CARE, DISEASE AND HEALTH: SOCIAL REPRESENTATIONS AMONG PEOPLE ON DIALYSIS TREATMENT

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ABSTRACT

Objectives: to analyze and compare the representational structure of health care and illness among people undergoing dialysis.

Method: qualitative research guided by the Theory of Social Representations in its structural approach, with 165 participants, including adults, of both sexes undergoing hemodialysis and peritoneal dialysis in four nephrology services in Curitiba and its surrounding region. The data were collected between June 2014 and May 2015, through free evocations of the terms “disease care” and “health care” and treated through the Ensemble de Programmes Pemettant L’Analyse des Evoctions software and four quadrants analysis.

Results: the results show that the representations of health care and disease share disease content, but it has a distinct organization, health with the focus of life habits and biomedical dimension, and the disease emphasizes the evaluative aspect.

Conclusions: the representations of health care and disease interact with behaviors, attitudes and positions of care and provide elements to understand and support individual resources and adjustment of the disease.


CUIDADO, DOENÇA E SAÚDE: REPRESENTAÇÕES SOCIAIS ENTRE PESSOAS EM TRATAMENTO DIALÍTICO

RESUMO

Objetivo: analisar e comparar a estrutura representacional do cuidado com saúde e a doença entre pessoas em tratamento dialítico.

Método: pesquisa qualitativa norteada na Teoria das Representações Sociais em sua abordagem estrutural, com 165 participantes, adultos, de ambos os sexos e tratamentos de hemodiálise e dialise peritoneal de quatro serviços de nefrologia em Curitiba e região. Os dados foram coletados entre junho de 2014 e maio de 2015, por meio das evocações livres aos termos indutores “cuidado com a doença” e “cuidado com a saúde” e tratados pelo software Ensemble de Programmes Pemettant L’Analyse des Evoctions e análise do quadro de quatro quadrantes.

Resultados: os resultados revelam que as representações de cuidado com a saúde e a doença compartilham conteúdo da doença, mas possuem organização distinta, a saúde com o enfoque dos hábitos de vida e dimensão biomédica e a doença ressalta o aspecto avaliativo.

Conclusão: as representações de cuidado com a saúde e a doença interagem com comportamentos, atitudes e posicionamentos para o cuidado e fornece elementos para compreensão e apoio dos recursos individuais e ajustes da doença.

CUIDADO, ENFERMEDAD Y SALUD: REPRESENTACIONES SOCIALES ENTRE PERSONAS EN EL TRATAMIENTO DIALÍTICO

RESUMEN

Objetivo: analizar y comparar la estructura representativa del cuidado con la salud y la enfermedad entre las personas con tratamiento dialítico.

Método: investigación cualitativa fundamentada en la Teoría de las Representaciones Sociales, en su abordaje estructural, con 165 participantes adultos de ambos sexos y tratamientos de hemodiálisis y diálisis peritoneal de cuatro servicios de nefrología, en Curitiba y región. Los datos fueron obtenidos entre Junio del 2014 y Mayo del 2015 por medio de las evocaciones libres a los términos inductores “cuidado con la enfermedad” y “cuidado con la salud”, tratados por el software Ensemble de Programmes Penettant L’Analyse des Evocations y el análisis del cuadro de cuatro cuadrantes.

Resultados: los resultados revelan que las representaciones del cuidado con la salud y la enfermedad comparten el contenido de la enfermedad, pero poseen una organización distinta, la salud con el enfoque de los hábitos de vida y la dimensión biomédica, y la enfermedad resalta el aspecto evaluador.

Conclusión: las representaciones del cuidado con la salud y la enfermedad interactúan con comportamientos, actitudes y posicionamientos para el cuidado, y además, proveen los elementos para comprensión y apoyo de los recursos individuales y ajustes de la enfermedad.


INTRODUCTION

The treatment of chronic kidney disease (CKD) is a challenge for the person who is at an advanced stage, they require adherence to dialysis and rigorous therapeutic plans in order to stay alive. This therapeutic strategy imposes a series of behavioral changes on the person, one of the biggest stressors to the person is the adaptation of their lifestyle to the treatment. Consistent with the therapeutic task, care entails concerns, requires daily coping, and produces manifesto knowledge in the form of an active set, based on beliefs and representations.1,2

Throughout the years, the representations of health and disease have been constructed according to society’s ways of being, expressed in the different cultures and forms of organization, and depend on the understanding of the being and the interrelationships with its environment. These, in addition to interacting with behaviors, compose a dynamic that manifests itself with the production of knowledge and shapes definitions for care with health and disease.3 As social objects, health and renal disease are the essential elements for the formation of representations. Renal disease, previously unknown, becomes part of the health concern, which can be thought of and which should be acted on and implemented.

Representations of health and care can be seen in different ways, pronounced as impairment, conditioned to medical and tranquil care when associated with the adoption of healthy habits.4 The dimension of choice and adherence to healthy lifestyles relates to the person and directly influences their cognitive and emotional response to their disease and behavior in order to deal with it.5 It is emphasized that the perception of the disease focuses on emotional (awareness of the disease, understanding of it and emotions generated) and cognitive aspects (identity, consequences of illness, personal control and treatment efficacy).6

Among the positive and beneficial approaches associated with caring for kidney disease, support from family and friends is considered to be a precursor in adapting to the disease and is a source of optimism, positivity and quality of life.7 The person’s knowledge of illness, trust, and social support are factors that strengthen care and promote disease management.8

In the therapeutic relationship, shared understanding of the disease and treatment beliefs are significant to people so that they can be active participants and involved in health and disease care. Thus, this discussion consists of the opportunity to broaden and improve care based on a person’s needs and to consolidate knowledge to mitigate the burden of chronic kidney disease. In addition, subjectivities and representations provide the accumulation of knowledge of the person, which includes attitudes to promote health.5 The psychological and physical stress experienced by the person with CKD encompasses the disease, the fear of doing the hemodialysis treatment, dietary restriction, liquids, the ability to travel, among others, in addition to individual needs.9

The specific needs of the CKD group are still an issue which need to be considered in health and disease care because they provide a space for the person’s representations to be retrieved and discussed. Thus, representations of health care and illness are presented not only as a form of communication and access to the world of the person with CKD, but also are essential because they help to face
the reality of the disease. They allow the person to understand and maintain control of the care in the face of adversity which is essential in their daily life. In view of such considerations, the objectives of this research was to analyze and compare the representational structure of care with health and illness among people undergoing dialysis treatment.

**METHOD**

This study had a qualitative approach, based on the Social Representation Theory (SRT). This allows to recover common sense knowledge in order to contemplate attitudes, positioning and construct new perspectives on care. The SRT is a “system of preconceptions, images and values that has cultural significance and persists independent of individual experiences”.

More specifically, the structural approach or Central Core Theory of Social Representations was used. This theory considers that the organization of representation around the central nucleus deals with cognitive contents. And this “central system is linked to norms and values, cultural, and ideological conditions and defines the homogeneity of the group.”

Around the “central system, the peripheral, more flexible and less limiting, with a functional character, constitutes the essential content of the representations.”

The research was conducted in four nephrology services in the city of Curitiba-PR and metropolitan region, which were intentionally selected due to the ease of access to a population of different social strata and for being part of the network of services considered as reference in this specialty.

Participants included people with CKD on hemodialysis and peritoneal dialysis. Including adult participants of both sexes, aged between 24 and 59, with more than six months of dialysis therapy, in a regular treatment program in four nephrology services, located in Curitiba and metropolitan region. Exclusion criteria were people with restricted oral communication, cognitive problems, hearing problems, and who were hospitalized at the time of interview or were post-transplant patients.

The sample consisted of 165 participants, which was obtained by convenience, according to the presence of the participants at the treatment site on the day scheduled for data collection, indicated by the health professionals, and selected according to established criteria (Figure 1).

Data collection was carried out by the first author between June 2014 and May 2015. A questionnaire was applied consisting of sociodemographic variables as well as free word evocations. This collection technique allows to highlight the semantic universe of the studied object. The terms “health care” and “disease care” were used as inductors and people with CKD were asked to say five words or expression, in the order of in which they appeared in the minds of the participants.

The collection was performed by appointment, in the premises of the nephrology services,
individually, in a reserved place before and after the treatment, and after identification the participants the data were recorded in writing in the instrument. The identification consisted in assigning an ordinal number to each participant in ascending order of application of the instrument.

The analyzed data with the help of the Free Evocation of Words Technique, ensured the elaboration of the four-frame houses, through the 2005 version of the Ensemble Permettant L’Analyse des Evocations (EVOC) software, seeking to identify the structuring of representational contents.\(^{13}\) The product of the evocations was previously organized, resulting in a corpus for analysis. The analysis technique consisted in the construction of a four-frame houses in which the evoked words are distributed, according to the criterion of higher frequencies and mean order of evocations (OME).\(^{14}\)

The four-frame houses corresponds to four quadrants with four sets of terms. In the upper left quadrant, the terms that are truly meaningful for the participants are located and are probably the central nucleus of the representation studied. The terms located in the upper right and lower right quadrant are repetitively the first and second periphery, and those located in the lower left quadrant constitute contrast elements.\(^{13}\)

Due to the stimulus used in the production of data, people with CKD linked several words to health and illness, spontaneously consubstantiating a semantic world for the object. In order to understand the semantic world, it was necessary to group the words used by the participants and, thus, to understand the meaning used by them.

Therefore, we chose to identify the meaning of the words in relation to the object, we used the polarization of the terms evoked in negative and positive aspects for care. This classification refers to the dimension of attitudes in social representations, or rather, the positioning assumed before the object, favorable or unfavorable, and defined as positive aspects for care with those who oppose the disease, such as medical supervision, the practice of physical activity, among others. Just as the negative elements consist of restrictive actions necessary to care for the disease, such as dialysis, medication, among others.

The study observed the ethical and legal requirements present in Resolution n. 466/2012, of the National Health Council. The research project was submitted and approved by the Ethics and Research Committee (CEP), under Certificate of Presentation for Ethical Assessment (CAAE) number 26511414.9.0000.0102 (Opinion No. 655.501/2014). Due to the need to expand the collection fields for the peritoneal dialysis group, the project was approved once again by the CEP (Opinion no. 1,015,044 and CAAE 26511414.9.0000.0102), maintaining the confidentiality and anonymity of the participants who signed the Term of Informed Consent. There were no conflicts of interest in the conduct of this research.

RESULTS

From the total number of people with CKD on dialysis, one hundred (60.60%) were on hemodialysis and 65 (39.39%) were on peritoneal dialysis, there was an emphasis in the age group of 41 and 59 years among dialysis patients using both treatments (111 participants - 67.27%) and with female predominance (86 participants - 52.12%). Regarding the time of diagnosis of the disease, there was a predominance of the period of over five years in 88 (53.33%) participants and, in terms of time in treatment, the majority had been in treatment for between six months and five years (104 participants - 63.03%).

The analysis of the structure of representations of care with health and disease among people with CKD in dialysis treatment, from the evocations produced, exposes the presented and discussed results comparing the inductive terms according to the location of the elements in the respective quadrants. The analysis of the evocations produced resulted in the four-frame houses presented in Tables 1 and 2. In these tables, six dimensions corresponding to the terms “disease care” and “health care” are found. They are: evaluative, life habits, biomedical, affective, social and well-being.

The evaluative dimension is related to the judgment to achieve health and how essential and necessary it is to control the disease (controlled diet, correct medication, blood pressure control, correct diet/nutrition, treatment, fluid control). The life habits dimension can be interpreted as a behavior that favors health or is dependent on it, expressed by the terms diet, physical exercise, physical activity and hygiene.

The biomedical dimension manifests the terms related to the health-disease process in its biological professional base (medication, medical follow-up and treatment). The affective dimension refers to the nature of the bonds, of the emotions favorable to the health and the support during the illness and care (family support). The social dimension is constituted by terms that relate to the functionality of the person associated with the practical issues for which
being healthy is necessary (working). The concept of well-being portrays the broad concept of health, considering the states and the daily disposition associated with care and quality of life (tranquility/calmness, life, rest, and well-being).

For the term “disease care”, 824 words were evoked, of which 196 were different. The minimum defined frequency was 13, with the words with a lower frequency being excluded from the composition of the four quadrant table. The average calculated frequency of the remaining terms was 29. The average order of evocations (OME) was 3.0, on a scale of 1 to 5. The realization of the necessary calculations was elaborated by the software itself, and was based on Zipf’s Law. The four quadrants table was constructed from the previously defined parameters (Table 1).

In relation to the term “health care”, 826 words were evoked, among which 178 were different. The minimum frequency set was 11, with the words with lower frequency being excluded. The mean calculated frequency of the remaining terms was 23. The average order of evocations (AOE) was also 3.0 and the calculations follow the same parameters for the construction of Table 2.

Table 1 - Analysis of the evocations of the term “disease care” among people with CKD in dialysis treatment of nephrology services. Curitiba-PR, 2015

<table>
<thead>
<tr>
<th>AOE*</th>
<th>&lt;3</th>
<th>≥3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Freq† Med</td>
<td>Term evoked</td>
<td>Freq†</td>
</tr>
<tr>
<td>³ 29</td>
<td>Nutrition/Diet</td>
<td>81</td>
</tr>
<tr>
<td></td>
<td>Fluid Control</td>
<td>55</td>
</tr>
<tr>
<td></td>
<td>Dialysis</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Hygiene</td>
<td>31</td>
</tr>
<tr>
<td>&lt; 29</td>
<td>Care</td>
<td>27</td>
</tr>
<tr>
<td></td>
<td>Salt Control</td>
<td>19</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

*OME: average order of evocations; †Freq: total frequency of the term evoked.

Table 2 - Analysis of the evocations of the term “health care” inducer among people with CKD in dialysis treatment in nephrology services. Curitiba-PR, 2015

<table>
<thead>
<tr>
<th>AOE*</th>
<th>&lt;3</th>
<th>≥3</th>
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</thead>
<tbody>
<tr>
<td>Freq† Med</td>
<td>Term evoked</td>
<td>Freq†</td>
</tr>
<tr>
<td>≥ 23</td>
<td>Nutrition/Diet</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>Physical exercise</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Medical Monitoring</td>
<td>27</td>
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<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 23</td>
<td>Periodic examinations</td>
<td>21</td>
</tr>
<tr>
<td></td>
<td>Correct Medication</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>Care</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Correct Diet</td>
<td>14</td>
</tr>
</tbody>
</table>
**DISCUSSION**

The analysis of the evocations of both inducing terms, “disease care” and “health care”, reveals similarity in the contents of the central nucleus associated with life habits, proving that food is essential and is confirmed as an element that gives value to the representation of health care and disease. The central core has three functions: generator, organizer and stabilizer, respectively producing the meaning, internal organization and stability of representation. Thus, the term *nutrition* has a generating function, which also gives meaning to the organizing function, unifies and stabilizes the representation.

Nutrition is an object of care representation for the person with CKD, which is deployed in different approaches: as a necessity associated with health care and as a control linked to care with the disease. This is because the basic components of a representation were identified: the formulation of knowledge about the object and a favorable or unfavorable group positioning (attitude).

Health care implies the adoption of essential positions to silence the organs and avoid harmful events, aimed at nutrition, physical exercise and the maintenance of medical treatment, and disease care means to suppress the clamor of the organs, allied to a broad representational field composed of a set of diversified terms to designate “disease care” revealing a representation with elements of strong evaluative dimension, such as fluid control, controlled nutrition, blood pressure and salt control, biomedical dimension, dialysis, medication and transplantation.

Dietary intervention in CKD has a broad character and, in addition, dialysis requires specific guidelines to optimize nutritional conditions. Its importance in health care includes preventive measures, since the high body mass index (BMI) is a risk factor for CKD and can be modified through adequate diet. Among people with kidney disease, nutrition is associated with perceptions of health and disease with a focus on the centrality of diet over the functioning of body and mind.

The emphasis of the evaluative aspect in CKD care shows that this practice in people with end-stage renal disease is linked to the constraints in managing salt, liquid and food limitation in order to prevent complications that consist of stressors of the disease and which require regulated behavior. A study on the link between stressors and renal dietary adherence reveals that the restriction to a given food is associated with better knowledge regarding the food and complications related to it. This same study shows that people with high perceived control are more adherent to fluid control. Consequently, the evaluative aspect promotes care related to the disease.

The central organization of the representation of disease care shows that the notions of life habits (hygiene) and biomedical dimension contents (dialysis) emphasize the meanings of the disease and the treatment. Hygiene goes beyond a measure of health surveillance, it forms a knowledge that structures and transforms the person with CKD, because new ways of thinking, feeling and acting are introduced at home in order to manage the disease. This knowledge allows the care and maintenance of their condition of life and health. This is due to the consensus among people with CKD that peritonitis or infection of the peritoneal wall due to contamination due to breakage of technique can lead to failure of the therapeutic modality, hospitalization and death, and results in fear, anguish and guilt.

This central organization is reinforced in the peripheral elements of disease care with biomedical lexical dialysis, medication and transplantation that indicate aspects that demand a position necessary to maintain disease control. These elements require adherence, incur suffering, and depend on personal beliefs. People’s beliefs regarding the use of prescribed specific medication are related to the necessity of the drug for current and future health maintenance and concerns regarding their potential adverse events.
Dialysis therapy causes high stress on the person due to the extensive drug regimen and the dialysis schedule. Thus, the evoked terms dialysis, transplantation and medication have a negative connotation regarding the representation of disease care, since they are elements that produce concerns, limitations, and which modify the routine and lifestyle of the person prior to treatment.

The central structure of the representation of health care maintains the meaning around the life habits, and highlights indispensable elements such as nutrition and physical exercise in the central contents of the representation and reveals positive attitudinal focus on the part of the participants, as well as reinforcing the inference that there is an effort of the same in evaluating the need for the person to position himself to have health. Medical supervision linked to the biomedical dimension highlights the importance of supervision as a health care measure. These aspects evidenced that health care is based on what is imperative for the person linked to the maintenance of physical needs as a factor of health protection with benefits to reduce risks and damages.

The peripheral organization of the health care representation mixes expressions of the disease associated with life habits such as hygiene and physical activity, evaluative contents such as controlled diet and fluid control, as well as the biomedical dimension with the evocation of the medication. With the exception of physical activity, the other contents emphasize care related to dialysis treatment such as hygienic measures and health/disease warnings.

The analysis of the proximal peripheral elements in both terms induces the sharing of lexical biomedical dimension, medication, and evaluative, controlled diet. In relation to the disease care, these negative meanings reinforce the elements of the central nucleus. In health care, this notion is broadened by lexical fluid control. While still referring to health care, the addition of the terms physical activity and hygiene associated with the lifestyle dimension proposes a set of attitudes to preserve health.

The distant periphery reveals the sharing of the evaluative element associated to the blood pressure control lexical in both inductor terms, which highlights the negative element of the disease linked to health care. It is noted in the disease care, that the presence of these elements in the content of biomedical dimension (transplantation), besides confirming the organization of the central nucleus, accentuates the negativity of the care representation.

There are positive traits linked to care in both terms, in the distant periphery, with the term family support. These findings corroborate aspects described in a study on social representation in CKD that indicates the affinity of care and the overlapping psycho-affective and social relationships in the experience, and confirms a consistent association between emotional support from friends and relatives and informative assistance from health professionals and the management of the physical and psychological burden in peritoneal dialysis.

In relation to the contrast zone, the contents of health care and illness show a sharing of the term care that marks a subsidy and forms an essential response to the disease. The contrast element of the representation of care with disease signals salt control and accentuates the definition of the evaluative component in the representation from the central elements and is directly linked to the burden of the disease. People with CKD have strict salt restriction which aims to decrease the compulsion to drink liquids, maintain blood pressure control, and decrease weight gain between treatment sessions.

The health content contrast zone presents a variety of terms of biomedical notion (periodic examinations, correct medication, treatment) and evaluative notion (make the treatment), which portray specific aspects related to health care, characterizing the priority of the therapy. They reveal the contents of the disease merged within health.

It is important to note that the distant peripheral elements, linked to the disease-bearing object, mark the defense of the central core, unlike the distant periphery of the health-care object, which presents elements with a regulatory role, or rather, the new elements of social dimension and well-being. The latter have an essential role in adapting representation to the evolutions of the context and can be both integrated and conflicted with the foundations of representation.

Likewise, representations defined by the same content and with different organization are observed, which is similar to Abric’s approach, which states that “the organization of content is essential and simple identification of content is not enough for its recognition and specification”. At the first periphery, the “buffer” function of the representation is identified and possesses the defense function. Thus, health and disease objects show prevalence of elements linked to the contents of the disease.

In view of the detail of the organization of the social thought of the participants, it is possible to
point out that, in the midst of developing their own position on health care, people with CKD use affective, social and well-being elements. These evoked terms remind us that care for health and illness is to maintain life satisfaction and good mental health.

Health care shows the social dimension of work and the elements of well-being, tranquility, life with expression and domains associated with functionality and quality of life. These expressions indicate that the positioning of people with CKD is based on elements that promote quality of life and which favor care. The definition of quality of life approaches perceptions, values, cultural context and is related to its objectives, concerns, expectations and standards. Quality of life related to health has become an indicator of health and well-being for people with CKD.

Health care has a strong correlation in the maintenance of the pattern of activities that interfere with social, satisfaction and well-being. The social dimension of work, besides being associated with the need for survival, provides pleasure and satisfaction. The association of work with leisure, besides promoting well-being, influences the expansion of the social network.

The evocation ‘work’ does not appear to be related to disease care in this research. This is probably due to the relationship between the complexity of CKD and the mental health component, which encompasses vitality, emotional aspects and has a significant impact on the person’s life, since the decrease in the willingness to work forms one of the domains with negative correlation with quality of life.

Another expressive representational dimension in this research was the affective one. Participants seem to favor health and disease care, qualifying it by verbalizing the term family support. The presence of affective elements produces a positive effect, which helps the person with CKD to cope with the disease and manage emotions. Maintaining the bonds, when present, promotes resistance to achieve adherence to care, as it reduces the burden of disease and treatment.

The term care, present in the contrast zone of evocations of health care and illness, is less frequent, but considered of great importance to the participants and supports the representation present in the other quadrants. It focuses on the perception of care as essential for health as a kidney patient. Positive feelings of warmth and attention are attached to care.

The delay in the closure of the data collection in the peritoneal dialysis group, is considered a limitation to this study as well as having a limited number of adults in the modality, there was a low frequency of people scheduled for routine appointments.

CONCLUSIONS

The thinking of people with CKD in relation to the representational object health care brings together a diversity of terms that allowed the adoption of positions that are largely favorable to care. On the other hand, the representation of disease care demanded positions, most of which were unfavorable to care, because they incur the submission, rules and limitations resulting from the context of the disease and the treatment.

The group of participants presented a representational structure coined in the dimension elements of life habits, and highlights the role attributed to nutrition in health and disease care. Nutrition, represented as essential to care and for maintaining good health, is an integral and fundamental part of treatment in order to prevent the progression of CKD. The unfolding of this life habit, considered the basis for health is also represented as a source of restrictions, therefore negative, and conforms terms of the evaluative dimension which are part of the treatment.

It is also worth noting a representation that reproduces the affective dimension tied to relationships, ties and family support. This term presents a symbolic approximation with care, present in the contrast zone. The term support denotes positive social interaction for health and disease care, which is related to sharing, availability, and contributes to the reduction of treatment stressors with a strong impact on emotional and personal adjustment.

Among the implications for practice, knowledge of the social thinking of the person with CKD on health and disease care provided a basis for understanding and supporting individual resources and adjustments in the disease. Thus, a renal care program that takes into account social representations may allow nurses and health care professionals to explore the expression through the language of the person’s symptoms, thoughts of possible causes, and the course of the disease. This could provide an opportunity to address uncertainties, concerns, misunderstandings and non-adaptive beliefs.

Representations of care with the health and disease and cognitions of people with kidney disease are considered to be important determinants for renal care as they interact with behavior, attitudes, and care positions, with implications for future research and clinical practice.


