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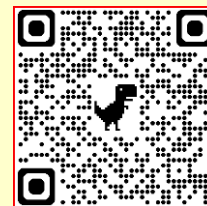
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Disease Uncertainty in Maintenance Hemodialysis Patients Analysis of Correlation with Psychological Distress

Yining Zhao¹, Yi Zhang^{2*}, Chenshuang Li³, Xinguo Yuan⁴, Shijun Li⁵, Luhan Ding⁶, and Qiaoyin Su⁷

^{1,2,3,4,5,6,7} School of Nursing, Pingdingshan University, Pingdingshan 467000, China

Corresponding Author: Yi Zhang

School of Nursing, Pingdingshan University, Pingdingshan 467000, China

ABSTRACT

Objective Investigate the disease uncertainty and psychological distress status of maintenance hemodialysis patients, and explore the correlation between them, so as to provide a basis for improving the mental health level of patients.

Methods Using a convenient sampling method, in November 2024, 100 patients in Beijing 3 armour hospital were selected. A general data questionnaire was used to collect patients' baseline data, and the Distress Thermometer (DT) and the Disease Uncertainty Scale were administered to patients to analyze the relationship between the two factors.

Results The average score of psychological distress in maintenance hemodialysis patients was 3.55 ± 2.302 , with 51% of patients experiencing significant psychological distress. The average score of illness uncertainty was 97.52 ± 23.322 . Single-factor variation analysis showed significant differences in caregivers' physical status and differential residence mode ($P < 0.05$). Multiple regression indicated that the degree of disease uncertainty, residence style, and caregiver physical state were the influencing factors of psychological distress ($P < 0.05$). Pearson Correlation analysis showed that levels of disease uncertainty were significantly and positively associated with psychological distress status.

Conclusions The levels of disease uncertainty and psychological distress in maintenance hemodialysis patients are not very optimistic, which is related to factors such as caregivers' physical state and residence style, and the two factors are positively correlated. Nursing staff should pay attention to the changes in patients' psychological state, implement personalized psychological nursing, and strengthen health education, so as to effectively improve the mental health status of patients.

KEY WORDS: Maintenance Haemodialysis; Disease Uncertainty; Psychological Distress; Correlation.

Introduction

Maintenance Hemodialysis (MHD) is one of the primary replacement therapies for patients with End-Stage Renal Disease (ESRD) [1]. When the glomerular filtration rate (GFR) falls below 15 ml/(min·1.73 m²), renal replacement therapy—including kidney transplantation, hemodialysis, and peritoneal dialysis—is initiated based on the primary disease, residual renal function, clinical manifestations, and complications [2]. Studies indicate that the global prevalence of chronic kidney disease (CKD) is approximately 13.4%, with 4.902 to 7.083 million patients requiring renal replacement therapy worldwide [3], posing as a significant public health challenge [4]. In China, the average mortality rate among MHD patients from 2020 to 2022 was as high as 6.88% [5]. Although MHD effectively delays disease progression, its unpredictable, complex, and long-term nature imposes substantial psychological stress on patients, leading to psychological distress [6]. Psychological distress, characterized by fear, worry, anxiety, and depression, is a multifaceted negative emotional experience that adversely affects treatment adherence, coping abilities, and therapeutic outcomes [7]. Research suggests that illness uncertainty disrupts cognitive processes, exacerbates negative emotional crises, and diminishes patients' confidence in treatment [8].

To improve the quality of life and psychological well-being of hemodialysis patients, Ting et al. (2023) [9] conducted a survey revealing that most MHD patients experiencing psychological distress lack adequate knowledge about their disease. Wen Xianxiu et al. [10] demonstrated that declines in psychological resilience or ineffective coping strategies intensify illness uncertainty, thereby increasing self-perceived burden and impairing daily functioning. Further analysis by Wu Hong et al. [11] highlighted that illness uncertainty negatively correlates with quality of life, mediated by emotional states. Skojec TA et al. [12] also identified illness uncertainty as the most influential factor affecting psychosocial adaptation in MHD patients. Elevated levels of illness uncertainty have a significant impact on psychological distress and overall well-being in this population.

This study aims to evaluate and analyze the relationship between illness uncertainty and psychological distress in MHD patients, providing evidence for the development of targeted psychological nursing interventions to enhance mental health, treatment efficacy, and quality of life.

1. Participants and Methods

1.1 Research Subjects

Using convenience sampling, a questionnaire survey was conducted on 100 maintenance haemodialysis patients at a certain tertiary hospital in Beijing from November to December 2024. Inclusion criteria: ① diagnosed with ESRD; ② aged ≥ 18 years; ③ undergoing regular dialysis for ≥ 3 months; ④ informed consent and voluntary participation. Exclusion criteria: ① critically ill patients with multiple comorbidities; ② those who have recently experienced significant life changes; ③ those with impaired consciousness or communication barriers.

1.2 Research Instruments

1.2.1 General Information Questionnaire

Researchers designed and conducted a survey to understand the baseline data of 100 MHD patients. The survey included 12 items: gender, age, living arrangement, place of residence, educational level, average monthly income per family member, number of children, self-care ability, age at which dialysis began, frequency of dialysis (per week), physical condition of the primary caregiver, and

identity of the primary caregiver.

1.2.2 The Distress Thermometer (DT表)

The Distress Thermometer (DT) was used to assess the psychological distress of MHD patients. The scale uses a single-item self-assessment format with a visual analogue scale scoring from 0 to 10, where 0 indicates no distress and 10 indicates extreme distress. A score of 4 or higher is considered the threshold for severe psychological distress.

1.2.3 The scale was developed by Mishel (MUIS-A)

The scale was developed by Mishel [13] and was adapted into Chinese by Xu Shulian et al. It has a Cronbach's α coefficient of 0.89 and a content validity index of 0.96, indicating good internal consistency and reliability. It is used to assess the level of illness uncertainty among MHD patients. The scale employs a Likert 5-point rating scale, ranging from 1 (strongly disagree) to 5 (strongly agree). It comprises four dimensions: unpredictability, ambiguity, information deficiency, and complexity.

During data analysis, Item 15 is excluded, and Items 6, 7, 10, 12, 21, 25, 27, 28, 30, 31, 32, and 33 are reverse-scored. The total score is categorized as follows: low level (32–74.7 points), moderate level (74.8–117.4 points), and high level (117.5–160 points).

1.3 Data Collection Methods

Data were collected using a paper-based questionnaire administered on-site. Questionnaires were distributed after obtaining consent from the hospital, the department, and the patients. The purpose and significance of the study were explained to the participants using standardized language. Any questions raised by the participants were answered objectively by the researchers without any suggestive language. For participants with writing difficulties, the researchers recorded their responses with their consent. A total of 100 questionnaires were distributed, and all 100 were returned validly, resulting in a 100% valid return rate.

1.4 Statistical Methods

Data analysis was performed using SPSS version 20.0. For normally distributed continuous data, results were presented as mean \pm standard deviation ($\bar{x} \pm s$). Comparisons between groups were conducted using independent samples t-tests and one-way ANOVA. Categorical data were described using frequencies and percentages (%). Multiple linear regression analysis was used to assess the impact of various factors on psychological distress. Pearson correlation analysis was employed to examine the relationship between illness uncertainty and psychological distress among maintenance hemodialysis (MHD) patients. A p-value of less than 0.05 was considered statistically significant.

2. Results

2.1 Illness Uncertainty Scores in MHD Patients

The average score of the Modified Uncertainty in Illness Scale (MUIS-A) among 100 maintenance hemodialysis (MHD) patients was 97.52 ± 23.322 . Among the four dimensions, the highest score was observed in the ambiguity dimension (42.00 ± 12.022), while the lowest score was in the unpredictability dimension (12.50 ± 3.217). For detailed information, see Table 1.

Table 1. Illness Uncertainty Scores in MHD Patients (n=100, scores, $\bar{x} \pm s$)

Items	Total score	Average score
Unpredictability	12.50 \pm 3.217	2.50 \pm 0.643
Information	22.19 \pm 6.311	3.17 \pm 0.901

Deficiency		
Complexity	17.42±3.736	2.48±0.533
Ambiguity	42.00±12.022	3.23±0.924
Total score	97.52±23.322	2.95±1.284

2.2 Psychological Distress Scores in MHD Patients

Among 100 maintenance hemodialysis patients, the average DT score was (3.55±2.302). Forty-nine patients (49%) had mild psychological distress, and 51 patients (51%) had severe psychological distress. Details are shown in Table 2.

Table 2. Psychological Distress Scores in MHD Patients (n=100, scores, $\bar{x}\pm s$)

Item	Mild Group (n=49)	Severe Group (n=51)
Psychological Distress	3.48±2.246	3.68±2.304

2.3 Baseline Data and Univariate Analysis of Psychological Distress in MHD

Patients

The psychological distress of maintenance hemodialysis patients is associated with different living arrangements and the physical condition of caregivers, with statistically significant differences ($P < 0.05$). No statistically significant differences were found in other factors. See Table 3 for details.

Table 3 Baseline Data and Univariate Analysis of Psychological Distress in MHD Patients (n=100, scores, $\bar{x}\pm s$)

Item	category	Number of Cases (n)	Psychological Distress Score	F/t	P
Gender	male	72	3.60±2.510	0.327 ^b	0.744
age	female	28	3.43±1.687		
	18~30	6	4.16±2.639	1.105 ^a	0.351
	31~50	10	2.70±1.567		
	51~60	26	3.15±2.524		
	>60	58	3.81±2.259		
Educational Level	Primary School and Below	42	3.14±2.090	1.989 ^a	0.121
	Junior High School	41	3.61±2.201		
	Senior High School/Vocational School	6	5.50±3.391		
	Junior College and Above	11	3.82±2.523		
Living Arrangement	Non-living Alone	84	3.14±1.952	4.144 ^b	<0.001
	Living Alone	16	5.69±2.845		
Residential Area	Rural Area	26	3.62±2.174	0.168 ^b	0.867
	Urban Area	74	3.53±2.360		
Per Capita Monthly Household Income (in Yuan)	<3000	5	2.80±1.789	0.322 ^a	0.725
	3000~5000	40	3.68±2.368		
	≥5000	55	3.53±2.316		
Number of Offspring	≤2	39	3.59±2.663	0.137 ^b	0.891
	>2	61	3.52±2.062		
Self-care Capacity	Completely	38	3.61±2.707	1.258 ^a	0.289
	Partially	60	3.60±2.019		
	Completely unable	2	1.00±0.000		
Dialysis Frequency (times per week)	≤2	53	3.42±2.248	0.620 ^b	0.536
	≥3	47	3.70±2.377		
Dialysis Vintage (years)	0.25~	77	3.61±2.289	0.478 ^b	0.634
	≥3	23	3.35±2.386		
Primary Caregiver	The Patient Themselves	25	3.08±3.174	1.019 ^a	0.365
	Family Member	73	3.67±1.826		

	Others	2	5.00±5.657		
Caregiver's Physical Condition	Worse	7	6.43±3.505	37.336 ^a	<0.001
	Average	52	4.52±1.754		
	Better	41	1.83±1.282		

注：a为F值 b为t值

2.4 Multiple Linear Regression Analysis of Psychological Distress in MHD

Patients

Based on the results of independent samples t-tests and one-way ANOVA, significant demographic variables (living arrangement and caregiver's physical condition) and the scores of the illness uncertainty scale were selected as independent variables, with the psychological distress status of MHD patients as the dependent variable. A multiple regression model was established for statistical analysis (details of the coding of independent variables are shown in Table 4). The statistical results indicated that the scores of illness uncertainty, living arrangement, and the physical condition of the caregiver were ultimately included in the regression equation. This suggests that illness uncertainty scores, living arrangement, and the physical condition of the caregiver are significant predictors of psychological distress ($P < 0.05$). Detailed data are presented in Table 5.

Table 4: Coding Explanation of Variables Related to Psychological Distress in MHD Patients

Independent Variable	Coding Explanation
Living Arrangement	Non-living Alone = 1, Living Alone = 2
Caregiver's Physical Condition	Poor = 1, Fair = 2, Good = 3
Illness Uncertainty Score	Enter raw data

Table 5: Results of Multiple Linear Regression Analysis on Psychological Distress in MHD Patients

Factor	Regression Coefficient	Standard Error	Standardized Coefficient	t	P
(Constant)	-2.493	0.982	—	-2.539	0.130
Living Arrangement	1.759	0.286	0.282	6.141	<0.001
Illness Uncertainty Score	0.063	0.006	0.639	11.247	<0.001
Caregiver's Physical Condition	-0.920	0.214	-0.242	-4.291	<0.001

2.5 Correlation Analysis between Illness Uncertainty and Psychological Distress in MHD Patients

A correlation analysis was conducted between the scores of illness uncertainty and its dimensions and the scores of psychological distress. The results showed a significant positive correlation between illness uncertainty and psychological distress among MHD patients ($r = 0.828$, $P < 0.05$). This indicates that higher levels of illness uncertainty are associated with more severe psychological distress. Additionally, each dimension of illness uncertainty also showed a significant positive correlation with psychological distress. For detailed information, see Table 6.

Table 6: Correlation Analysis between Illness Uncertainty and Psychological Distress in MHD Patients (n=100)

Statistical Value	Illness Uncertainty Total Score	Ambiguity Dimension	Complexity Dimension	Lack of Information Dimension	Unpredictability Dimension
r	0.828	0.788	0.567	0.742	0.719
P	<0.001	<0.001	0.001	<0.001	<0.001

3. Discussion

3.1 Current Status of Illness Uncertainty in MHD Patients

Illness uncertainty is a cognitive state regarding a disease, referring to an individual's inability to judge situations related to their symptoms [14]. Research has shown that the level of illness uncertainty affects patients' psychological and emotional states, which in turn impacts their quality of life [15]. It is an important factor that cannot be ignored among patients with chronic diseases. In this study, the average score of illness uncertainty among MHD patients was 97.52 ± 23.322 , indicating a moderate level overall. Among the different dimensions, the highest score was observed in the ambiguity dimension (42.00 ± 12.022), which is similar to the findings of Li Yajuan [16]. The reasons for this pattern are multifaceted. Hemodialysis requires patients to strictly control their intake of fluids and salt, adhere to regular hospital visits, and

maintain medication regimens. These demands necessitate significant adjustments to patients' daily routines. During the initial adaptation phase to hemodialysis, patients may experience substantial emotional fluctuations and differences. Frequent hospital visits not only increase the economic burden on patients but also disrupt their daily lives, leading to feelings of fatigue and frustration. Moreover, the unpredictable nature of the disease's progression and the uncertainty of potential complications can erode patients' confidence in treatment. Additionally, among older patients, misconceptions about the disease may arise due to difficulties in accurately understanding medical information, which can negatively impact treatment adherence. Younger patients, on the other hand, may experience increased negative feelings due to concerns about their future development. These objective and subjective factors

directly contribute to heightened levels of uncertainty and its associated negative experiences.

3.2 Psychological Distress in MHD Patients

The results of this study show that the average psychological distress score among 100 MHD patients was 3.55 ± 2.302 . Among them, 51 patients had severe psychological distress (score ≥ 4), with an incidence rate of 51%, which is slightly lower than the 59.7% reported by He Lifang^[17]. However, both studies indicate that psychological distress is prevalent among maintenance hemodialysis patients, with more than half experiencing severe distress. The psychological distress status of MHD patients is not optimistic. Analyzing the reasons, it may be due to the higher proportion of patients over 60 years old in this study, whereas He Lifang's study included relatively younger patients. Middle-aged and young patients often bear more family responsibilities compared to older patients, with some even being the primary breadwinners of their families. The long-term, complex, and unpredictable nature of hemodialysis significantly increases the burden of their family roles. On one hand, they need to support their families, and on the other hand, they become a burden due to their illness. Besides the physiological symptoms such as nausea, vomiting, headaches, fatigue, puncture pain, and uremic breath, they also endure substantial family and life pressures. Moreover, compared to older patients, symptoms like uremic breath have a greater impact on the social and work lives of younger patients. Therefore, younger patients are more concerned about the current state, progression, and prognosis of their disease, which leads to a higher incidence of psychological distress among them. Clinical caregivers should pay more attention to the daily discomfort and psychological health education of patients, promptly identify and guide patients, and explain disease-related knowledge to alleviate their psychological distress.

3.3 Analysis of Factors Influencing Psychological Distress in MHD Patients

The regression analysis reveals that illness uncertainty, caregiver physical condition, and patient living arrangements are key factors influencing psychological distress in MHD patients. Specifically, illness uncertainty and living arrangements show positive correlations with psychological distress, while caregiver physical condition shows a negative correlation. This means higher illness uncertainty and certain living arrangements are linked to greater psychological distress, whereas better caregiver health is associated with reduced patient psychological distress.

3.3.1 Living Arrangement

Social support, as a known buffer against psychological distress, can effectively alleviate patients' psychological distress and promote mental health^[18]. The results show that living arrangements are an influencing factor of psychological distress among MHD patients. Patients living alone had higher psychological distress scores than those who were not living alone, indicating a higher likelihood of experiencing psychological distress among the former. This finding is consistent with the studies by Gao Zhaorong^[19] and Xu Ting^[20].

The reasons can be analyzed as follows: MHD patients who are not living alone are more likely to receive encouragement, comfort, and support from family members during routine hemodialysis. They also benefit from family care, supervision, and encouragement in daily activities such as diet and exercise. When patients experience irritability or resistance, family members or friends can promptly provide psychological comfort in ways that are suitable for the patients. Additionally, the families of younger patients are more proactive in seeking kidney transplants, which can effectively

relieve anxiety and depression, provide significant psychological support, and enhance patients' confidence in treatment.

In contrast, patients living alone rely on themselves during hemodialysis treatment. They are more likely to experience ineffective individual coping in the face of sudden illness-related or life-related events compared to those who are not living alone. This may lead to thoughts of escape or self-abandonment. Under significant psychological pressure, the lack of companionship and emotional outlets makes it difficult for them to maintain stable mental states, leading to negative emotions such as distress, loneliness, and even nihilism.

In clinical practice, healthcare workers should fully respect patients living alone, listen to their needs, and increase the frequency of communication with them. They should use encouraging language and actions to support patients, gain their trust, and establish an effective two-way communication mechanism.

3.3.2 Caregiver's Physical Condition

Family members of haemodialysis patients are considered to be key factors in disease management and improved quality of life^[21]. The physical condition of the caregiver has a direct effect on the quality of care. The results of this study showed that the different physical status of caregivers was the influencing factor of the psychological distress of MHD patients. This suggests that patients with better physical condition of caregivers have less psychological distress than patients with poor physical condition of caregivers. This is consistent with the findings of Jiang Zhenying^[22]. Peer support is a potential resource to provide haemodialysis patients with additional emotional support and informational assistance while improving their self-efficacy and self-management skills^[23]. The findings of this study also confirm this point, and analyse the reasons for this: in the physiological aspect, when the caregiver is in poor physical condition, the needs of the patient may be ignored or unable to be met, which can affect the quality of care. In terms of psychology, the caregiver's own frustration and sadness are invisibly transmitted to the patient, which is easy to cause the patient to have a negative psychological experience. The patient's long-term depressed mood will also affect the caregiver's mentality, and when negative emotions persist and affect each other, it is not only detrimental to the patient's mental health, but also causes great psychological pressure on the caregiver. When we carry out clinical nursing work, we can mobilise several patients' family members to "narrate the family care model"^[24], so that the family members can truly empathise and experience the patient's feelings, and we can also pay attention to the emotional state of the family members, encourage the family members, and strengthen the family's confidence in treatment, so as to enhance the relationship within the family, enhance the patient's family support strength and vitality, and reduce the degree of psychological pain of the patient.

3.3.3 Uncertainty in Illness

Research shows that disease uncertainty levels affect MHD patients' psychological distress, similar to Wu Jiabin's^[25] findings. When patients face the unknown, they worry about disease severity, treatment outcomes, impact on life and family, even death. This uncertainty becomes a major psychological burden. Many end-stage renal disease patients lack accurate disease knowledge, leading to high uncertainty and loss of treatment confidence^[26]. When their psychological resilience is weakened and physiological state is uncontrollable, patients may magnify their helplessness and become anxious and disappointed over potential treatment failure.

Therefore, clinical nurses should be sensitive to patients' disease

uncertainty, communicate more with them, and explain unclear issues simply. This boosts treatment confidence, eases psychological pressure, and promotes mental health.

3.4 Correlation Analysis between Illness Uncertainty and Psychological Distress in MHD Patients

This study indicates a significant positive correlation between disease uncertainty and psychological distress in maintenance hemodialysis patients ($r = 0.828$, $P < 0.05$), consistent with the findings of Zeng Xiangyu [27]. All four dimensions of disease uncertainty are positively correlated with psychological distress.

The ambiguity dimension's positive link with psychological distress implies more ambiguous disease symptoms lead to less comprehensive and accurate disease knowledge, increasing anxiety and depression levels, which are positively correlated with psychological distress [28].

The complexity dimension's positive correlation shows the treatment and care burden on patients. As end-stage renal disease progresses, multiple systems are affected, leading to complex treatment plans. Also, the complexity of dialysis fistula care causes patients to be overly cautious.

The information deficiency dimension's positive correlation indicates insufficient disease diagnosis knowledge and resource access, especially in elderly patients who may not understand medical staff and rely on caregivers, affecting their psychological state.

The unpredictability dimension's positive correlation means greater difficulty in predicting disease progression and prognosis intensifies psychological distress. Due to various influencing factors, doctors can't always give definite answers, leading to patient disappointment and increased psychological suffering.

Scholar Li [29] believes improving health literacy by understanding health information can alleviate psychological distress. Reducing patients' disease uncertainty by enhancing their perception is crucial. During induction dialysis, clinical staff should strengthen disease knowledge dissemination, answer questions, and prepare patients for the maintenance dialysis stage. Providing diverse information access, encouraging participation in kidney patient groups, and boosting social confidence can improve disease uncertainty and psychological distress, promoting mental health.

4. Conclusions

In summary, disease uncertainty and psychological distress levels are both moderate in MHD patients, indicating an overall unsatisfactory situation. The psychological distress of MHD patients is influenced by differential living arrangements, caregivers' physical conditions, and disease uncertainty, which shows a significant positive correlation with psychological distress. Clinical staff should enhance their awareness of psychological nursing and develop personalized psychological nursing intervention programs to boost patients' treatment confidence and improve their quality of life.

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