Insufficiency"; "Renal Insufficiency"; "Renal insufficiency"; "Qualitative research"; "Qualitative Research"; "Qualitative Research"; connected by the Boolean operator and.

Regarding the establishment of criteria for inclusion and exclusion of studies, the following were included: primary studies with qualitative and qualitative methodologies published in the period from 2011 to 2015, due to the need to know the results of the current literature and are available in full in English, Spanish or Portuguese and that answered the question of research. Summaries of communication in congresses, news and letters to the editor were excluded.

Data collection was done by five reviewers. An own instrument was developed, including the following information: authors, year of publication, outline, levels of evidence, population and main results.

The search, conducted in PubMed / MEDLINE, initially, generated 82 articles. After using the search filters, language, publication period (2011 to 2015) and reading the titles and abstracts, following the

inclusion and exclusion criteria, 20 articles were pre-selected for the analysis in full.

In the LILACS database, the initial search generated 19 articles. After reading the titles and abstracts, four studies were selected. The BDEnf database generated 43 articles. Of these, 24 were pre-selected, based on the inclusion and exclusion criteria described above and, after reading the titles and abstracts, three articles were selected for the analysis in full.

In total, 27 studies of the three electronic databases consulted and classified based on the levels of evidence recommended in the literature, ie: Level 1 - meta-analysis of multiple controlled studies; Level 2 -

individual study with experimental design; Level 3 - study with quasi-experimental design, as study without randomization with single group pre and post-test, time series or case-control; Level 4 - study with non-experimental design as descriptive correlational and qualitative research or case studies; Level 5 - report of cases or data obtained in a systematic, verifiable quality or program evaluation data; Level 6 - evidence derived from a single descriptive or qualitative study; Level 7 - opinion of reputable authorities based on clinical competence or opinion of expert committees, including interpretations of non-research based information.⁶

Figure 1. Articles included in the integrative review. Pelotas (RS), Brazil, 2016.

RESULTS AND DISCUSSION

The analysis of the 27 studies pointed out that the majority of researches, with a qualitative approach, on CRF care were carried out by researchers from Departments and / or Nursing Schools (33.3%).⁷⁻¹⁵ Of these, the highest number produced was in Brazil (18.5%).⁷⁻¹¹ Regarding the level of evidence, the studies were classified in level six.

Prevalence of studies performed by Primary Care and Public Health teams¹⁶⁻¹⁹ (14.8%), Medicine and Nephrology²⁰⁻²³ (18.5%), Palliative Care and Psychiatry²⁴⁻²⁶ (11.1%) also prevailed. and Geriatrics²⁷⁻²⁸ (7.4%). Two studies did not present the area of the researchers²⁹⁻³⁰ (7.4%), and the others (3.7%) represented the areas of Rural Health and Clinical Social Medicine, Occupational and Environmental Dermatology.³¹⁻³²

For the countries of the scientific journals, where the studies were published, the majority were from the United Kingdom (37.0%), being: BioMed Central Health Services Research^{12-13,16} (11,1%); Social Science and Medicine 18,24 (7.4%); Health²⁵, Child: Care Health And Development²⁶, Palliative Medicine¹⁴, BioMedical Journal Open³¹ and Peritoneal Dialysis International²⁹ (3.7%).

The scientific journals of Brazil, that had published studies (25.9%), were: Nursing Journal of UERJ⁷⁻⁸ (7 PubMed / MEDLINE 4%); Nursing Network Magazine of the Northeast^{9,11} (7.4%); Revista de Enfermagem da UFSM¹⁰, Physis: Revista de Saúde Coletiva¹⁹ and Revista Bioética³⁰ (3.7%).

The scientific journals of the United States, in which the studies were published (14.8%), were: Clinical Journal of the American Society of Nephrology²²⁻²³ (7.4%); Journal of Palliative Medicine²⁷ and Chronic Illness¹⁷ (3.7%).

Studies published in scientific journals in other countries were Ghana Medical Journal³³ (in Africa), Canadian Family Physician²⁰ (in Canada), Acta Derm Venereo³² (in Germany) and Asian Nursing Research¹⁵ (in Taiwan). All of them had a publication (3.7%).

Regarding the language used for the publication of the studies, it was observed that the majority used English^{12-17,20-29,31-33} (74,0%) and Portuguese^{7-11,19,30} (25,9%). In addition, it was verified that most of the studies dated from the years 2015 and 2014.^{13-19,21-26,28-32} Both the years 2015 and 2014 represented 33.3% of the total, followed by the years 2013^{9-12,20,27} (22, 2%) and 2012^{7-8,33} (11.1%). In 2011, no published studies on the topic were published.

The majority of the studies aimed to understand the experiences and / or perspectives of people with CRF (55.5%)^{7,9-10,15,17-18,24,26-33} Of these, 14.8%^{9-10,18, 33} patients were asked to be diagnosed, pre-dialytic or in conservative treatment, 14.8%^{24,26,28,31} with dialysis patients and 7.4%²⁷⁻²⁸ patients undergoing palliative and renal transplantation.

Other studies investigated the experiences and perceptions of the social support network of people with CRF (22.2%).^{8,11-14,25} Of these, 14.8%^{8,11,13,25} of the studies were performed with the caregivers or relatives of people with CRF and 7.4%^{12,14} with the health team.

Among the objectives of the studies, we also searched for specific systems, strategies or treatment tools (18.5%).^{16,21-23,26} In addition to addressing CRF prevention interventions and discussing CRF in children (7, 4%).^{12,14}

With respect to the sample, the published studies included the participation of several groups of people with different age groups and of both genders, thus, they constituted: people with CRF and relatives or caregivers^{19,23}; health workers and family members or caregivers^{12,27}; professionals and people with CRF.³⁰

Other studies developed the research in specific population, being carried out with: African-American^{21,28} and Aboriginal^{20,31}, with 7.4%; elderly people²⁴, youth⁷, caregivers²⁵, family¹¹, children¹³, health staff¹⁴, people on hemodialysis³² and people with CRF with encapsulated peritoneal sclerosis²⁹, all represented by 3.7%.

Regarding the methodological approach, 85.1% were qualitative studies.^{7-8,11,13-21,23-33} Of these, 55.5% explained the type of design, being 3.7%³³ ethnographic; 7.4 %^{15,23} data-based theory, 11.1%,^{7,24,29} phenomenological and 33.3%^{8-11,14,16,20} descriptive and / or exploratory studies. The other studies (14.9%)^{9-10,12,22} were mixed (quantitative-qualitative).

After outlining the profile of the selected studies, the results allowed the development of categorization of the following themes: Chronic renal failure - between diagnosis and treatment decision; The contextualization of care in chronic renal failure; The description of the relationship between health team, person with chronic renal failure and his family; The support network in the context of chronic renal failure.

♦ Chronic renal failure - between diagnosis and treatment decision

CRF, sometimes, manifests itself insidiously, remaining asymptomatic for long periods. For this reason, when diagnosed in its

initial phase, the health team demands, the correct clarification of the consequences and different treatment modalities. In this sense, it was observed in the analyzed studies, that the disclosure of the diagnosis is not always effective and depends on factors related to the person's profile, because the more participant in their self-care, the greater the chance of receiving information about their health situation.¹⁸

The lack of information regarding CRF and its outcomes was an aspect evidenced in most of the studies. In some cases, it has been observed the minimization of the consequences of the renal failure by the team, which implies a low adherence to the treatment by the person. In addition to the selective disclosure of the diagnosis, the lack of sharing of decisions about the different treatment modalities and the use of technical and prescriptive language of the professionals are factors identified as barriers to understanding about self-care.^{18,33}

As with other chronic diseases, the diagnosis of CRF often refers to the feeling of "slow death," and for this reason may bring some of the feelings recognized as stages of grief, namely: denial, anger, bargaining, depression and acceptance.⁷ The diagnosis of CRF in younger individuals often causes "shock" and depression.¹⁶

Also, the studies pointed out that young individuals are more likely to undergo dialysis, in addition to the possibility of kidney transplantation. The elderly, however, face CRF as a natural aspect of aging and prefer conservative treatment in order to preserve quality of life, since dialysis is seen as causing disabling symptoms.²⁴

Regarding the conservative treatment of CRF, this may reduce the progression of the disease and postpone the initiation of Renal Replacement Therapy (RRT), increasing the quality of life through the preservation of clinical, psychological and social conditions. In some cases, the progression of CRF leads people on conservative treatment to fear hemodialysis.²⁵⁻²⁶ Still, even in more advanced stages of the disease, conservative treatment may be seen as an alternative to dialysis, considered less aggressive and a continuity of the care received in primary care.²⁵ The family or caregiver, on the other hand, presents opposing feelings as a hope in the effective control of illness and anxiety when trying to predict when renal function will decrease and cause death.⁸

Peritoneal dialysis was identified, among the studies analyzed, as a treatment that requires specific technical skills. However, it

generates concern on the part of people with the CRF and family or caregivers, resulting in losses in the personal, social and economic spheres, related to changes of habits and management of the time with possibility of loss of the labor productivity.¹¹

Considering the above, it can be said that the diagnosis phase of CRF represents a critical moment for the person, the family or the caregiver, and even for the health team. The feelings experienced are diverse and professionals must be alert to situations that may lead to withdrawal from treatment.

The studies analyzed presented a lack of knowledge regarding the causes of CRF, the types of treatment, the consequences of the evolution of the disease and the necessary care to minimize disabling symptoms. Besides ignorance, it was found that decisions about treatment are rarely shared by the team with the person and the family or caregiver. These notes have important implications for the work of nurses who can act as educators and facilitators throughout the process of diagnosis and treatment experienced by the person and his / her relatives or caregivers.

♦ The contextualization of care in chronic renal failure

Those who live the CRF are in palliative care, because the literature points out that palliative care is directed at the comfort of people who have some chronic illness, such as renal failure, regardless of the termination process. Thus, palliative care is not limited only to promoting improvement in the quality of life of the person with cancer, since its purpose is to provide a dignified coexistence with the disease.³⁴ Despite these findings, it was observed, in the studies, that the term palliative care was viewed as negative by health care providers as it plunges as the end of life.

Another of the issues highlighted in the studies analyzed was the care process to be performed in the CRI, being related to health and treatment. Thus, one of the issues debated was that care needs to be individualized, since each person experiences illness in a unique way, besides being standardized by health professionals. In this context, it was pointed out the existence of a complex care, since it involves actions related to the daily habits (diet, social activities), often associated to the accomplishment of procedures in the home as part of the treatment, in which difficulties understanding of the technique to be performed (care of the arteriovenous fistula, care of peritoneal dialysis at home). Or even, as also mentioned,

a lack of financial resources, in which difficulties can occur to modify the diet due to the need to buy specific foods or the acquisition of medicines of continuous use that are not available by the public network.

Because CRF involves complexity in the execution of care, it is critical that comprehensive care be given to people, as the discovery of the disease generates a number of uncertainties and changes in life, making the routine abruptly changed. In this way, the professional's performance becomes relevant, from basic care to guidelines on the changes that have occurred, in order to improve the quality of life.³⁵ Thus, the intervention needs to be extended to the families or caregivers involved in the process of illness, either by the change and adaptation to the new reality of the entity or by the care itself and family dynamics, that is changed after the installation of renal failure.³⁶

Furthermore, the studies pointed out the importance of multidisciplinary teams in health education, which people with the CRF and their families or caregivers receive guidelines for care, often coming from explanatory leaflets. In addition, some studies analyzed the need for health education groups to receive information from the onset of renal failure.

Health education is one of the main vehicles for the prevention of chronic noncommunicable diseases, since it allows the access of information to a considerable number of lay people. Moreover, its execution contributes, significantly, to the clarification of doubts and to the transmission of knowledge about the different modes of treatment, of controlling the progression of renal failure and its risk factors, such as obesity, hypertension and diabetes.³⁷ Promoting health education from primary care and referral for evaluation to a specialized nephrology service, still at an early stage of CRF, is an effective measure since it enables pre-dialysis education and implementation of actions preventative measures that slow or stop disease progression.³⁸

In contrast, the studies analyzed also demonstrated the occurrence of the person's knowledge deficit with CRF on the disease and on the treatment. Also, mention was made of the delay in diagnosis or the lack of information associated with the necessary procedure / treatment and the risks of CRF, which end up hindering the care actions to be performed and / or followed.

When renal insufficiency is progressing to chronicity, underdiagnosis and inadequate treatment can lead to complication, since its

terminal phase implies a drop in the quality of life, with risk of death. In this context, early diagnosis in primary care, established in the early stages, of the disease, allows the adoption of preventive measures (changes in lifestyle, diet, physical activity, adherence to treatment), facilitates diagnosis, disease staging and the referral to the nephrologist. These steps are essential for the care of people who are in the risk group for CRF.³⁸

♦ The description of the relationship between health team, person with chronic renal insufficiency and family

The relationship between the multidisciplinary team, people with CRF and families or caregivers is described, in the literature by the different aspects that make up the interpersonal relationship. Thus, in the attention to the person with CRF, some factors are considered essential, among them, the appreciation of cultural aspects and the use of simple language by professionals.³¹ However, in the absence of these factors, adherence to treatment may be considered insufficient by the person with the CRF, because he does not receive, nephrologists answers, that answer his doubts.²⁸

For professionals, attention to the person with CRF occurs without differentiation of treatment, regardless of health history. For others, care is individualized and the relationship between professionals and people is a process of learning exchange.^{27,39} Thus, it is the responsibility of health professionals to seek strategies to work according to the reality of each person and family or caregiver.¹¹

In the relationship between the multidisciplinary team and the person with the CRF, the actors face barriers that prevent the achievement of the objectives. Among them, there is the deficient knowledge of the professionals, responsible for making the treatment a challenge, to cause the delay of the diagnosis, making the search for this a long and sinuous path.^{27,29,33}

Another obstacle is the lack of knowledge of people with CRF about the disease and the need to make treatment decisions. Such evidence is due to problems of communication between professionals and patients.^{17,29} This fact triggers negative feelings at the beginning of treatment and may lead people with CRF to misunderstand the need for treatment, but generates acceptance as "work of destiny", and the treatment imposed, a form of survival.^{15,26}

In the analyzed studies, in which people with CRF had the opportunity to talk and to

know the modalities of renal substitutive treatment, participating in the decision making, they did so because they had doctors who explained the available options.²² Thus, it is evident that the professional and personal relationship with the CRF influences the planning of the assistance and, consequently, the adaptation, the maintenance of the treatment and the achievement of the objectives.

Also, the studies highlighted some successful initiatives, such as the performance of a nurse in the community, where such intervention was able to reduce morbidity in people at risk of developing CRF.²⁰ Another way was to promote educational activities with the sharing of information between family members and staff, conveying safety in relation to treatment for the person with CRI, since knowledge is collectively constructed.¹²

Given the complexity experienced, it was observed, in the studies analyzed, a recommendation for the health team to assist the person with CRF and their relatives or caregivers in the process of adaptation and restructuring after diagnosis.⁸ In this sense, there may be an opportunity for the involvement of the triad team, person and family or caregiver in care planning.

♦ The support network in the context of chronic renal failure

Considering the studies analyzed, it was observed the importance of support networks for people with CRF and their families or caregivers, since the support received since diagnosis influences the whole process of living with a chronic disease.²⁵ It was also noted the comprehensiveness of the emotional, psychological and practical aspects of this experience.²⁶

The formal support network formed by the renal replacement therapy service was pointed out in some studies, highlighting the lack of understanding, on the part of the professionals responsible for dialysis, in addition to a non-effective communication,^{23,26} this factor is responsible for compromising the performance of the care and success in treatment for CRF.

In this context, the formal support network can be strengthened in groups led by nephrologist physicians, but with the presence of the entire team to conduct conversations and clarifications, starting soon after diagnosis and remaining routine during the course of CRF treatment. In this way, person-centered care planning can be done, which would lead to improvements in care.²³ It was also observed, in a study, that people refer to

the need for the presence of professionals from the interdisciplinary team to provide them with general support.²⁷

The informal support network, according to the studies analyzed, was formed by family and religion. Family support was seen as fundamental and, often a determining factor in the lives of people with CRI, as it helps and motivates them to move forward in the face of the most difficult changes in their lives.^{17,26,28,31}

As analyzed, in a study, the family often does not understand the changes in routine caused by CRF, however, it remains with the person.²⁸ And at this moment in which the family is, it is fundamental that there is professional support for the reorganization of your routine.⁴⁰

Still, it was found in the studies that spiritual support can be considered an important source of hope, being found in faith.^{17,28} Another interesting question was the use of spiritual support by young people during the confirmation of the diagnosis of CRF, and this disease was considered supernatural, since both these individuals and their relatives or caregivers did not believe that there was a physiological cause for the development of renal failure.³³

Spiritual belief becomes necessary for people who experience CRI as they seek hope and strength to maintain quality of life. However, receiving the diagnosis can be, represented as a divine punishment. Thus, substitutive renal therapy services, need effective communication between individuals, families or caregivers so that health professionals recognize the spiritual needs.

CONCLUSION

It was observed that studies with a qualitative approach on CRF were performed mainly by nurses, focusing, preferentially, on the experiences and perspectives of people in different stages of the disease and on the treatment modalities. The articles were published, mostly, in medical journals in the English language, and a large portion described studies conducted in the United Kingdom, with a descriptive and exploratory methodological approach.

In all studies, CRF was evidenced as an emerging public health problem. Thus, the issue ceased to be only a problem for health services, in terms of the costs and demands that it represents, and began to be the object of research in order to improve the care offered.

The general picture about the studies about the attention to CRF showed the need to know the person's vision regarding their illness, in order to better share treatment decisions, support network and health professionals. This will enable the development of person-centered care tools, which may increase adherence to treatment and, consequently, improve clinical outcomes.

It can be considered that the studies analyzed in this integrative review present a current and relevant theme for the health area, with aspects that may contribute to the understanding of the attention given to people with renal insufficiency and the way in which they experience the therapy during the course of the illness. However, the limitations found for the search of scientific productions on the subject was the lack of access to all the publications in the established period, for not being available in full.

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