

ORIGINAL RESEARCH ARTICLE

Stigma in maintenance hemodialysis patients: A cross-sectional study

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Abstract

This study aimed to explore stigma and its predictors among patients undergoing maintenance hemodialysis. We utilized corresponding scales to measure both stigma and quality of life, and examining their correlations. Clinical and laboratory data were obtained through self-reported scales and medical records, screening for possible predictors associated with stigma. We recruited 115 patients in this study, with an average age of 52.14 ± 11.84 years. The level of stigma indicated correlations with all modules of the SF-36 scale. Specifically, bodily pain, general health, vitality, social functioning, role-emotional, and mental health modules had significant relationships with stigma ($P < 0.05$). Internalized stigma was significantly related to uremic pruritus and the duration of hemodialysis ($P < 0.05$). Enacted stigma revealed a significant relationship with uremic pruritus, the Beck Depression Inventory score, and the Beck Anxiety Inventory score ($P < 0.05$). Overall, stigma appears to exert negative impacts on the quality of life of patients undergoing incident hemodialysis. The occurrence of internalized stigma may be related to uremic pruritus and the duration of hemodialysis, while enacted stigma may be associated with uremic pruritus, depression, and anxiety.

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1. Introduction

Stigma was initially defined as “the situation of an individual who is disqualified from full social acceptance”.^{1(preface)} Unfriendly attitudes, such as stereotypes, prejudice, and discrimination held by others, have adverse consequences for people with stigmatizing conditions.^{2,3} Importantly, stigma exacerbates the physical and mental health challenges of people already suffering from chronic illnesses.⁴ Kurzban and Leary⁵ specifically found that individuals with illness have worse prospects and could not offer physical, social, emotional, and economic value to others. This conceptualization suggests that stigma should be prevalent and similar among patients with different chronic illnesses. Stigma can lead to adverse consequences, such as social isolation and a lack of social support, which can become a very powerful stressor and further cause more adverse psychosomatic reactions.⁵

There are approximately 3 million patients with end-stage renal disease (ESRD) worldwide undergoing maintenance hemodialysis. They belong to a special population of chronic illness patients, and their management should follow the biopsychosocial

medical model. Hemodialysis can save the lives of those suffering from ESRD, but the therapy itself also brings psychological and symptom burdens that impair the quality of life and prognosis.^{6,7} Presently, there are few reports on stigma in patients with ESRD. The present study aims to understand the situation of stigma in patients undergoing hemodialysis and explore the effect of stigma on their quality of life. Furthermore, we attempt to identify possible predictors associated with the occurrence of stigma in these patients. This may help nephrologists develop strategies to alleviate this psychological condition and improve their quality of life.

2. Methods

2.1. Participants

All maintenance hemodialysis patients registered at the Blood Purification Center of Jinshan Hospital, affiliated with Fudan University, in January 2023 were regarded as candidates. Inclusion criteria were as follows: (i) patients with ESRD undergoing hemodialysis for at least 3 months; (ii) willingness to participate in the study and sign an informed consent; and (iii) ability to read. Patients experiencing severe acute complications were excluded from this study. This study adhered strictly to the principles outlined in the Declaration of Helsinki (2013) (approval no. JIEC2022-S83).

2.2. Data collection and definitions

We collected data using medical records and self-reported questionnaires, which included: (i) Epidemiological information: age, gender, household location, marital status, children's status, living arrangements (alone or with others), education level, occupations, religious belief, etc.; (ii) clinical information: primary diseases, duration of dialysis, blood pressure, status of kidney transplantation candidacy, types of daily oral medications (e.g., antihypertensives, furosemide, sodium bicarbonate), Charlson comorbidity index (CCI),⁸ dysfunction of vascular access, residual urine volume, presence of uremic pruritus, and restless legs syndrome; (iii) lifestyle information: smoking and drinking habits, engagement in social and recreational activities, and commuting time to dialysis facilities; and (iv) recent laboratory data: hemoglobin (Hb), calcium (Ca), phosphorus (P), parathyroid hormone (PTH), albumin (Alb), prealbumin (preAlb), triglyceride (TG), total cholesterol (Chol), and dialysis adequacy indicators (Kt/V and urea reduction ratio [URR]).

2.3. Evaluation of stigma

The Stigma Scale for Chronic Illness (SSCI), comprising 24 items, was utilized to assess the level of stigma in patients undergoing incident dialysis. The scale is divided

into two modules: internalized stigma and enacted stigma.⁹ Internalized stigmas includes 13 items regarding self-perception (e.g., embarrassment and self-blame). Enacted stigma includes 11 items regarding the unkind attitude of others toward the patients (e.g., avoiding and discrimination). The Likert rating system is used to score 1 – 5 points based on the options of “no,” “rarely,” “sometimes,” “often,” and “always,” with a total score of 24 – 120 points. A higher score represents a higher degree of stigma. The SSCI instrument has satisfactory content validity and internal consistency and is considered a generic tool to measure stigma in different chronic illnesses.¹⁰

2.4. Evaluation of depression and anxiety

The Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) were used to evaluate the degree of depression and anxiety.^{11–13} Both the BDI and BAI contain 21 questions, which are effective in diagnosing depression and anxiety in many studies, especially in patients with chronic somatic diseases.^{14,15} Each question has four options: 0 – 3. The cumulative score range of all items is 0 – 63. A higher score represents more severe symptoms.

2.5. Measurement of quality of life

We utilized the medical outcomes study 36-item short-form health survey (SF-36) to measure the quality of life. The scale consists of eight modules: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health. Each module has a score range of 0 – 100. A higher score represents a higher level of quality of life.¹⁶

2.6. Statistical analysis

Quantitative data were expressed as mean $\pm$ standard deviation (SD), while categorical data were expressed as frequency and percentage (*n*; %). Pearson correlation analysis was employed to examine the correlation between stigma and quality of life. Multiple linear regression analysis was used to identify the predicted factors associated with internalized stigma and enacted stigma, respectively. We adopted the SPSS software version 23.0 to analyze the data, with statistical significance set at $P < 0.05$.

3. Results

After screening, 115 patients were enrolled in this study, with an average age of 52.14 ± 11.84 years and 74 (64.35%) being male. Most patients were married ($n = 84$; 73.04%) and had children ($n = 103$; 89.57%). The average duration of hemodialysis was 89.73 ± 64.79 months. The average value of the CCI was 3.13 ± 1.75 , and 13.91% of patients were awaiting transplantation. The average scores for BDI and BAI were 18.11 ± 12.15 and 9.41 ± 9.85 , respectively (Table 1).

Table 1. Epidemiological, lifestyle, clinical information, and recent laboratory examinations

Variables	Mean±SD/n (%)
Age (years)	52.14±11.84
Gender	
Male	74 (64.35)
Female	41 (5.65)
Household location	
Local	101 (87.83)
Non-local	14 (12.17)
Marital status	
Married (cohabitation)	84 (73.04)
Single	31 (26.96)
Raising children	
Yes	103 (89.57)
No	12 (10.43)
Living alone	
Yes	14 (12.17)
No	101 (87.83)
Education status	
Primary school or below	8 (6.96)
Junior middle school	46 (40)
Senior middle school	39 (33.91)
University or above	22 (19.13)
Unemployment	
Yes	52 (45.22)
No	63 (54.78)
Religious beliefs	
Yes	16 (13.91)
No	99 (86.09)
Primary diseases	
Glomerulonephritis	74 (64.35)
Diabetic nephropathy	18 (15.65)
Renal vascular disease	7 (6.09)
Others	16 (13.91)
Duration of hemodialysis (months)	89.73±64.79
Systolic pressure (mmHg)	
<140 mmHg	35 (30.43)
140 – 159 mmHg	60 (52.17)
160 – 179 mmHg	20 (17.40)
≥180 mmHg	0 (0.00)
Diastolic pressure (mmHg)	
<90 mmHg	64 (55.65)
90 – 99 mmHg	41 (35.65)

(Cont'd...)

Table 1. (Continued)

Variables	Mean±SD/n (%)
100 – 109 mmHg	5 (4.35)
≥110 mmHg	5 (4.35)
Types of daily oral medications	
<5	41 (35.65)
5 – 10	60 (52.18)
>10	14 (12.17)
Residual urine volume (mL/24 h)	
>1000	5 (4.35)
500 – 1000	12 (10.43)
100 – 500	26 (22.61)
<100	72 (62.61)
Uremic pruritus	
Yes	48 (41.74)
No	67 (58.26)
Restless legs syndrome	
Yes	30 (26.09)
No	85 (73.91)
Waiting for kidney transplantation	
Yes	16 (13.91)
No	99 (86.09)
Charlson comorbidity index (CCI)	3.13±1.75
Vascular access failure during the past 12 months	
Yes	16 (13.91)
No	99 (86.09)
Smoking	
Yes	30 (26.09)
No	85 (73.91)
Alcohol	
Yes	13 (11.30)
No	102 (88.70)
Social activities	
Yes	19 (16.52)
No	96 (83.48)
Recreational activities	
Yes	65 (56.53)
No	50 (43.47)
Travel time to dialysis facilities (min)	
<30	55 (47.83)
30 – 60	22 (19.13)
>60	38 (33.04)
Hemoglobin (g/L)	108.68±16.96
Serum calcium (mmol/L)	2.33±0.30

(Cont'd...)

Table 1. (Continued)

Variables	Mean±SD/ <i>n</i> (%)
Serum phosphorus (mmol/L)	2.12±0.68
Parathyroid hormone (pg/mL)	342.39±290.38
Albumin (g/L)	38.41±2.93
Prealbumin (g/L)	321.92±66.28
Triglyceride (mmol/L)	1.99±1.57
Cholesterol (mmol/L)	3.74±1.20
Dialysis adequacy indicators	
Kt/V	1.27±0.25
URR	68.13±7.09
BDI	18.11±12.15
BAI	9.41±9.85

Note: Data are presented as mean±standard deviation (SD) or *n* (%).

Abbreviations: BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; URR: Urea reduction ratio.

The average score of the SSCI was 43.09 ± 14.95 . Within the SSCI, the scores for internalized stigma and enacted stigma were 25.91 ± 9.26 and 17.19 ± 6.72 , respectively (Table 2). Correlation analysis indicated that the total score of the SSCI was negatively related to all modules of the SF-36. Specifically, bodily pain, general health, vitality, social functioning, role-emotional, and mental health revealed significant relationships ($P < 0.05$) (Table 3).

Multivariate linear regression analysis revealed that internalized stigma was significantly associated with uremic pruritus ($\beta = 4.113$; 95% confidence interval [CI]: 1.723 – 6.503; $P = 0.001$) and duration of hemodialysis ($\beta = -0.018$; 95% CI: -0.001 – (-0.036); $P = 0.042$) (Table 4). Enacted stigma was significantly associated with uremic pruritus ($\beta = 2.941$; 95% CI: 0.626 – 5.256; $P = 0.013$), BDI score ($\beta = 0.153$; 95% CI: 0.051 – 0.255; $P = 0.004$), and BAI score ($\beta = 0.149$; 95% CI: 0.024 – 0.274; $P = 0.020$) (Table 5).

4. Discussion

Stigma is a common phenomenon concomitant with different chronic illnesses, disabilities, and contagious diseases, causing much distress to those who are stigmatized.^{17,18} Moreover, stigma poses indirect but adverse implications for public health efforts aimed at combating the diseases or conditions concerned.¹⁹ The consequences for the affected patients may manifest as psychological stress, social isolation, and an increased risk of disability and disease progression.^{20,21} Enacted stigma affects self-perception and anticipation of discrimination, while internalized stigma involves internalizing negative stereotypes, resulting in low self-esteem and behavioral futility.²² For ESRD patients, losing renal function and

Table 2. Stigma scores in MHD patients

Variables	Values (mean±SD)
Stigma (total)	43.09±14.95
Internalized stigma	25.91±9.26
Enacted stigma	17.19±6.72

Abbreviations: MHD: Maintenance hemodialysis; SD: Standard deviation.

Table 3. Correlation between the total score of stigma and each domain of the short-form health survey (SF-36)

Domains	<i>r</i>	<i>P</i>
Physical functioning	-0.078	0.406
Role-physical	-0.140	0.134
Bodily pain	-0.212	0.023*
General health	-0.232	0.012*
Vitality	-0.231	0.013*
Social functioning	-0.319	0.000*
Role-emotional	-0.308	0.001*
Mental health	-0.332	0.000*

Note: * $P < 0.05$.

Table 4. Factors associated with internalized stigma in MHD patients

Variables	β	95% CI	<i>t</i>	<i>P</i>
Uremic pruritus	4.113	1.723 – 6.503	3.413	0.001*
Duration of hemodialysis	-0.018	-0.001 – -0.036	2.060	0.042*

Note: * $P < 0.05$.

Abbreviations: CI: Confidence interval; MHD: Maintenance hemodialysis; SD: Standard deviation.

Table 5. Factors associated with enacted stigma in MHD patients

Variables	β	95% CI	<i>t</i>	<i>P</i>
Uremic pruritus	2.941	0.626 – 5.256	2.521	0.013*
BDI	0.153	0.051 – 0.255	2.986	0.004*
BAI	0.149	0.024 – 0.274	2.374	0.020*

Note: * $P < 0.05$.

Abbreviations: BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; CI: Confidence interval; MHD: Maintenance hemodialysis; SD: Standard deviation.

depending on hemodialysis for survival becomes a focal point of stigma.

The quality of life of maintenance hemodialysis patients is also a field that nephrologists should actively pay attention to. Our findings suggested that stigma is negatively correlated with all modules of quality of life in maintenance hemodialysis patients. Beyond physical suffering, these

patients face significant life changes such as economic burdens, interpersonal relationships, and modifications in social and family status. A review suggested that stigma affects marriage, interpersonal relationships, mobility, employment, access to treatment and care, education, leisure activities, and social and religious participation,²³ all of which contribute to a diminished quality of life.

Uremic pruritus is a common and distressing symptom in patients with ESRD, affecting up to 46% of hemodialysis patients.^{24,25} Moreover, it is associated with multiple health-related complications and is independently associated with mortality.²⁶ Our study suggested that uremic pruritus was associated with both internalized and enacted stigma in hemodialysis patients. Uremic pruritus, which is a chronic stressor, can significantly impact one's mental well-being and may contribute to the experience of stigma. On the other hand, systemic inflammation is a common characteristic of brain and kidney lesions in ESRD patients, making it quite reasonable to hypothesize that inflammatory mediators may contribute to the cross-talk between the kidneys and brain.²⁷ Systemic inflammations may be a common pathogenesis of uremic pruritus and neuropsychiatric disorders, which is probably associated with stigma. The well-identified role of cytokines in mediating peripheral and central nervous system communication reinforces this hypothesis.²⁸

Our study suggested that internalized stigma was negatively associated with the duration of hemodialysis. For patients with ESRD, the initiation of dialysis itself can be regarded as an acute stressor that produces a series of psychosocial reactions, which may manifest as emotional, cognitive, and behavioral disturbances. Higher BDI scores were noted in patients at the initiation of hemodialysis.^{29,30} However, individuals may gradually adapt to this stressor through adaptive coping strategies, leading to an alleviation of adverse psychological reactions over time. Therefore, a methodological, thorough, and comprehensive evaluation should be conducted before the initiation of hemodialysis, and psychological conditions should be identified and addressed as soon as possible.³¹

Previous findings on neurological and psychiatric disorders suggested that depression and anxiety are related to stigma.^{32,33} Our study also found that depression and anxiety are related to enacted stigma. Enacted stigma involves experiences of prejudice, discrimination, and stereotyping directed at individuals by others. In essence, it still belongs to an individual's subjective perception, influenced by one's cognitive and emotional patterns. Aaron Beck^x, the founder of cognitive therapy, believes that patients with depression and anxiety have negative cognitive and emotional patterns. These patterns

influence how individuals receive, filter, edit, and process information obtained from objective environments. Such negative cognition and emotion may distort information from others, leading to misunderstanding others' attitudes as prejudice or discrimination.

There are several limitations to our study. First, there is currently no established norm or standard value for assessing stigma specifically related to ESRD, so a quantitative comparison could not be conducted. Second, although the various scales we used have been proven to be very effective, they may not capture stigma as comprehensively as a structured clinical interview. Therefore, clinical trials with larger, multi-center samples and more refined psychological assessments are warranted in the future.

5. Conclusion

Stigma is prevalent among maintenance hemodialysis patients, significantly impairing their quality of life. Internalized stigma appears to be associated with uremic pruritus and duration of hemodialysis, whereas enacted stigma correlates with uremic pruritus, depression, and anxiety. Therefore, timely identification and effective intervention by nephrologists are crucial for enhancing the quality of life among patients undergoing maintenance hemodialysis.

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Conflict of interest

The authors have no potential conflicts of interest to disclose.

Author contributions

Conceptualization: All authors

Formal analysis: All authors

Investigation: Wei Ye

Methodology: Wei Ye

Writing-original draft: Wei Ye

Writing-review & editing: Wei Ye

Ethics approval and consent to participate

This study was conducted in compliance with local regulations and the revised established principles of the Declaration of Helsinki (2013). The Medical Ethics Committee of Jinshan Hospital affiliated with Fudan University (approval no.: JIEC2022-S83) approved the

study, and written informed consent to the investigation was obtained from all participants.

Consent for publication

Not applicable.

Availability of data

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

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