

“Alive Day is the Day”: A Qualitative Study of Experiences of Learned Helplessness in Maintenance Haemodialysis Patients

Chunyan Xie ^{1,2,*}, Li Li ^{2,3,*}, Yamin Li ¹

¹Clinical Nursing Teaching and Research Section, the Second Xiangya Hospital of Central South University, Changsha, Hunan Province, 410011, People's Republic of China; ²Xiangya Nursing School of Central South University, Changsha, Hunan Province, 410013, People's Republic of China; ³The First Affiliated Hospital of Xinjiang Medical University, Urumqi, Xinjiang, 830011, People's Republic of China

*These authors contributed equally to this work

Correspondence: Yamin Li, The Second Xiangya Hospital, Central South University, Changsha, Hunan, 410011, People's Republic of China, Email aminny@csu.edu.cn

Background: Learned helplessness (LH) is a common psychological phenomenon among chronic disease patients. However, LH remains underrecognized in the context of maintenance haemodialysis (MHD) patients. This qualitative study is the first study of this topic to be conducted in a Chinese cultural context, and its purpose is to explore the LH experiences of MHD patients and to highlight their interpretations of LH.

Methods: We employed a qualitative research design. A purposive sampling method was used to recruit participants. The sample size was determined by data saturation. Data were obtained from MHD patients in a blood purification centre located in Hunan Province, China. Data were collected from June to September 2022. The researchers conducted in-depth, semistructured interviews with participants after obtaining informed consent. Texts were transcribed verbatim from the audio recordings of these interviews. Data processing and analysis were based on Giorgi's phenomenological approach.

Results: Twenty-two respondents completed the interviews (aged 29–75 years, including ten females and twelve males). Four themes emerged from the interviews: (1) triggers of helplessness (hope is gone; witnessing renal friends' helplessness; out of control; nothing works); (2) being tied down (limitation; perceived loss; social isolation; giving in); (3) I am just a loser (self-image disorder; low self-concept; negative attitudes; guilt; abandonment); (4) alive day is the day (fatalism; my duty; downwards comparison).

Conclusion: The study reveals that multiple stressors drive MHD patients' LH. These salient phenomena demonstrate the importance of recognizing MHD patients' LH. We suggest that support services should be developed alongside a framework that addresses MHD patients' LH from the beginning of treatment.

Keywords: maintenance haemodialysis, learned helplessness, qualitative study, phenomenology, patient experiences

Background

End-stage renal disease (ESRD) is increasing on a yearly basis and has become a public health threat.¹ ESRD refers to the progressive and irreversible loss of kidney function.^{2,3} ESRD patients are strongly dependent on renal replacement therapies (RRTs) for life support, including kidney transplants, haemodialysis (HD), or peritoneal dialysis (PD).⁴ Although kidney transplants are the preferred method of treatment, organ shortages and economic factors have reduced access to such transplants.⁵ HD is currently the primary treatment used for ESRD patients.⁶ Maintenance haemodialysis (MHD) requires the patient to receive regular in-hospital haemodialysis lasting 4–5 hours 2–3 times per week. More than 90% of ESRD patients in China are treated with MHD, with an annual rate of increase of 20%. By 2021, approximately 750,000 MHD patients will be located in China.

MHD patients face many challenges related to their health status and ongoing treatment. As a result, they experience many emotional and psychological problems.⁷ For example, MHD patients exhibit a higher rates of anxiety and

depression than other patients with chronic renal disease (CKD).⁸ Most MHD patients have been reported to experience persistent learned helplessness (LH).^{9,10} The concept of LH originates from psychology. According to Seligman, LH refers to the powerless, hopeless psychological state that occurs when an individual experiences an uncontrollable outcome.¹¹ The essence of this phenomenon is a learned negative motivation. LH is a common psychological experience for most chronic disease patients.^{12–15} The psychological and somatic effects of LH may lead to various complications, such as decreasing quality of life and increasing rates of hospitalization, depression, and suicide.^{16–18} In addition, patients' LH hinders their self-care behaviours and adherence, thus increasing the likelihood of adverse health outcomes.^{19,20}

The National Institute for Health and Care Excellence (NICE) highlighted the need for incorporating emotional and psychological support to renal guidelines.²¹ Patient support is usually targeted at groups that require psychological or psychiatric interventions, and the need to address MHD patients' LH may remain unidentified. According to theory, LH is not a direct result of a traumatic event but is rather learned by the individual during the process of coping and can interact with various factors.²² Therefore, to understand and address LH in the context of sick patients, it is necessary to venture beyond the biomedical framework and explore the role played by the social environment in this context.²³

Patients' experiences of MHD treatment are highly individualized. Qualitative research can provide a more holistic view that may be more meaningful to health care practitioners.²⁴ Qualitative methods have been used to study the experiences of MHD patients in terms of disease symptoms, quality of life, and waiting for a kidney transplant.^{5,25} No qualitative studies have investigated LH in MHD patients. Therefore, we sought to explore how MHD patients experience LH and how they interpret it in a specific Chinese context.

Methods

Aims

The study aimed to explore how MHD patients experience LH and how they interpret LH in a specific Chinese context.

Study Design

This study used Giorgi's phenomenological approach²⁶ to obtain evidence regarding the experience of LH by collecting subjective data from MHD patients. The Standards for Reporting Qualitative Research (SRQR)²⁷ checklist was used to ensure quality reporting of this qualitative study ([Supplementary Materials 1](#)).

Participants and Setting

A purposive sampling technique was used to select participants from a blood purification centre at a comprehensive hospital located in Hunan Province, China. Participants were selected based on the following criteria: (i) age ≥ 18 years, (ii) diagnosed ESRD, and (iii) receiving regular HD for ≥ 3 months. Each participant was asked to sign an informed consent form.

The Research Team and Reflexivity

The first author is a Ph.D. candidate with extensive experience in nursing psychology. The second author is a nursing manager in nephrology, and the third author is a nursing professor. The iterative discussions among authors improved our understanding of hidden information. The experience of researchers from different jobs contributed to improving our understanding of the materials.

Data Collection

The authors interviewed 22 participants individually between June and September 2022. All interviews lasted between 30–45 minutes and followed a semistructured interview outline ([Supplementary Materials 2](#)). Participants were encouraged to discuss their LH experiences since receiving MHD treatment freely. During the interview, they were asked to clarify any points that were unclear to the interviewers. When they found it difficult to understand the questions, they asked the interviewers for clarification. This interaction featuring the creation of shared meaning helped the interviewers

keep an open mind. The interviews were audio-recorded to facilitate transcription and analysis. The text noted instances of participants' nonverbal communication, such as weeping, self-deprecation, shaking heads, or tears in their eyes.

Data Analysis

The analysis continued throughout the period of data collection. The interpretation of the text moved back and forth across five steps that were inspired by Giorgi's²⁶ "discovery-oriented" approach to phenomenology. Step 1) The authors listened to the interviews and read the texts to obtain a sense of the overall material. Step 2) The entire materials were divided into meaningful units. NVivo software was used to simplify this process. Step 3) The nature of the meaningful units was considered in accordance with the purpose of the study. Step 4) Moving back and forth during this analysis helped the authors integrate the units into a description of the final set of themes. Step 5) The authors continually assessed and discussed the nature of themes and the relationships among them.

Rigour

As described by Graneheim and Lundman,²⁸ the study was tested for credibility, reliability, and transferability. With regard to credibility, the use of open-ended questions in the dialogue ensured that the findings accurately represented the participants' experiences. This approach allowed participants to openly express the experiences they felt were most important without the influence of the researchers. The authors repeatedly discussed the texts until they reached consensus regarding how the data should be labelled and categorized. In addition, the authors presented the results to several participants, who verified that the findings were consistent with their own experiences.

Regarding reliability, the authors discussed the data throughout the analysis to ensure a consistent selection of themes. The researchers were clinical nurse specialists with knowledge of the context of a blood purification centre, which served as a reliable research tool. The entire process was supervised and reviewed by the senior coauthor.

Finally, to ensure transferability, the authors described the participants' general characteristics and ethical situation in detail to enable the reader to understand the analytical process.

Ethical Approval

Ethical approval for the study was obtained from the ethical review committee of Behavioural Medicine and Nursing, Xiangya Nursing School, Central South University (E202255). The study complies with the guidelines contained in the Declaration of Helsinki. The participants' informed consent included the publication of anonymized responses.

Results

Demographic Characteristics

Twenty-two MHD patients aged 29–75 years participated in the interviews. They had been treated for MHD for a minimum of half a year and a maximum of 12 years. Ten female patients and 12 male patients were involved in this study. Seven participants had college diplomas, and only three had professional jobs. Two participants had received kidney transplants. Their characteristics are shown in [Table 1](#).

Findings

Theme 1: Triggers of Helplessness

We talked to respondents about their most helpless moments since receiving MHD and the potential sources of LH. They mentioned repeated losses of hope and the lack of control over their disease and life as important triggers of feelings of helplessness. Respondents reported that their symptom control and life management efforts had been ineffective. They gradually realized that no one and nothing could help them escape their helplessness because kidney failure was irreversible. In addition, witnessing the helplessness of others also increased their feelings of helplessness. This domain included four categories:

Subtheme 1.1: Hope is Gone

During the interviews, we learned that some interviewees had been forced to receive MHD treatment because of

Table I Participant Characteristics (n=22)

ID	Gender	Age	Employment Status	Education	Duration of MHD (Years)	Transplant
P1	Male	40	Full-time	College education	0.9	No
P2	Male	65	Retiree	Elementary Education	10	No
P3	Female	61	Retiree	College education	7	Yes
P4	Male	51	Unemployed	Elementary Education	8	No
P5	Male	72	Retiree	College education	2	No
P6	Male	48	Unemployed	College education	5	No
P7	Female	54	Unemployed	Secondary education	2	No
P8	Female	68	Retiree	Elementary Education	10	No
P9	Female	38	Unemployed	Secondary education	3	No
P10	Male	41	Unemployed	Elementary Education	2	No
P11	Female	43	Unemployed	Secondary education	4	No
P12	Male	40	Full-time	Secondary education	5	No
P13	Female	47	Unemployed	Secondary education	7	No
P14	Female	70	Retiree	Elementary Education	6	No
P15	Male	75	Retiree	Secondary education	12	No
P16	Female	54	Part-time	Secondary education	9	No
P17	Male	52	Unemployed	Secondary education	7	No
P18	Female	38	Full-time	College education	3	No
P19	Male	29	Unemployed	Secondary education	0.5	No
P20	Female	35	Unemployed	College education	1	No
P21	Male	44	Part-time	Secondary education	3.5	No
P22	Male	40	Unemployed	College education	6	Yes

recurrent peritoneum infection. Some interviewees had experienced multiple failed kidney matches while waiting for a transplant. Some respondents had received kidney transplants but needed to return to a blood purification centre due to the failure of the transplanted kidney. These interviewees described their current situation as a helpless, hopeless crisis. They also mentioned that kidney failure had ruined their lives forever and that there was no hope of recovery. MHD had destroyed their plans for the future. After experiencing multiple destroyed hopes, they gradually lost all hope, leading to a sense of helplessness regarding the future. This helplessness also emphasized their previously high expectations for treatment:

I had high hopes for peritoneal dialysis but often came to the hospital with infections. I have no choice but to come here. I guess I can only live like this in the future.

The matching failed again. I am so scared. It's hard to find a kidney source. I don't know how long I have to wait (sigh). Maybe I will die before that day.

I don't want to change my kidney again. I spent so much money on this. You see, I'm lying here again. You know, it's so sad.

Subtheme 1.2: Witnessing Renal Friends' Helplessness

Respondents tended to call their fellow dialysis patients "renal friends". Renal friends have frequent contact with one another in the closed hospital environment and tend to feel compassion for each other. When one such friend experiences a negative event, the psychological impact on other patients is substantial. Participants often inferred the death of one patient by noting his or her absence, which left an "empty bed". They mentioned witnessing other renal friends' negative events, such as family breakdowns, failed kidney transplants, resuscitations, and deaths. They could also project those events onto themselves and experience a degree of helplessness:

It's useless to change a kidney. I know a transplanted kidney has an expiration date. My colleague came back to dialysis a few years after kidney transplants. This is suffering!

Seeing the death of a kidney friend in the bed next to mine made me feel that life is so fragile. It was such a shock to me. Why was she fine the day before and suddenly died during dialysis without any signs? I do not know which day will be my turn.

A renal friend died while on dialysis. The doctor resuscitated him, and he still died. So, I think there is no point in resuscitation. I hope that I can be euthanized one day without pain. Please don't resuscitate me. I just want to pass away quietly.

Subtheme 1.3: Out of Control

The fluctuating and recurrent nature of chronic disease symptoms often causes the presence of the disease to be perceived irregularly and forcibly by patients. For participants, the symptoms, complications, and intense discomfort associated with dialysis imposed significant limitations on their lives, constantly reminding them of their status as patients. Participants exhibited pruritus, hypotension, and arteriovenous fistula (AF) stenosis, uncomfortable symptoms that caused them to feel a lack of mental and physical control over their lives:

I always had trouble sleeping the night before each dialysis visit, worrying that my arteriovenous fistulas would be bad and that my blood pressure would be unstable during dialysis. These are simply out of my control.

I was irritable when my skin itched, and my heart rate was fast. The stress was so high that I often had trouble sleeping. Yet there is nothing I can do about it.

It's not up to me! When you have this disease, it follows you like a shadow. When you feel good, you seem healthy, making you forget about it. But it's not. The disease may just hide somewhere in your body for a while. Sometimes, it can come out of nowhere and take you by surprise.

Subtheme 1.4: Nothing Works

A large number of participants felt that their attempts at self-management had little effect on symptom control and disease outcomes. Participants repeatedly used the phrase "nothing works", implying that they had tried every possible solution but nevertheless failed. This repeated failure caused them to experience a state of helplessness. Participants believed their symptoms of discomfort would never subside and that they might one day die due to uraemia or heart failure. For the participants, "nothing works" entailed more helplessness in the future:

I'm not a medical professional, and I don't have as much literacy as you. Knowing more about dialysis won't help. It's not very effective.

The centre often gives lectures. At first, I attended a few. Later, I didn't think it was too useful, so I didn't attend. I leave it all to the doctors if there are any problems.

I usually take care of my arteriovenous fistulae, such as using potato chips, ointment, and hot compresses. It doesn't feel like it's helping.

Theme 2: Being Tied Down

Participants described their experience of feeling helpless regarding their need to live with MHD day in and day out. They mentioned that their shifting living spaces caused their self-role to transition back and forth between "patient" and "normal". Their confinement to the bed and the dialysis machine forced them to accept the role of the patient. Interviewees referred to this situation as "being tied to the machine", "lying like a fool", and "being part of the dialysis machine". The experience of being tied down caused them to feel as if they were extremely restricted in all areas of their lives, and they lost access to various internal and external resources, such as jobs, friends, time, freedom, self-esteem, and self-worth. This experience of "being tied down" also caused them to be socially isolated and to give in to reality. This domain involved four categories:

Subtheme 2.1: Limitation

Respondents' daily diet was severely restricted. They were required to be extremely careful with respect to their daily

protein, sodium, phosphorus, and potassium intake. Respondents indicated that such dietary restrictions were challenging for them and often caused them to feel helpless:

I used to love eating fruits, but now they are forbidden because they are too high in potassium and phosphorus. Watching others eat fruit is difficult for me. It's torture!

I heard from my doctor that some proteins also contain potassium and phosphorus. Dialysis can cause me to lose a lot of protein, so I have to supplement it to increase nutrition. But I also have to limit the potassium and phosphorus in the protein. I really don't know what to do.

Controlling fluid intake was always a difficult problem for the interviewees. Due to the severe thirst caused by the retention of toxins in their blood, most patients viewed controlling fluid intake as the most difficult part of their lives:

It's hard not to be able to eat as you like. Alcohol is not allowed, and even water has to be controlled. Especially in summer, I'll be dying of thirst.

My body feels bad now. I have to restrict even a sip of water. You don't know; this feeling is too painful!

Subtheme 2.2: Perceived Loss

For some interviewees, the frequent need to travel between the hospital and community for dialysis schedules and the need for rest from dialysis-related fatigue entailed that they lost time and freedom. MHD deprived them of the energy and strength to perform activities they enjoyed, such as applying make-up, cooking, and travelling, which jointly symbolized their former state of health:

I used to love to travel and take pictures. Now that I'm sick, I can't go far anymore. There's not a bit of freedom to speak of.

Once I received haemodialysis, I was welded to the machine, and I could never leave Changsha in my life.

After I got this disease, I gave up a lot of hobbies. I used to love fishing and playing mahjong. Now, I can't do anything anymore because there is no time or strength.

The MHD pattern of at least three treatments per week for approximately 4 hours each limited the interviewees' careers and prevented them from playing their normal social roles. When patients are the sole source of family income, especially male and elderly patients, they often feel that they are losing their social value and express a strong sense of frustration:

With this disease, I am incapable and have to rely on my son, putting burdens on my family.

I often feel quite useless for myself. After retirement, I can't create much value for society and even waste medical resources.

How ridiculous to say that as a man, you have to depend on your wife to support your family! I'm like a loser, dragging down my family.

MHD patients depend on health care providers to support most of their bodily functions. This dependence is inevitable in many cases and entails that participants lose their autonomy and independence. They often have no choice but to relinquish control. After the loss of their autonomy and sense of control, the helplessness of the interviewees seemed to become even more pronounced:

It's come to this, and I have no choice but to listen to my doctor.

I don't dare to doubt the dialysis plan, or the doctor will be angry.

I can only listen to my doctors. After all, they are the professionals.

Subtheme 2.3: Social Isolation

The specific treatment modality of MHD has caused patients' time to become fragmented. Their shrinking living space and lifestyle changes caused them to gradually withdraw from their friend circles. Most interviewees expressed their reluctance to seek help from friends. On the one hand, they were ashamed to discuss their health conditions. On the other hand, they thought that talking to friends would not be of any substantial use. Overall, the interviewees were socially isolated and unable to discuss their condition:

After I started therapy, I slowly distanced myself from my friends around me. They all have their own lives. There is no need to disturb them.

Now, I don't even get together with my friends much anymore. It's not convenient. I'm afraid to bother others because I can't eat this or that.

After I get sick, I don't want anyone to visit me. I'm so tired after every dialysis treatment that I have no extra energy to greet them. It's too much trouble.

Subtheme 2.4: Giving in

MHD patients are somewhat constrained by the current health care system and are therefore forced to accept, be silent, and compromise, which implies some degree of submission. The subtheme "giving in" reveals that in the process of MHD treatment, participants felt as if they have no choice but to accept the support offered by medical staff, regardless of whether they felt comfortable doing so. They expressed their resignation to fate and exhibited a state of "waiting to die":

I've lived to this age, and I'm going to die anyway. Nothing else matters.

I don't have any enthusiasm anymore. I don't know which day I will die. I don't even know if there is a tomorrow after today.

Look at us lying here, one by one, lined up here at Yama. And I don't know when he will find me.

Theme 3: I Am Just a Loser

Despite their various experiences and backgrounds, participants shared many similar feelings and reflections in the face of illness and expressed similar evaluations of their self-state. Regarding each participant's LH experience, "I'm just a loser" emerged as a theme, which suggested a lack of perceived self-value on the part of MHD patients. The complexities of "I'm just a loser" entailed five subthemes:

Subtheme 3.1: Self-Image Disorder

Both ESRD and MHD can cause changes in the patient's appearance. Some participants felt bad about their bodies because of deformities and bloating. For instance, factors such as anaemia, skin pigmentation, endocrine disorders, and AF often lead to a general feeling of self-image disorder, which particularly applies to female patients. This situation causes such patients to feel less attractive:

I've become so ugly now. You see, my skin is dark and a bit oedematous. I haven't dared to look in the mirror for a long time.

It (i.e., AF) is like an earthworm coiled around my arm. It's so ugly that others get scared when they look at it. So, I wear long-sleeved clothes to cover it in the summer.

I used to pay a lot of attention to dressing up daily. Now, I look like a ghost, so I'm not in the mood to dress up. I don't like to go out anymore because I'm afraid of being laughed at.

Subtheme 3.2: Low Self-Concept

ESRD limits the patient's ability to work, and frequent MHD severely affects their work and life. As a result, many MHD patients lose their jobs and the corresponding financial resources. Most interviewees perceived their contribution to

society and family as having been diminished, resulting in a decreased or lost sense of self-worth. In this situation, they often referred to themselves as “losers”:

Now, I feel like a loser. I can't earn money anymore and keep spending my wife's money. I have no dignity as a man.

I used to have a high status and a strong personality in my company. But after I got sick, everything changed completely. I always feel that people are gloating behind my back and laughing at me for not being as good as them anymore.

When I got sick, I lost my friends around me. They look at me differently. It's the feeling of being a loser when you're in trouble, you know? My neighbours aren't as warm to me as they used to be.

Subtheme 3.3 Negative Attitudes

MHD patients often need more social support and opportunities to interact with the outside world. After starting MHD treatment, the patient's relationship networks often changes substantially. Patients are often very vulnerable and become very sensitive to interpersonal relationships. On the one hand, they crave the care of others. On the other hand, patients are sceptical and negative with regard to external support systems and find it difficult to be understood by others:

When you're sick, everyone else's concern is fake. No one wants you to get well.

Now, I don't talk to others about my illness actively. Any concern from friends is just superficial support because they can't solve anything.

With this disease, I don't want to talk or communicate with anyone. I want to be alone because no one can understand my pain.

Some respondents denied the possibility of experiencing different emotions in the future and believed they could never feel happy again. They claimed that laughter was just a disguise for them:

It's impossible to be truly happy with this disease.

There is no lowest point in my emotions, only a lower point. (bitter laugh)

Difficulties come, and I can never laugh from inside again.

Subtheme 3.4: Guilt

This theme refers to the patients' guilt regarding dragging their family down with their illness. Respondents expressed a sense of uselessness because they could not contribute to their families and needed their families' care. As a result, respondents often perceived themselves as burdens to their families and society. They felt a distinct sense of guilt and shame regarding the financial pressure and caregiving burden they put on their families. They also feared socializing with friends and neighbours due to the fear of prejudice and causing trouble for others. In this regard, respondents often described themselves as “burdens” and “encumbrances”:

My poor health is a drag. My daughter's boyfriend's family minds this. She has not married until now, and I feel indebted to her.

In this condition, I can't take my wife out to travel after retirement. She has been busy most of her life, and now she has to take care of me. I feel that I owe her too much.

After I got sick, I didn't dare to hold other people's children, worrying that they would dislike me. I know they don't think so, but I have low self-esteem. I can't affect other people's moods, right?

Subtheme 3.5: Abandonment

Respondents reported that they were more likely to abandon treatment and self-management when they felt helpless about the future. It was difficult for them to persevere with regard to the diet, water restrictions, and physical activity recommended by their physicians when they experienced LH. Some of the respondents even expressed the notion of

giving up on life and shared self-destructive experiences, especially participants with lower economic status and more comorbidities. The perception of the irreversibility of ESRD and the experience of a failure of symptom control magnified their helplessness. The feeling of helplessness decreased their motivation to adhere to treatment and live:

If I run out of money, I'll give up treatment. It doesn't matter if I live or not. It's my fate.

After not working, finances become my biggest problem. I do not have the financial conditions to pay for a kidney transplant, and the cost of dialysis is a big problem for me (tears in his eyes). If I don't have any money, I won't get dialysis. Let fate take its course.

I have so many problems in my body. I take a dozen kinds of medicine as a meal every day. I feel that there is no hope for my life. Because I take too much medicine, I often vomit. Sometimes, I really want to die.

Theme 4: Alive Day is the Day

Participants acknowledged that their helplessness may never end and that it was helpful to find a way to come to terms with this reality. When discussing their ways of coping with chronic LH, most respondents expressed an approach based on passive acceptance and compromise. The phrase that they used most often was “alive day is the day”. In a way, “alive day is the day” reflects a natural approach to life in which one does not dwell on the facts of one’s illness and does not make any assumptions about the future. In their experiences of coping with LH, participants tended to find a fatalistic explanation for their disease. The interviewees highlighted their responsibility to their families, which offered them the courage to live while facing this fate. They also found self-esteem and solace in social comparisons with groups that were less fortunate than themselves. We derived three subthemes from this theme:

Subtheme 4.1: Fatalism

Respondents reported a sense of fear and helplessness when they were told that they had lifelong incurable ESRD and needed MHD. At this point, their minds were filled with questions such as “why me?”. The interviewees tried to explain their disease by reference to fate, karma, and reincarnation. Explanations such as “fate cannot be disobeyed”, “destiny”, and “this is all my karma” seemed to mitigate their anxiety regarding death, decrease their uncertainty, and allow them to rationalize their illness and suffering. This fatalism seemed to help them cope with their helpless state:

Life is too unfair to me. I can only blame my bad luck.

Sometimes in life, there must be something. That's my destiny. I must have done something bad in a previous life, and now I'm here to pay my debt.

I always ask: ‘why me?’ I can only blame my bad fate. Sometimes, I complain about the unfairness of life. How people are so different from each other? (shaking his head)

Subtheme 4.2: My Duty

Taking responsibility for one’s family was a common coping strategy used by participants. Chinese culture has always aimed at a family reunion, which is the embodiment of familism. Respondents reported that children, parents, and family were important motivators with regard to preserving their will to live. In the face of overwhelming helplessness, patients constantly mentioned the significance of their existence as an important psychological resource that allowed them to accept and endure helplessness. This situation implies that they were willing to persevere for the sake of their families. They developed the courage and motivation to continue living based on their family responsibilities.

With respect to their parents, respondents consider living to be an expression of “filial duty”:

Alive day is the day! My only hope is that my parents will be healthy. I hope I can die after them so they won't be sad about my death.

Let it be! It is useless to complain. We can't live only for ourselves. We must be responsible for our family and think more about our parents. My parents, it's not easy for them to raise me, and now they have to take care of me when they are old. So, I have to live and can't let them down.

Among married respondents, the growth and future of their children were often identified as their biggest concern. Many interviewees tended to look to their children as an important form of spiritual support to help them persevere:

As the saying goes, 'there are old and young at home'. I am the backbone of the family. My child cannot grow up without his father, so I must keep living.

My only hope for survival is to be there for my daughter as she grows up. I also want to see her get married and have children.

Subtheme 4.3: Downwards Comparison

Respondents discussed a particular way of helping themselves through helplessness, namely, downwards social comparisons. This strategy included comparisons with others with serious illnesses (disabilities, cancer, paralysis) or lower social status. Respondents tended to choose a lower-level reference point to evaluate themselves, which provided temporary relief from their intense feelings of injustice and helplessness. This downwards comparison strategy can help patients move from being helpless to being survivors:

Worse off than some, better off than many. For me, it's enough to keep living.

This disease (i.e., ESRD) is a little better than cancer. I can barely live regardless of my quality of life.

Compared with other people in poor health, I can take some comfort. And compared to homeless people, I am still lucky. I have everything I should have. There's nothing to regret.

Simultaneously, the respondents noted that they were encouraged to focus on people in worse situations who were striving diligently to live. Some respondents even highlighted their willingness to help others in any way they could and to contribute to society (eg, by community volunteering or organ donation):

Look at how hardy some disabled people are and how strong their desire to survive is. Their courage especially touches me.

I've learned about organ donation before. If conditions allow, I would like to donate my organs after I die. It would be a contribution to society.

Discussion

This study is a preliminary phenomenological exploration of LH in MHD patients in the context of disease, treatment, and survival. Although the experiences of participants in this study varied, they largely acknowledged that they faced similar challenges. First, the study confirms the correlation between LH and a lack of control.^{29,30} As a key aspect of living with ESRD and MHD, LH stems primarily from the patient's perception of being "out of control". Respondents reported feeling a strong sense of powerlessness and hopelessness at the beginning of their ESRD diagnosis and HD treatment.³¹ They understood that this process indicated an uncontrollable decline in kidney function.³² Multiple complications and dietary restrictions increased their perceived lack of control. For these participants, these barriers seemed almost insurmountable.³³ Patients who were chronically exposed to this condition experienced a lack of control over their bodies and minds, thus leading to LH.³⁴ Health care providers and authorities should implement effective interventions (eg, empowering education) to increase the perceived control of MHD patients.³⁵

MHD patients' LH is also the result of the perception that "nothing works" even after all their efforts. According to Seligman, when an individual exhibits a specific response, if the expected result does not occur, the cognition that "nothing works" is formed, thus leading to the destruction of hope and inducing helplessness.³⁶ Due to the irreversibility of ESRD, MHD patients are prone to accept the implication that "trying is futile". They believe in the futility of their health-related behaviours and the inevitability of bad outcomes. "Nothing works" causes them to feel helpless and

hinders their self-management behaviours or treatment adherence. Using cognitive therapy³⁷ and behaviour change theory³⁸ to develop and implement supportive interventions can help reduce MHD patients' LH.

Loss of hope and LH are empirically linked,³⁹ including among MHD patients. Experiences such as the failure of PD, matching, and kidney transplants destroy their hopes and cause them to continue thinking about the helplessness that they have experienced. Health professionals should help patients take account of their future options and remain hopeful regarding treatment and life. Support techniques, such as three good things,⁴⁰ gratitude journaling,⁴¹ and humour interventions,⁴² can enhance hope. Notably, respondents repeatedly noted that their helplessness increased when they witnessed renal friends' negative events. According to Bandura, humans can also learn from observation.⁴³ When individuals project others' experiences of helplessness onto themselves, a feeling of being unable to change and powerlessness arises,⁴⁴ which is known as vicarious helplessness.¹¹ The group helplessness and vicarious helplessness effects of renal friends should be emphasized and monitored.⁴⁵

Charmaz⁴⁶ argues that chronic illnesses can restrict patients, causing them to experience social isolation, shame, and guilt. These experiences affect their sense of self and can lead to self-identity loss. This view echoes two themes of this study, ie, "being tied down" and "I am a loser." Similar to the findings of Perez et al⁴⁷ being tied down is characterized by restriction, a sense of loss, social isolation, and submission. Patients must visit the hospital 2–3 times per week for 4–5 hours of HD, during which they must lie in a hospital bed.⁴⁸ The restrictions on the patient's life, body, and time are so pronounced that the patient is referred to as being "on duty" without vacation. This treatment mode feels like "being tied to a machine" for the patients. In addition, patients must shape their diet and water intake in accordance with severe restrictions. Understandably, this potential lifestyle causes extreme helplessness for the patient.⁴⁹

Patients are likely to experience multiple losses because of their illness.⁵⁰ The losses highlighted by this study include loss of time and freedom, independence, body image, self-worth, and potential future losses. Similar losses have been documented in the context of other chronic illnesses.^{51,52} In this study, one-third of the participants referred to "giving in", which mirrors similar descriptions in other studies of chronic illnesses.^{47,53} Participants often claimed that "there's nothing I can do" because they were aware of their inability to control their illness and were forced to accept it. This forced acceptance coping style increases helplessness and resignation.⁴⁷ The subtheme "social isolation" reflects the reality of MHD patients' shrinking social circles due to the state of "being tied down". The fixed treatment model consumes most of the patient's time and energy, leaving them with no opportunity to socialize.⁵⁴ On the other hand, they actively seek new social circles, such as the "kidney friends circle", because they can provide each other with psychological comfort and exchange their experiences with disease management.⁵⁴ Medical staff and social workers should help patients rebuild their social confidence and social skills.⁵⁵

Respondents tended to define themselves as "losers". This theme reflects the self-image disorder, low self-concept, guilt, negative attitudes, and abandonment or behaviours of MHD patients experiencing helplessness. Similar to the findings of Yilmaz et al⁵⁶ treatment and comorbidities often lead to changes in patients' appearances, and patients feel shame and helplessness due to self-image disorder.⁵⁷ In addition, patients often develop a low self-concept and a sense of uselessness due to their inability to realize their self-worth. Care and support from family members cause patients to feel warm but simultaneously lead to guilt.^{24,58} Chinese people are introverted and are accustomed to suppressing their negative emotions. Therefore, after the internalization of helplessness, MHD patients are prone to experience negative perceptions such as denial and avoidance. These negative attitudes, in turn, exacerbate their current helplessness and weaken their motivation to use social and psychological resources to help them cope with the difficulties they face.²⁴ Acceptance-centred counselling modalities, such as acceptance and commitment therapy (ACT),⁵⁹ play important roles in helping individuals adjust to MHD and the accompanying life changes, improve their negative attitudes, and increase their self-identity.

Lazarus and Folkman suggested that the impact of stressful events depends on the individual's interpretation of those events.⁶⁰ As treatment progresses, MHD patients develop an "alive day is the day" mentality. "Why me" is a sign of helplessness and implies a sense of powerlessness in the face of fate.⁶¹ Patients try to explain and cope with the disease through fatalism. This attribution style functions as a cultural resource to explain the helplessness of MHD patients and can help them alleviate that helplessness to some extent. On the other hand, fatalism may change their attitudes and behaviours regarding their experience of the disease.⁶² Once patients attribute their disease to fate; such patients may

believe that death is unpredictable and inevitable and that no one and nothing can change the outcome.⁶³ This belief represents a significant barrier to patients' health behaviours and adherence. Medical staff can make an effort to identify patients' cognitive biases and use professional psychological training procedures to ensure that patients' perceptions remain objective and rational.

The findings of this study also highlight the critical role played by family responsibility in coping with helplessness in people with MHD. These findings are similar to those of other studies.⁶⁴ In China, the traditional cultural value of "filial piety" remains prominent.^{65,66} Staying with parents, decreasing their worry, and dying after them represent the beliefs of MHD patients that allow them to commit to living with helplessness. In addition, raising children is often an important spiritual motivation for Chinese patients, which can even serve as an expression of their self-worth.⁶⁴ Supported by a sense of family responsibility, patients find meaning in their existence and persistence in treatment.⁶⁷ The "alive day is the day" model also includes a downwards comparison strategy that is consistent with Wills' Downward Comparison Theory.⁶⁸ This theory suggests that when individuals experience adverse events, they tend to compare themselves to others who are worse off than they are to maintain their self-esteem and subjective well-being.⁶⁹ This situation suggests that future studies should intervene with regard to positive social comparisons and guide patients to find meaning and motivation in their lives.^{70,71}

Limitations and Strengths

Collecting the interviewees' body language and expressions as additional information offers the reader rich insight into the LH experiences of MHD patients. The first author (interviewer) has a strong background in nursing theory and psychology. This background may have influenced her conversations with and reflections on the participants during the study. The other authors are researchers and managers with extensive experience in the health sciences. Throughout the analysis, the authors attempted to remain open to the text and to reflect critically on each other's interpretations. Discussions with researchers outside the team led to a deeper understanding of the text.

However, it should be noted that the sample was drawn from a specific geographical and sociocultural context. Second, the study did not include patients who did not experience helplessness, which may have caused some potential messages regarding successful coping with helplessness to be missed. Another limitation of this study is that some participants shared their experiences of helplessness from more than a decade ago, which may have affected the accuracy of their memories.

Conclusion

This study describes the unique phenomenon of LH and its properties as experienced by people with MHD. From a theoretical perspective, the findings of this study support the claim that greater attention must be given to psychological processes and variables when designing relevant interventions and conceptualizing LH in the context of MHD patients within a resilience framework. From a practical perspective, this study highlights the need to assess the motivation for and behaviour associated with LH in patients with MHD.

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Disclosure

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