

Stigma perceived by men on hemodialysis

Estigma percebido por homens em tratamento hemodialítico

Estigma percibido por hombres en tratamiento hemodialítico

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Abstract

Objective: To analyze the experience of stigma in narratives about the chronic illness of men on hemodialysis.

Method: Qualitative study conducted with 24 men in a Hemodialysis Unit in a city located in the Northeast region of Brazil. Data were extracted with in-depth individual interviews, which were analyzed according to the Discourse of the Collective Subject and interpreted under the light of stigma theory.

Results: The narratives indicate the marks of the disease, when men are placed at odds with their own bodies and perceive themselves as different. The results show components of stigma such as discredit, loss of status, estrangement and labeling. The men also perceive the consequences of stigmatization, adopt self-preservation measures and emphasize the importance of the care received from nurses to face this reality.

Conclusion: Stigma creates barriers to socialization, access to health and social security and affects body image, adaptation and coping with chronic illness.

Resumo

Objetivo: Analisar a experiência do estigma em narrativas sobre o adoecimento crônico de homens em tratamento hemodialítico.

Métodos: Estudo qualitativo desenvolvido com 24 homens em Unidade de Hemodiálise em cidade localizada na região nordeste do Brasil. Os dados foram extraídos de entrevistas individuais em profundidade, submetidas à análise metodológica do Discurso do Sujeito Coletivo e interpretados à luz da teoria do estigma.

Resultados: As narrativas indicam as marcas da doença, quando estranham o próprio corpo e se percebem diferentes. Evidencia componentes do estigma a exemplo do descrédito, perda do status, afastamento e aplicação de rótulos. Também percebem as consequências da estigmatização, adotam medidas de autopreservação e ressaltam a importância do cuidado recebido de enfermeiras para seu enfrentamento.

Conclusão: A estigmatização cria barreiras para a sociabilidade, acesso a bens e serviços de saúde e seguridade social, e repercute sobre a imagem corporal, adaptação e enfrentamento do adoecimento crônico.

Resumen

Objetivo: Analizar la experiencia del estigma en narrativas sobre la dolencia crónica de hombres en tratamiento hemodialítico.

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Conflicts of interest: none to declare.

Métodos: Estudio cualitativo desarrollado con 24 hombres en Unidad de Hemodiálisis en una ciudad ubicada en la región nordeste de Brasil. Los datos se obtuvieron mediante entrevistas individuales en profundidad, sometidas al análisis metodológico del Discurso del Sujeto Colectivo e interpretados a la luz de la teoría del estigma.

Resultados: Las narrativas indican las marcas de la enfermedad, al extrañar el propio cuerpo y se perciben distintos. Evidencia componentes del estigma como ejemplo del descrédito, pérdida del estatus, alejamiento y atribución de clasificaciones. De la misma forma perciben las consecuencias de la estigmatización, adoptan medidas de autopreservación y destacan la importancia del cuidado recibido de las enfermeras para el enfrentamiento.

Conclusión: La estigmatización crea barreras para la sociabilidad, acceso a bienes y servicios de salud y seguridad social y tiene y repercute sobre la imagen corporal, adaptación y enfrentamiento de la enfermedad crónica.

Introduction

As it is an insidious disease that progressively attacks several systems, Chronic Kidney Disease (CKD) can cause significant organic disorders and require therapeutic measures that change one's appearance and abilities.⁽¹⁾ These changes modify how individuals perceive themselves and are perceived by others, how they respond to social roles, and how they interact in everyday relationships.⁽²⁾

Both the disease and its treatment have financial effects that bring an additional burden for families, for the health system and for the social security system.⁽³⁾ For men, chronic disease tends to change their role as provider, as the disease and its treatment make them depend on care, reduce their autonomy and their freedom.⁽⁴⁾

All these changes modify the image of men and stimulate the circulation of representations⁽⁵⁾ associated with the experience of the stigmatized subject, on which we intend to focus in this article. Stigma is considered a derogatory view that disqualifies subjects, classifying them as deviant.^(6,7)

Stigma goes beyond criticism of the individual and discourteous treatment, as it includes blame, labeling, stereotypes, discredit, estrangement, loss of status, discrimination and social exclusion.⁽⁶⁻⁸⁾ It can reach the stigmatized person through family members and even through health professionals who provide them with care.⁽⁹⁾ The consequences include lower adherence to care, psychological and emotional illness and breakage of bonds, which affect the quality of life.⁽⁸⁻¹¹⁾ In this sense, understanding the experience of stigma among chronically ill patients is one of the prerequisites for the development of plans for its prevention and coping.

Thus, this study was based on the following guiding question: is there an expression of stigma

perceived in the narratives of men with CKD on hemodialysis? In order to answer this question, this study aimed to analyze the experience of stigma in narratives about the chronic illness of men on hemodialysis.

Method

Qualitative study carried out in 2018 and 2019 with male patients of the Unified Health System (SUS), who were receiving hemodialysis treatment in an institute of urology and nephrology, located in a large city in Bahia, Brazil.

The inclusion criteria were: having a medical diagnosis of CKD at an advanced stage and being on hemodialysis treatment. The exclusion criteria were: men who were not in stable health conditions, with altered level of consciousness, as well as men experiencing pain, emotional and psychological changes and/or discomfort at the time of data collection.

The data collection instrument consisted of broad questions about the concepts presented in Erving Goffman's Theory of Stigma,⁽⁶⁾ expanded in the work of Link and Phelan.⁽⁷⁾

Data collection was carried out through an in-depth individual interview, guided by an instrument previously developed and validated with a research group in the field of men's health, with questions that addressed the experience of illness and the hemodialysis treatment. The understanding of the stigma was obtained through the guiding question: how has the fact of being a chronic kidney patient on hemodialysis marked your life? According to the speeches, other questions emerged: How did these changes affect your health? How did you react to these experiences?

Which coping strategies have you developed to adapt to the situation?

The questions were answered orally by the participants, based on the mediation of the researcher who took the interviews, which were carried out after previous appointment. The interviews occurred right before or after hemodialysis sessions, individually, in a space provided by the hemodialysis unit, with an average duration of 45 minutes. The answers were recorded in an MP4 player, and were later fully transcribed, preserving the interviewees' speeches. The empirical material collected was organized and systematized with the support of the NVIVO Software version 11, which made it possible to create theoretical nodes/codes, categories and subcategories of discourse analysis.

Considering the large sample size, it was decided to end the interviews based on theoretical exhaustion, which occurred when 24 participants responded to the questions and the findings became repetitive, in addition to line-by-line reading in the search for common points, convergences and complementarities.⁽¹²⁾ Thus, this number of participants made it possible to understand the object and identify common themes, which allowed reaching the objective of the study. It is important to highlight that the team that collected the data had expertise and training in the area but did not have a close relationship with the institution or with the participants.

Data analysis was guided by the Discourse of the Collective Subject (DCS) method, which is a method for the construction of a collective thinking, aiming at revealing people's thoughts, attributing meanings and expressing positions regarding a given phenomenon.⁽¹³⁾

Added to this method, the data were analyzed based on current references and on Erving Goffman's Theory of Stigma, which understands stigma as situations or ways in which individuals are completely misunderstood in society, being disapproved of, rejected or dismissed by other groups. This phenomenon occurs due to the set of attributes that allow individuals to be included in a group and not in others, according to three identities: social, personal and ego identity.

The research was approved by the Research Ethics Committee, under opinion number: CAAE: 49022315.1.0000.5654, and no.1.278,407, in compliance with Resolution 466/2012 of the National Health Council.

Results

The study participants were between 41 and 59 years old, self-identified as brown, were married, had incomplete primary education, lived on an urban area and were predominantly Catholic. Most did not have an occupation, were retired and received government benefits.

The participants were on hemodialysis treatment for an average of 3 to 15 years, and all of them used an arteriovenous fistula. To have access to the hemodialysis unit, most resorted to public transportation or to the company of family members, especially their children. They had previous comorbidities, with emphasis on Arterial Hypertension and Diabetes *Mellitus*.

Furthermore, summarizing the results of the narratives, Chart 1 represents the categorical structure of the stigma perceived by men undergoing hemodialysis treatment.

Discourse synthesis 1: Perception of disease marks

The discourse synthesis 01 illustrates the perceptions of men undergoing hemodialysis treatment about the marks that become apparent on their bodies, due to the changes caused by the disease and by the therapeutic processes/procedures. The perception of these changes, which include aspects such as shape and color, consistency of skin and hair and presence of care devices such as catheters and fistulas, place them at odds with their own image.

Central Ideia 1A: The imposition of the marks of the disease - men find their own bodies odd and perceive themselves as different

"[...] I began to find my body odd, mainly because I used a catheter that was hanging around my neck, after all, my body changed after hemo-

Chart 1. Categorical structure of the stigma perceived by men undergoing hemodialysis treatment

Components of stigma	Family and friends	Work	Healthcare units	Reactions to cope with perceived stigma
Labels	Incapable Useless Uninterested Reckless Lazy	Sick Disabled Lazy	Guilty for being sick Stubborn Reckless	<ul style="list-style-type: none"> · Reflect on isolation and loneliness · Adopt measures to preserve their image · Try to hide fistulas and catheters with their clothes · Avoid talking about the problem · Avoid contact so as not to answer questions · Isolate at home · Try to think optimistically · Search for information on the internet · Resort to religiosity/spirituality · Accept support from nursing professionals
Stereotype	Problematic	Weak Sick	Reckless Sloppy	
Discredit	Discrediting the narratives of fatigue	Discrediting the narratives of suffering	Discrediting the narratives of fatigue and indisposition	
Estrangement	(Us) capable, hardworking (Them) incapable and lazy	(Us) capable and hardworking (Them) weak and lazy	(Us) normal, professional (Them) patients, sick	
Loss of status/ discrimination	Exclusion from decision-making Broken bonds Lack of support Abandonment	Contempt of colleagues Exclusion from activities Job loss	Delayed care Discourteous treatment Service by less qualified professionals	

dialysis. I got thinner, my face and body were darker, I stopped urinating and even the smell of sweat was different. In addition to bugging me and being uncomfortable, the catheter attracted the attention of people, who started to look at me differently. Then came the fistula and the situation only got worse. I really wanted to give up”. (DCS of men).

Discourse synthesis 2: Perception of stigma

In discourse synthesis 02, men describe how the components of the stigma experience are expressed in their daily lives, indicating the continuous disqualification that comes from the subjects with whom they interact, the perception of people's estrangement, loss of affective bonds and verbal violence.

Central Idea 2A: Discredit and loss of status - men perceive disqualification and devaluation

“[...] after I started hemodialysis, I began to experience many difficulties due to discrimination. The barriers started at work. People didn't understand and looked at me differently and I ended up being fired [...] at work they fired me, because they thought that after the disease and hemodialysis, I would no longer be able to do the job [...] they treated me with contempt, they stopped counting on me for not believing in my ability. [...] I experienced several situations of discrimination by people in public transport from home to the hemodialysis service. Coworkers also acted with prejudice”. (DCS of men).

Central idea 2B: Estrangement - men perceive the estrangement of close people

“[...] many people turned away from me. I started getting different treatment, even from family members. I was practically friendless. Work colleagues abandoned me. I felt very alone”. (DCS of men).

Central idea 2C: Labeling - men get derogatory nicknames

“[...] because of the disease, I went through embarrassing situations, such as being called weak, useless, incapable, lazy, the man with the hose in his neck and the lumps in his arms. People do not understand the disease, they talk with no knowledge, and those who already knew me would treat me as if I were the disease, always talking about hemodialysis and my health situation”. (DCS of men).

Discourse synthesis 3: Reaction to stigmatization

In discourse synthesis 03, men talk about how they feel and how they react to stigmatization, with emphasis on psychological and emotional distress, changes in sleep patterns, rejection at work, and isolation. They illustrate how they try to protect their deteriorated image and highlight how nursing professionals contribute to avoiding stigmatization.

Central idea 3A: Assessing the consequences of prejudice - men perceive the effects of stigma

“[...] not only because of the disease, but because of all the discrimination and prejudice that I've

been going through, I have to face many barriers and difficulties. As I lost my job, everything became more difficult. I started having difficulties to get to the hemodialysis service, to find another job that would accept me with my situation, and also to keep up with the expenses of the treatment and of the house. I feel humiliated for not being able to support my family. [...] I even thought about ending life. I lost my appetite, I was alone, I had difficulty to sleep at night and all of this has affected my mind". (DCS of men).

Central idea 3B: Coping mechanisms - men adopt self-preservation measures

"[...] it is not easy to experience the disease and people's prejudice, but I have been trying to overcome that. Sometimes, I had to hide from people to avoid comments about me. I've been trying to be strong and to avoid thinking about giving up. I try to think about living [...] I cling to God [...] I try to get information with professionals about myself, my health, my treatment, the use of medication, so that I can be more informed and confident to deal with the problems and situations of discrimination that I dislike". (DCS of men).

Central idea 3C: Receiving support from healthcare professionals - nurses contribute to combat stigma

"[...] since I arrived at the hemodialysis service, I was very well treated by the nurses and by the social worker. They talk to me a lot; they support me and explain everything so that I have no doubts about the treatment and about what can happen to my health. In addition to teaching me everything about the disease, the catheter, the fistula and care, they also helped me to deal with people's prejudice and discrimination, to accept myself and to learn to live with the disease and the fistula". (DCS of men).

Discussion

The men that participated in this study revealed the impact of the stigma arising from the hemodi-

alysis treatment, whether due to physical marks or to self-devaluation, which reflect on the way they understand their self-esteem. Thus, stigma is seen as a decisive aspect in the social construction of the disease that these men carry in their daily lives. A phenomenological study points out that the marks on the body from the treatment make people feel insecure and timorous. Their body embarrasses them in such a way that it prevents them from establishing relationships with others. The disease becomes evident in all its magnitude, as it transforms the body into an instrument that makes it appear with all its intensity, consolidating its presence in the person's life.⁽¹⁴⁾

Thus, the emotional aspects of men on dialysis cannot be disregarded, as, during treatment, symptoms appear progressively and become limiting factors for activities of daily living.⁽¹⁵⁾

The diagnosis of CKD and the evolution of the treatment affects the different areas of the life of individuals, causing changes in their physical, psychological, affective, family and social conditions and putting them in a situation of vulnerability that requires support networks to cope with the disease and its stigmatizing effect.^(14,16)

The evidence found in the men's speeches reveal the impact of the marks of the disease in their daily lives, the discredit and loss of social status, the estrangement of people, labeling, and the consequent reaction to stigma. The literature points out that the social experience of individuals with CKD is marked by stigmas that arise from the changes in body image, which affect the perception of these bodies that do not meet aesthetic standards.^(15,17-19)

Consequently, the analysis of the social impact of the CKD marks on the lives of men showed that they felt at odds with their own body due to the changes in their body image and had feelings of discomfort due to social judgment. These findings corroborate those of a study that assessed 30 adults undergoing hemodialysis in a clinic in Rio de Janeiro and found that the experience of using a fistula leaves marks on the body, which change its appearance and make it imperfect. Such changes cause low self-esteem and draw the attention of

others, embarrassing those whose body is marked. Thus, they react by camouflaging the fistula, without which there is no life.⁽²⁰⁾ Other studies present similar results.^(21,22)

The perceptions of stigma of men on hemodialysis demonstrated that this population experiences discredit and loss of social status, and face several barriers, including discrimination and prejudice in the workplace. In line with this issue, a study with individuals in a hemodialysis center in Teresina-PI showed that people with CKD were distressed about the loss of work function due to the treatment, as they needed to leave their obligations in the job everyday, which caused companies to see them as a cost and suspend or even fire them from their jobs, forcing them to seek retirement.⁽²³⁾

Regarding the perception of stigmatizing situations, men report the estrangement of people in their daily lives due to CKD and explain the suffering of abandonment and loneliness and the different treatment they receive from family members. Therefore, the new reality imposed on individuals on hemodialysis makes them experience moments of intense stress, fear regarding the treatment, distress due to the abandonment of family and friends, social isolation, deprivation of leisure and weaknesses in health literacy.^(16,23)

It is worth noting that these labels set men apart from the hegemonic standards of masculinity imposed by society and cause a loss of a social power based on the model of the male provider of the family. This affects their mental health and quality of life.

The social repercussions led to the emotional fragility of individuals with CKD, along with loss of autonomy and independence, feelings of distress, disgust for life, sadness, and even depression and suicide attempts.^(23,24)

Aiming to reduce or eliminate the source of judgments and discrimination, men take self-preservation measures, such as isolating themselves and hiding the fistula/catheter, in an attempt to avoid exposure to stigmatizing situations. In addition, they resort to other types of coping measures, such as social support from

health professionals and religiosity/spirituality.⁽¹⁵⁾ Religiosity/spirituality favors adaptation, reduces the burden of the disease and improves mental health.⁽²⁵⁾ A study on quality of life after kidney transplant showed that individuals who nourished their religiosity/spirituality through daily practice had higher scores on vitality and physical aspects.⁽²⁶⁾ On the other hand, a study with Men who have Sex with Other Men (MSM) and live with HIV/AIDS, who already face stigma related to gender, sex and disease, found that, in spite of religiosity being a protective factor against stigma and expanding quality of life, those who attended religious spaces more often were more stigmatized.⁽²⁷⁾ Thus, for religiosity/spirituality to allow transcendence, increased resilience, reduction of stress and psychological and social well-being for chronically ill men it must consider the intersectionality of stigma with other forms of marginalization and the different ways of being a man.⁽²⁸⁾

Any discussion that addresses men and their experiences in the health-disease process leads to inevitable reflections on the gender perspective and the implications of these relationships on health, illness and care.⁽²⁹⁾ Furthermore, masculinity is understood as a configuration of gender practices,^(30,31) based on which the male identity is structured and men's attitudes, behaviors, perceptions, emotions are constructed. And, above all, it expresses a set of behaviors, values and attributes that are socially and culturally associated with men.⁽³²⁾

A limitation of this study is the fact that the data collection was carried out in the health institution, which may have limited the understanding and deepening of the phenomenon due to the possibility of censorship imposed by the institutionalized setting.

Conclusion

The experience of stigma of men with chronic illness undergoing hemodialysis is evidenced by the marks of the disease and the treatment, which make them perceive themselves as different and experience prejudice in their daily lives. These

marks bring out the components of stigma, such as discredit, loss of status, estrangement and labeling. In this context, men perceive the consequences of stigmatization in the barriers to access services, public transportation and social security, as well as in the loss of work function and employability, the impact on family's livelihood and the experience of humiliation, which affect their mental health.

Collaborations

Capistrano RL, Sousa AR, Araújo IFM, Almeida ES, Menezes HF, Silva RA, Silva RAR and Carvalho ESS declare that they contributed to the study design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

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