

ORIGINAL ARTICLE

The lived experience of late midlife hemodialysis patients with diabetic nephropathy

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ABSTRACT

Background: Diabetic nephropathy is the primary reason that patients receive hemodialysis (HD), a frequent and lifelong treatment. However, HD is burdensome for middle-aged individuals, who still have personal and professional responsibilities, and can have a significant and disruptive impact on their lives.

Aim: This study seeks to better understand the daily life experiences of middle-aged patients with diabetic nephropathy who are receiving HD.

Methods: This qualitative study used purposive sampling to recruit participants from a teaching hospital in southern Taiwan from November 2014 to May 2015. The data was collected through in-depth interviews from 12 middle-aged diabetic nephropathy patients receiving HD. Data analysis was performed using Colaizzi's phenomenological method.

Results: The significant statements were categorized into four themes and 10 subthemes: (1) Mental and physical suffering: shock and refusing HD, loss of control in certain aspects of life, burdened with complications from diabetes and HD conditions. (2) Social isolation: barriers to normal life and leisure activities, financial hardship resulting in reduced self-esteem. (3) Moving toward a new adjusted lifestyle: acknowledging illness and accepting HD, changing their perspective towards HD, learning to improve their own health, and (4) End-of-life evaluation: appreciation of life and death, coming to terms with mortality, and increased time spent with their families.

Conclusions: The findings of this study showed that middle-aged patients receiving HD typically underwent a process of mental and physical suffering to adaptation and end-of-life reflection. These findings can help health care providers and family members better understand the experiences and hardships of patients receiving HD, which allows for better support and improved nursing care.

Key Words: Diabetic nephropathy, Hemodialysis, Lived experience, Middle-aged, Qualitative study

1. INTRODUCTION

According to the 2014 United States Renal Data Systems (USRDS), Taiwan was ranked first in prevalence and second in incidence worldwide for end-stage renal disease (ESRD) in 2012. Diabetic nephropathy is one of the main

reasons patients develop ESRD and later receive hemodialysis (HD).^[1,2] After receiving HD, many patients suffer from physical discomfort and mental distress and experience social difficulties with respect to employment^[3] and family responsibilities.^[4]

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Late midlife is the stage of transition from midlife to older adulthood, during which individuals often continue to hold financial responsibilities, such as caring for their parents and helping with their children and grandchildren. In Ericson's lifespan development model, generativity in midlife is the step before ego integrity in the last stage of development.^[5] The chronic and progressive nature of ESRD, which requires going for HD two to three times a week, however, may make it difficult for patients to fulfill their family and social responsibilities. Review of the literature has found that few study of HD focus on this age group. The lived experiences of late midlife diabetic nephropathy patients with HD have not been explored and must be studied to provide nurses with greater insight into their patients' lives and understand what their patients are going through. In doing so, nurses will be more prepared to identify the patients' suffering and be more empathetic to their difficulties. When patients are understood by their providers, they feel more safe and secure, allowing them to better adapt to and live a fulfilling life with HD.

Literature review

The American Diabetes Association^[6] reports that 20%-40% of diabetic patients will develop ESRD and will need to receive renal replacement therapy to stay alive. Because HD is effect at removing uremic molecules and excessive fluid, it has become the most common treatment for patients with ESRD. Although HD can alleviate renal function damage, this long-term treatment also has a great impact on patients' everyday lives. At the physiological level, patients often experience fatigue, pruritus, muscle cramps, nausea, and restless sleep.^[7] During the HD process, diabetic HD patients are more susceptible to complications of hypotension than nondiabetic HD patients.^[8] At the psychological level, it often is difficult for patients to accept that their condition is irreversible and that they will need HD for the rest of their lives. Being forced to rely on HD to survive and having numerous restrictions placed on their daily lives can make the patients feel enslaved to dialysis.^[9] The patients often feel a loss of control in their lives, powerlessness, loneliness and fear that something will go wrong with the fistula.^[10]

Some patients miss the time lost to dialysis, and the inability to use it for other activities.^[10] In the HD center, health care providers focus primarily on the pathophysiology of the treatment, such as lab values and physical complications, and rarely have time for the patients' emotional needs. Patients will sometimes still feel ill, for example, despite having normal lab values. Furthermore, in an open dialysis center, patients often lack the privacy to discuss personal issues with their nurses.^[11]

Patients receiving HD often encounter obstacles to social

interaction^[12] and may experience social isolation.^[13] Those who continue to work often need to adjust their work schedule around treatment. Their colleagues are forced to pick up the slack, and the patients feel that they are a burden in the workplace.^[11] Furthermore, the physiological discomfort caused by diabetes and HD as well as the need for frequent treatment may restrict the patients' career options, forcing them to switch to less demanding jobs or even stop working altogether. The long hours required for treatment inevitably leave less time for family and can be disruptive to family life as well. Forced to go from being a caregiver to a care receiver,^[4] HD patients may perceive themselves to be a burden to others and feel ashamed to face their family members.^[3] Being unable to work and having additional medical expanses can also put a strain on the families' finances.^[3] At the spiritual level, HD patients experience hopelessness that they must depend on an HD machine for the remainder of their lives,^[3] and the feeling of disability diminishes their sense of self-worth.^[14] Other patients interpret receiving HD as "bad karma" and "having to pay for debts from past lifetimes" arising from the belief in reincarnation.^[15]

Middle age is the seventh of Erikson's stages of psychosocial development, and the developmental task of that stage is "generativity", in other words contributing something meaningful to society and future generations.^[16] Although Erikson does not give a specific task for late midlife, but he believed that active engagement in community activities and social well-being contribute toward the development goal of the last stage of life. If these tasks are unfulfilled, a person may feel "stagnant", lose self-esteem and purpose, and feel regret and loss of control of his or her fate. The patient's individual identity and public identity are greatly affected.^[5] Late midlife HD patients often face job loss, financial insecurity, physical illness and treatment. Multiple limitations stand in the way of generativity and, in order to overcome these obstacles, they may need to modify their perceptions of illness, change their approach to generativity, and reorient their life goals.

Taiwanese society views late midlife as the "mature years", during which the individual is responsible for guiding their young adult children in establishing their career and families while also taking care of their older parents. Late midlife HD patients suffering from chronic and progressive kidney disease and undergoing HD, however, are often unable to perform demanding work because of their reduced physical fitness. In addition, since dialysis is required three times a week for four hours each time, these patients can only engage in jobs with flexible hours.^[17] The challenge of managing these roles and responsibilities may often exacerbate psychological responses such as tension, frustration, and

depression.^[18] One qualitative study of HD with patients ages 30–45 in Sweden, showed that patients' in this age group have a strong need for freedom and desire for other activities besides undergoing HD. They tried to perceive dialysis as having only a small part in their lives. Several participants felt lonely and had difficulty initiating intimate relationships.^[10]

Despite these unyielding restrictions, which may impede patients from fulfilling their perceived responsibilities and pursuing their dreams, many patients transition from feeling captive to moving toward acceptance and reconciliation with these limitations.^[19] Many theories can explain the adjustment and experiences of people undergoing HD. According to the role theory perspective, HD has a similar trajectory to other chronic illnesses: patients undergo an initial treatment that limits their ability to fulfill some of their current responsibilities. Once their condition has stabilized but still requiring continual treatment, some patients incorporate changes to redefine themselves in a new social context and are able to adjust, even achieving a sense of generativity. Others view chronic illness as crippling and have difficulty accepting change and new behaviors.

2. METHODS

2.1 Design

The qualitative study was conducted using Colaizzi's phenomenological method^[20] which seeks to elicit contextually grounded phenomenon with richness and evidential value to gain insight into the human experience. The Colaizzi process for phenomenological data analysis consists of seven steps. The first six are similar to most qualitative data analysis; however, the seventh step is to validate the research

findings by returning to the participants and determining alignment between the results and the participants' experiences and feelings. This phenomenological approach is fitting for exploring the feelings, perceptions, and uniqueness of the HD experience of middle-aged HD patients with diabetic nephropathy.

2.2 Study participants

This study employs purposive sampling with the following inclusion criteria: (1) Patients diagnosed by a physician with diabetic nephropathy and requiring long-term HD – since most patients' physiological problems are alleviated three months after receiving HD,^[12] this study interviewed only patients who had already received treatment for three months or more and were still receiving treatment periodically; (2) Patients aged 40–64 years old; (3) Those having no hearing loss and able to communicate in Mandarin or Taiwanese Hokkien; (4) Those having no mental illness or organic brain disease; (5) Those consenting to participate and have their interviews recorded.

A total of 12 middle-aged HD patients with diabetic nephropathy (7 men and 5 women) were interviewed in this study (see Table 1). The average age was 57.9 ± 4.2 years, with nine people between 50 and 60 years of age. Of the 12 participants' social support, 10 were married and 10 lived with their family members. In terms of employment, 10 were unemployed, and two assisted in family businesses (restaurant and farming). A majority of the participants had completed senior high school ($n = 5$) and believed in Taoism ($n = 7$). The average length of HD treatment was 48.5 ± 25.1 months, with the majority of participants undergoing HD for 2–5 years.

Table 1. Participant demographics

Number	Gender	Age	Age of DM	Years on dialysis	Employed	Marital status
A	male	51	35	3y0m	No	Divorced
B	male	57	39	2y10m	No	Married
C	male	50	44	5y6m	No	Single
D	male	61	25	4y6m	No	Married
E	male	59	53	5y4m	No	Married
F	female	64	43	0y10m	No	Married
G	male	59	47	2y8m	Yes	Married
H	female	58	50	4y2m	No	Married
I	female	54	35	9y3m	Yes	Married
J	female	64	51	2y0m	No	Married
K	female	59	57	3y3m	No	Married
L	male	59	36	5y5m	No	Married

2.3 Ethical considerations

This study was approved by the hospital's institutional review board (IRB number: IRB469A). The research purposes, potential costs and benefits of participation, measures used to safeguard participant confidentiality, and rights to withdraw from the study at any time were explained to the participants in detail before the interviews. Patients who agreed to participate in the study were asked to sign a consent form.

2.4 Data collection

Participants were recruited at the HD room of a regional teaching hospital in southern Taiwan. This unit completed 4,400 HD treatments per month, including 280 long-term HD patients. From this subset, 28 were middle-aged HD patients with diabetic nephropathy. After the participants signed a consent form, a researcher conducted semi-structured 50-to-90-minute in-depth interviews with them in the hospital consulting room or at the participants' homes.

A preliminary study was conducted with two participants to produce a revised interview guide: (1) What are your feelings and thoughts after receiving HD? (2) How does HD affect your daily life? (3) What problems have you encountered after receiving HD? (4) How do you handle the effects of HD on your daily life? (5) What does HD treatment mean to you?

The interviews were recorded on two recording pens to document the participants' descriptions of their lived experiences. In addition, a reflective journal was compiled during the study period. No new themes emerged after 10 participants had been interviewed, indicating that the qualitative data had reached saturation. The researcher nevertheless continued to interview two additional participants to ensure data saturation.

2.5 Data analysis

Colaizzi's^[20] phenomenological method was adopted for this study and the data were analyzed following these seven steps: First, the recorded audio content was transcribed verbatim within 72 hours. These transcripts were read and reread to get the whole picture of the data. Any thoughts, feelings, and reflections that arose during the interview and the reading and rereading phase were written in a journal to develop a context of HD experiences. Second, significant words, phrases, and sentences in relation to the core meanings of the experience of middle-aged HD patients with diabetic nephropathy were extracted from the transcripts in an iterative process through discussions among the researchers, yielding a total of 30 core meanings. Third, clustered core meanings were grouped into 10 subthemes. Fourth, the subthemes were further clustered into four themes in the next level of abstraction. Two clin-

ical experts who hold master's degrees in nursing and are experienced in qualitative research were asked to review the extraction of core meanings, subthemes and themes. Fifth, when new core meanings emerged during the above process, they were incorporated into the phenomenological concept description until an exhaustive description had been reached. With the core meanings, subthemes, and themes established, a whole basic structure emerges. Sixth, redundant or inappropriate categories are removed to form a detailed holistic description. Seventh, to maintain the rigor of the qualitative study, two participants were invited to validate the research findings of the core meanings, themes, and subthemes.

3. RESULTS

Analysis of the data resulted in the identification of four themes and 10 subthemes. The four themes are: (1) mental and physical suffering, (2) social isolation, (3) moving toward a new adjusted lifestyle, and (4) end-of-life evaluation. These themes were constructed from different clusters of formulated meanings, and each includes several subthemes that illustrate different characteristics of that theme. Finally, a thematic map was developed for this study based on the four themes.

3.1 Mental and physical suffering

When informed by a physician of the need to receive HD, eight of the participants reacted with "shock and refused HD". Because they would have to undergo HD, cope with the side effects, and change their lifestyle, including diet, schedule, and physical activities, for the rest of their lives, these participants felt they were "losing control". In addition, being "burdened with complications from diabetes and HD conditions" had affected their physiological health, causing physical and mental suffering.

3.1.1 Shock and refusing HD

The participants were shocked when they were told HD is the only treatment for their kidney disease. Some participants regarded surgery for a fistula or graft and HD as intolerable, due to the enormous life changes and restrictions of this life-long treatment. Some felt that life was not worth living and viewed death as an escape from HD.

Mr. D: "Since 2010, when I started HD, I gradually lost time and my vigor, so I also thought about suicide. I was going to burn charcoal, stuff a blanket under the door and close the windows tightly . . . just because my way of life would be so different."

3.1.2 Losing control

The participants felt that in order to survive they had no choice but to accept HD. They had to modify their desires,

lifestyles, and life goals to cope with the disease. Physiological discomfort limited their activity and forced them to rely on their family members, which elicited feelings of shame and the sense of being a burden to their family. In addition, the effects of the disease rendered them unable to fully assume their original roles, causing them to devalue their own self-worth.

Ms. I: *“When I was about to start to receive HD, I thought I was going to be so useless! . . . I could not work anymore. . . , and it was as if my life had lost all color! Everything was dark. . . . I went from being perfectly healthy to needing to have HD. I was also in such a bad mood. I felt very helpless, like I was a burden on my family. My illness alone would be such a hassle to everyone in the family. It was a huge burden.”*

3.1.3 Burdened with complications of diabetes and HD conditions

At the physiological level, participants often experienced complications from diabetes, such as peripheral neuropathy in the feet, blurred vision, hypotension, fatigue, dizziness, anemia, dry mouth, loss of appetite, sleep disturbances, and itchy skin. Among these, hypotension was the most common symptom and the symptom that participants worried about the most.

Mr. B: *“If, for example, they inserted the needle at 5:00, my blood pressure would definitely drop by around 8:30. If I looked around and there was no nurse nearby, I would feel very worried. The blood pressure was really very low. . . . I felt dizzy and uncomfortable. . . . My vision was blurred if I watched television.”*

3.2 Social isolation

Companionship is a universal human need that enriches people’s lives. Most people belong to different social groups over their lifetime, during which people are bound by reciprocity, caring, and responsibility. HD patients with diabetic nephropathy often experience physical discomfort, a restricted schedule due to treatment, and complications from HD. This chronic condition forces them to curtail their activities within these groups. Financial hardship resulting from HD can add stress to relationships and cause low self-esteem. “Barriers to normal life and leisure activities” and “financial hardship hurting one’s self-esteem” are two subthemes under social isolation.

3.2.1 Barriers to normal life and leisure activities

Blurred vision prevented participants from taking care of themselves, and leisure and social activities were often restricted by physiological problems and the time consumed by undergoing HD. As a result, participants may no longer feel

included in their social support networks and withdraw from their former social circles. Some spent most of their time at home, isolating themselves from the world, and did not go outside except on days of treatment. With a diminished social network, life became much more dull and boring.

Mr. E: *“I could not participate in leisure activities anymore. I even had trouble walking, not to mention running. . . . My life was what others would call very boring. Other people’s lives were so interesting, but we had no choice.”*

3.2.2 Financial hardship hurting one’s self-esteem

For those who are approaching the end of their peak earning period in their late middle-aged years, job loss due to physical illness can trigger psychological distress. Ten participants could not work because of physiological discomfort and frequent HD treatment. The other two participants continued to work but had to reduce their hours. The financial strain was especially hard on the participants who used to be self-sufficient family breadwinners and were suddenly forced to reduce their expenses, depend on family and friends, and rely on government support to maintain a basic living.

Ms. I: *“If I worked for a long time, I got tired quickly. When farming, I could not exert myself too much and it could not be too hot. My health has gotten worse now. I try my best, but I can’t do as much as everyone else. . . . Some of my time was tied up with getting HD, and I wanted to work but was not able to. . . . With HD, my expenses increased, so my financial situation was not that great anymore. . . . but I received disability allowance each month. That was how I got by.”*

3.3 Moving toward a new adjusted lifestyle

Based on their physical symptoms of illness, the participants knew that medical attention was a must. The participants gradually accepted their irreversible condition and its treatment and were able not only to “coexist” with HD, but also to find strategies that allowed them to exercise control over their life and achieve new goals. Emotionally, participants moved from denial to acceptance in which they made adjustments to maintain a normal life within the limits of HD. The three subthemes are “accepting HD”, “changing their perspective towards HD”, and “learning to improve their own health”.

3.3.1 Accepting HD

Strong support from friends, family members, and health care providers helped patients realize their health condition was beyond their personal control and that they must give up part of their personal autonomy to the medical world in order to stay alive. Confronted with the impossibility of a cure, HD patients became accommodating toward dialysis and its associated restrictions on their daily lives. They be-

came open to receiving care from their social network (close relatives, friends, health professionals, and religious groups) and strived to become well.

Mr. G: *"I didn't want HD before. I already felt ill then. So...my wife thought I should go see a friend. My friend encouraged me to receive HD. Ever since then, I said OK. I told the physician that I wanted HD."*

3.3.2 Changing their perspective towards HD

Patients accepted HD through a variety of means. Some interpreted it religiously, as atonement for past misdeeds; some decided they had to change their negative outlook; some thought that they would first observe the benefits of HD; some adopted HD as a routine task; some simply managed to face the reality of HD. Searching for meaning and constructing meaning is a common coping mechanism humans use when facing difficulty. The participants defined their own meaning in life and tried to make rational decisions in the face of kidney failure and uncertainty about their future.

Mr. A: *"I eventually thought of it as just facing reality and having the courage to accept it. ... Perhaps it was because I had changed my perspective, I went (to receive treatment) happily and left happily! ... Anyway, I did not see it as treatment, I saw it as a few hours of work; I went there, chatted with the nurses, watched TV, and slept. Now, I just pretend I am there for vacation!"*

3.3.3 Learning to improve their own health

Participants became more knowledgeable about HD and endeavored to adhere to healthy behaviors that would prevent their symptoms from worsening. The participants gradually regained a sense of control over their own health. They started to modify their lifestyle habits and follow medical instructions to control their diet and perform fistula care. They also observed adverse physical reactions of HD, controlled their body weight, and made themselves comfortable during the HD process.

Ms. K: *"Like the nurses suggested, I ate healthy and drank less. I would have just a few sips of water instead of an entire cup. ... I ate boiled vegetables without adding salt or soy sauce. I just ate them like that, very bland, and I avoided oil. ... The nurse said that my blood vessels were hardened, so injections were painful. ... So I was very diligent with hot pads and exercise balls to protect my blood vessels."*

3.4 End-of-life evaluation

Late midlife is an age in which many confront the mortality of their parents, their peers, and themselves, and, as a result, late midlife adults tend to have an increased desire to connect with friends and relatives and reconcile their relationships with themselves and others. Many participants experienced

repeated disease-induced pain. As a result, they were acutely aware that their health was slowly deteriorating and that they were more likely to die earlier than their peers without HD. They had envisioned their death and had an opportunity to evaluate their life over the course of repeated hospitalizations. This made them "appreciate life and death". Because they felt that death was approaching, they also recognized the limited nature of life and learned to seize the moment. The participants focused more on "treasuring time with their families".

3.4.1 Appreciate life and death

Although the participants' symptoms were somewhat alleviated after starting HD, their health status often fluctuated over time. In addition, witnessing the death and decline of their fellow HD patients often caused the participants to feel as though death was present. Uncertain about how much more time they had, the participants could only live one day at a time while mentally preparing themselves for death. While recounting these feelings during the interview, they also lamented that they had few expectations left for their lives.

Mr. A: *"I had stayed in the intensive care unit twice while receiving HD. ... so I was already mentally prepared. I was going to die sooner or later anyway, and my illness was quite serious. I do not know when it will be time to go. ... But I have already told my son that if something happens to me suddenly, I do not want to be resuscitated. I feel that if people die, they should die with dignity."*

3.4.2 Treasuring time with their families

When asked what HD meant to them, many participants were grateful that their lives were being extended, enabling them to spend more time with their family members. Many of the participants were willing to maintain their health for the sake of their families and focused more on the health and happiness of their family members.

Mr. C: *"My mother is still alive. She is my responsibility no matter how much I have done for her ... and how much we have been through, good or bad. Now that I am on HD, as long as I can spend more time with her, as long as she is healthy and safe, then I am happy."*

4. DISCUSSION

There were four main themes in the lived experience of middle-aged HD patients with diabetic nephropathy: "mental and physical suffering", "social isolation", "moving toward a new adjusted lifestyle", and "end-of-life evaluation". The eight participants who experienced "mental and physical suffering" had difficulty facing the additional hardship of nephropathy after suffering from diabetes for many years

and thus resisted HD. This experience differs from that described by Tu,^[12] who believed that diabetic patients prepare mentally at an early stage of diagnosis for the possibility of having to receive HD at any time, and therefore do not resist the idea of it. This difference might be attributed to the sample size used in Tu's study, in which only two HD patients with diabetic nephropathy were interviewed. Such a limited sample cannot reflect how late middle-aged diabetic nephropathy patients react toward HD. However, our findings are in accordance with those of Harwood, Wilson, Cusolito, Sontrop, and Spittal,^[21] who reported that HD patients often experience negative emotions after receiving HD, including feelings of helplessness, sorrow, depression, and dejection, and the side effect that worried the participants the most was hypotension. Wu, Yang, Lin, and Lee^[22] also found that low blood pressure is the most common complication of HD.

The main causes of "social isolation" were physiological discomfort and the need to undergo HD frequently, which resulted in job loss or reduced hours, financial pressure,^[23] limited social interaction, and social isolation.^[3] Compared to past studies, this investigation mostly found similar reasons to why participants could not work. Blurred vision, which was not mentioned by past studies, was also an important factor preventing the participants in this study from working, most likely because this study focuses on diabetic HD patients. Participants with diabetic retinopathy and neuropathy frequently encountered obstacles in self-care and had to rely on others for assistance. Tsai^[24] similarly found that these obstacles further aggravated the restrictions imposed on the activities of daily living in patients with diabetic retinopathy and neuropathy.

In terms of "moving toward a new adjusted lifestyle", many participants gradually accepted HD with the help of their social support systems. Participants were able to rebalance their lives by keeping the disease and symptoms under control and fitting HD into their lifestyle to stabilize their conditions. This is consistent with Liu, Hsieh, Luo, Ma and Chang,^[25] which found that social support from family and friends, health professionals, and religious groups could help HD patients develop positive coping behaviors. In addition, the participants gradually accepted HD psychologically when they saw that the treatment could improve their physiological discomfort. Lin^[26] and Jonasson and Gustafsson^[19] also reported that participants felt physically healthier after receiving HD and were more willing to continue the treatment. Some participants started to change their lifestyle habits (e.g., quitting smoking and drinking, going to bed early, waking up early, and exercising regularly) after receiving HD. Similarly, Chueh and Tseng,^[27] who investigated the support demands of middle-aged male heart patients, reported that

after undergoing heart surgery, many patients quit smoking and drinking and started exercising more regularly. After realizing the severity of their disease, many middle-aged patients will actively change their lifestyle to improve their physical health. By using the three coping methods of "being open-minded and permitting others to assist them", "changing their perspective towards HD", and "learning to improve their own health", the patients learned to adapt to the challenges of living with HD.

The participants stated that HD inspired them to understand the value of life through end-of-life evaluation. With death in the foreseeable future, participants tended to live one day at a time, which is similar to findings in Jonasson and Gustafsson's study.^[19] Their HD patients felt content to live with as much time as they had left and were more appreciative of being alive. For many, unfulfilled responsibilities toward their family members gave them the strength and courage to accept HD. This change reflected the crucial role of family members in the long-term treatment of these patients.^[28] Hsu, Yen, Wang and Chen^[29] also found that many middle-aged people centered their lives on family and friendships despite their illnesses. Thus, the middle-aged participants hoped to spend more time with their family members. Similarly, Ko et al.^[3] discovered that HD patients were happy living with their family members. Lin,^[30] on the other hand, asserted that elderly patients adjusted to life with HD by reflecting on their experience.

In late midlife, healthy adults are more likely to take on multiple roles in their career, family, and community, and managing these roles is considered central to this stage of life. Chronic illnesses that require treatment, such as HD, may impede the execution of these roles, and HD patients must reinterpret their roles for themselves, possibly altering their standards of achievement and expected quality of life. While this reinterpretation may be difficult for the patients, the change tends to be more readily accepted by those around the patients.

Limitations

The study has two limitations. First, purposive sampling was used to recruit 12 HD patients with diabetic nephropathy in a regional teaching hospital in southern Taiwan, so these findings may not be representative of the lived experience of the majority of patients. Second, because we could communicate only in Mandarin and Taiwanese Hokkien during the interview, five patients who spoke other native languages were excluded from this study. The potential participants who were excluded due to language barriers may have different experiences in that difficulty communicating with health care providers is likely to cause additional problems in managing

the adverse effects of HD.

5. CONCLUSIONS

This qualitative study details the lived experiences of late midlife HD participants with diabetic nephropathy. Although the statements from the participants were subjective, their physical and psychological suffering and the diminished social networks were very real and the difficulties of undergoing HD were inescapable. Over the course of time, however, the participants gradually shifted from denial and escapism to accepting their condition and impaired lifestyle with social and professional support. Some participants even chose proactive strategies to promote their own health. Falling ill in late midlife forced the participants to become more aware of and place greater value on their remaining time alive and many focused on living in the present, despite the burden of dialysis. Having reflected on their lived experiences, the participants were still able to find way to achieve generativity.

Implications for practice

This study describes the reality of the participants' lived experiences of HD. Healthcare providers can use this information for planning educational material and developing support programs for patients and their family members. First,

this study recommends that nurses organize periodic group meetings for patients and their family members to discuss diabetic nephropathy, the outcome of the disease, prevention of kidney further deterioration, and HD procedures. Second, the study found that unemployment and the resulting sense of deficiency was one of the main factors that caused the late middle-aged participants to deny their own self-worth. Health care providers need to be educated about the problem and be aware of the financial hardship that may be imposed by HD. Third, healthcare providers should be more empathetic when encountering difficult patients and understand that it may take some time for patients to internalize the physiological effects on their body and the need for treatment. Fourth, healthcare providers should be open to discussing issues surrounding death and mortality, which may be on the mind of HD patients.

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CONFLICTS OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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