

The process of maintenance dialysis in depressed patients on hemodialysis

Kiyomi Bando, Masami Hasegawa*

Abstract

The objective of this study was to identify the process by which depressed patients on hemodialysis have maintained and continued their life-long dialysis therapy. A mood questionnaire was administered to 64 patients on maintenance hemodialysis. Patients considered as being depressed and having been on maintenance dialysis for more than 3 years were subjected to a semi-structured interview according to the suggested guidelines. Obtained data were analyzed by the modified grounded theory approach. A total of 10 subjects were selected as closely analyzed subjects. The analysis topic was defined as “the process of maintenance of dialysis that allows depressed patients on maintenance hemodialysis to continue their life-long dialysis therapy.” The results suggested that such a process allows depressed patients on maintenance hemodialysis to continue their life-long therapy by preventing them from giving up on life through the “belief to survive”, despite the “pain of living” from complications of dialysis and the need for life-long dialysis once the therapy was introduced, encouraging them to consider whatever they can do as a purpose in life, and allowing them to have a feeling of “joy of living”, while acknowledging the value of their existence. For patients on maintenance hemodialysis, the reliable behavior of medical professionals, thoughtfulness and understanding of their family, and reduced economic burden have a significant impact on their maintenance and willingness to continue the therapy.

Key words

maintenance hemodialysis, mood questionnaire, depression, process of acceptance, living

Introduction

With its aging population, Japan has seen an increasing number of dialysis patients every year, with more than 300,000 patients undergoing chronic dialysis therapy and about 295,000 patients on maintenance hemodialysis, according to a survey conducted by the Japanese Society for Dialysis Therapy in 2012¹⁾. Dialysis therapy is a life-long treatment that cannot be avoided once kidney function is lost, unless a diseased kidney is replaced with a healthy one through kidney transplantation or other means. Most patients with predialysis chronic kidney failure are given explanations about the need for dialysis therapy and how a life with dialysis will be, and they then make a decision to initiate therapy in

view of the plight of their current life. Hemodialysis is physically and psychologically painful as it requires patients to be restrained for 3-5 h per session and to engage in strict self-management, including food and water restriction. In an attempt to identify painful experiences suffered by patients on long-term dialysis therapy, Okazaki²⁾ conducted an interview survey with 3 patients with non-diabetic nephropathy who had been on hemodialysis for more than 20 years and identified factors such as being shocked when told of the need for dialysis, depression due to worsening of the underlying condition, pain caused by factors other than dialysis, dying leaving children behind, feeling sorry about being a burden to his or her family, physician's behavior and words.

Doctoral Course Division of Health Science, Kanazawa University Graduate School of Medical Science

* School of Nursing, Kanazawa Medical University

Patients on hemodialysis are thus considered to be significantly stressed, and it seems difficult for them to psychologically adapt to the therapy, even though they may be able to physically adapt to the therapy. Haruki³⁾ suggested that many patients on dialysis have a wide range of psychosocial problems ranging from life struggles to mental illness. He has also suggested that some patients get used to life with dialysis in about 3 years and start having the desire to participate in activities and work in the same way as healthy people do, but that they may develop depression once they realize that it is not easy to do so. A survey conducted by the Japanese Society for Dialysis Therapy¹⁾ revealed that about 40% of dialysis patients are depressed. Nishimura⁴⁾ states, on the basis of European and American research, that 15–60% of dialysis patients experience depression. Ezaki et al⁵⁾ screened 61 dialysis patients for depression using the Japanese version of the General Health Questionnaire (GHQ)⁶⁾. Results revealed that the incidence of depression was notably higher (24.6%) than that of the general population in Japanese cities (1.2%). “Depression” not only causes dialysis patients severe pain, but also reduces their quality of life. In addition, in dialysis patients with comorbid “depression”, the risk of death or hospitalization over one year is twice as high, and the number of days spent in the hospital and the number of hospitalizations increase by 30%. However, few dialysis patients are considered to be receiving an appropriate diagnosis and treatment.

As supporters of patients, nurses are required to cope with mental and psychological changes, as well as physical health management, in dialysis patients with psychological problems, especially in those in a state of depression, in cooperation with professionals in other areas. The Japan Academy of Nephrology Nursing states in the Nephrology Nursing⁷⁾ that of the significant factors in chronic renal failure nursing, “the ability to support the processes for patients and their families to accept dialysis and to adapt to it” is one of the reasons for the existence of nursing staff who have obtained qualifications through the certification system. In the nursing field, no research reports have been available on how depressed patients accept and continue hemodialysis therapy or on investigating depression in hemodialysis patients based on patient

narratives.

We thus considered that it is necessary to clarify how patients on hemodialysis, especially those currently in a state of depression, have maintained dialysis therapy, a therapy essential for sustaining their life. The objective of this study was to identify the process of maintenance of dialysis that allows depressed patients on maintenance hemodialysis to continue their therapy.

Methods

1. Selection of study patients

The term “depression” here is used to indicate a depressive state in a broad sense. Since it is rare in research that targets dialysis patients to use diagnostic criteria (for example, the Diagnostic and Statistical Manual of Mental Disorders (DSM) – IV published by American Psychiatric Associations (APA)), and because patients have been evaluated mainly by means of self-assessment, a “depressive state” not meeting the criteria for “depression” has been considered.

Therefore, among 64 patients undergoing maintenance hemodialysis at Hospital A on an outpatient basis, those subjected to an interview survey using the Self-rating Depression Scale (SDS)⁸⁾. The Japanese version of the SDS⁹⁾ was used in this study. Its reliability and validity have been ascertained.

The SDS is a diagnostic tool assessing 20 common symptoms of depression and has been used extensively in studies of depression in general populations. It uses a 4-point Likert scale to assess the frequency of occurrence of depression states. All 20 items of the SDS are scored ranging from 20 to 80. Those who scored 40 points or more according to the Japanese SDS criteria are considered as depressed. We used the Japanese SDS criteria in the present study.

Inclusion criteria: Patients who had been on maintenance hemodialysis for more than 3 years and who scored 40 points or more in the Japanese SDS were included. We excluded patients who had been in the medical treatment to their depression and patients on hemodialysis from diabetic nephropathy. Patients without any family member, or those who were

financially in a serious situation were not excluded.

2. Data collection procedure

In an interview, subjects were asked to talk freely about 1) feelings and thoughts they have had since they started dialysis; 2) development of symptoms, such as depression, melancholy and insomnia; and 3) changes in the symptoms listed in question 2 following the introduction of dialysis. The interview was carried out in private in a room at the study site and lasted for 30 min to 1 h, taking into consideration the subject's physical condition. The interview was recorded, with the permission of each subject, using an IC recorder to create a verbatim record, which was used as raw data.

3. Analysis methods

The modified grounded theory approach (M-GTA)^{10, 11)} was used to analyze data. Kinoshita¹¹⁾ stated that the M-GTA is suited for studies whose results are expected to be utilized in practical areas, such as human services, that have process characteristics. The present study was designed to clarify how the initially negative attitude of hemodialysis patients changes due to social interactions, including the efforts of the patient and the supports from surrounding people, during the course of therapy. The M-GTA involves the creation of analysis worksheets for close analysis without sectioning of data so that the perspective of the person who performs research can be reflected in the results. Such a feature of the M-GTA is compatible with our basic standpoint.

Prior to the study, we attended meetings and workshops on M-GTA and mastered the methods for analyzing data. Analyses were repeatedly reviewed and supervised by qualitative researchers in the field of psychiatric nursing.

4. Ethical considerations

The study was approved by the director of the study site. Study patients were informed of the purpose and methods of the study by means of a study participation request form and study protocol, which explained that their privacy will be strictly protected through anonymization and confidentiality. Patients were also asked to provide consent to recording with an IC recorder and to the disclosure of results as necessary, and they were given our contact information for any questions regarding the study.

It was also explained in both writing and orally that participation is voluntary and that the choice to not participate in the study or to withdraw from the study would not cause any disadvantage. Subjects were then asked to provide consent by signing the consent form before participating in the study. The interview was conducted by taking into consideration each participant's degree of fatigue, stress, and physical condition. This study was initiated after review and approval of the study protocol by the medical ethics committee at Kanazawa University.

5. Study period

The study period was between July 2009 and March 31, 2011.

6. Data analysis procedure

The data analysis procedure was based on the M-GTA procedure. Specifically, data were repeatedly read with attention paid to items related to the analysis topic; that is, the process of maintenance of dialysis that allows depressed patients on maintenance hemodialysis to continue their life-long dialysis therapy. The relevant data were then extracted as "variations". Similar variations and counter variations were identified by the constant comparative method. Extracted variations were analyzed to determine the type of experience or thought of each variation, in light of participant perceptions and actions.

The process of analysis was recorded for each concept using the analysis worksheet which consisted of "variation", "definition", "concept name", and "theoretical notes". After multiple concepts were created, the concepts were refined by the constant comparative method to examine the relationship between concepts. Categories were then created that served as the central axis for explaining the process of this phenomenon, and each category encompassed multiple concepts. Finally, a diagram showing the entire process was created, along with a story line using concept names and categories.

7. Definitions of terms

1) The process of maintenance that allows for the continuation of life-long dialysis therapy: A process that allows a patient to be aware of the condition of his or her underlying disease and the need for dialysis and to spend his or her life without sacrificing quality

of life, despite physical changes and restrictions imposed by dialysis.

2) Depressed patients on maintenance hemodialysis: Patients who had been on maintenance hemodialysis for more than 3 years and who scored 40 points or more in the Japanese SDS.

Table 1. Characteristics of patients

Dialysis patient	Age (years)	Sex	Diagnosis	Dialysis history (years)	Mood questionnaire result (SDS score)
A	77	F	Chronic glomerulonephritis	5	44
B	69	F	Chronic glomerulonephritis	5	41
C	62	M	IgA nephropathy	9	46
D	75	F	Lupus nephritis	32	42
E	61	M	Chronic glomerulonephritis	9	46
F	49	M	Chronic glomerulonephritis	27	46
G	59	F	Chronic glomerulonephritis	31	55
H	68	M	Chronic glomerulonephritis	22	40
I	62	F	Chronic glomerulonephritis	33	44
J	76	F	Renal sclerosis	16	46

SDS: Self-rating depression scale

Results

The characteristics of the patients and the results of the SDS are summarized in Table 1.

1. Selection of closely analyzed subjects and the analysis topic

Out of 64 patients, 40 patients scored 39 points or less, 16 patients with 40-49 points, and 8 patients

with 50 points or more. A total of 10 patients who had been on maintenance hemodialysis for more than 3 years were selected as closely analyzed subjects. The analysis topic was defined as “the process of maintenance of dialysis that allows depressed patients on maintenance hemodialysis to continue their life-long dialysis therapy.

2. Diagram and story line

1) Categories and concepts

A total of 4 categories and 13 concepts were generated by analysis, and the relationships are shown in Figure 1. Categories are indicated by « », concepts are indicated by [], and comments quoted from the interview data are indicated by “ ”.

2) Story line

Depressed patients on maintenance hemodialysis were accepting their life-long therapy as follows. They were aware of «pain of living», including [need for life-long dialysis] and [pain and frustration from recurrent complications]. At the same time, they had «belief to survive», believed in [strength by which they had overcome difficulties], and considered dialysis as [dialysis as therapy to survive]. When they faced difficulties, they decided to [come to terms with the current situation] and changed their mind to [consider death as the end of natural life]. They were supported by «factors that support acceptance», such as knowledge obtained through [exchange of

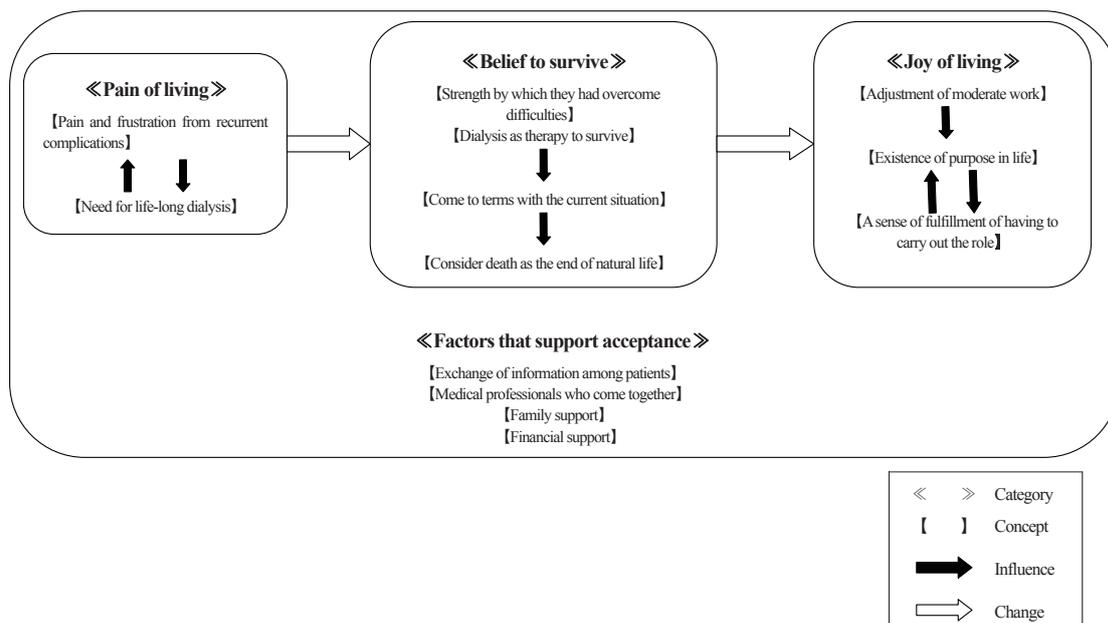


Figure 1. The process of maintenance dialysis in depressed patients on hemodialysis

information among patients] , a sense of security that they have with [medical professionals who come together] , [family support] , and [financial support] . They also had feelings of 《joy of living》 , such as performing [adjustment of moderate work] , finding [existence of purpose in life] , and having [a sense of fulfillment of having to carry out the role] .

3) Categories, concepts, and relationship between concepts

(1) The category 《belief to survive》 was identified as the core category. This category included patient belief in [strength by which they had overcome difficulties] and the concept that dialysis is [dialysis as therapy to survive] ; that is, they can do whatever they want to because they are on dialysis. When they experienced any complication, they decided to [come to terms with the current situation] and changed their mind to [consider death as the end of natural life] .

[Strength by which they had overcome difficulties]

“I'm kind of methodical and I get worried if I haven't done what I have to do. I am trying to avoid eating high-salt food and rarely drink water. I don't eat snacks either even when I find them. Because fruits contain a lot of potassium etc.” (C-3-8)

[Dialysis as therapy to survive]

“I was thinking that I should do my own things on my own because I did not want to think I have become a burden to my family just because I am sick. You do dialysis because you do not want to die, don't you? That's what I am telling myself.” (G-3-21)

[Come to terms with the current situation]

“I changed my job to come to terms with my situation, but I gave up straining myself when I was about 35. Taking into account my physical condition, I decided to take a part-time job, so I can work at my own pace. Since I don't have any fixed hours of work, I'm trying to consider dialysis as my job. It's a job to survive. You do it because you do not want to die, don't you? There is no easy job. That's the way I come to terms with my situation.” (F-2-19)

[Consider death as the end of natural life]

“Whenever someone who has come together is gone, I tell myself that the time will come to me one day and I get depressed. But then, I tell myself that I shouldn't think that way, because I have lived my life and everybody will die one day.” (G-4-39)

“I came to think that way after I turned 50. I have an opportunity to meet my classmates from my school days every year, and I have seen some of my friends passing away from cancer, suicide, and other reasons. When I think of losing my friends who have thought and talked together about our life, I have somehow come to think that dialysis is not a big deal. Everybody dies for a particular reason.” (F-2-20)

(2) The category 《pain of living》 included two concepts. The concept of [need for life-long dialysis] represented the idea that they have to continue dialysis to survive, while another concept [pain and frustration from recurrent complications] reflected the fact that they continue to experience pain of being told of the occurrence of complications every time they undergo dialysis.

[Pain and frustration from recurrent complications]

“I have experienced many complications despite all my efforts. I'm getting tired of having one problem after another. I have been working hard because I do not want to die, but I cannot help thinking that it's OK to die. I get upset. I feel I have overcome the dialysis, but lost to complications.” (D-2-14)

[Need for life-long dialysis]

“I didn't expect I would have to continue to stick a needle in my arm throughout my life. I don't want to imagine I have to do this until I die. I hope I will die while I am able to go to the bathroom and do other things myself, but I don't want to come to dialysis in a diaper. I feel like dying when I think of it. Although I was told that I would have to do this for an unlimited duration, but at that time I didn't think ‘an unlimited duration' means ‘as long as life lasts'. I was shocked to realize I would have to continue this throughout my life. I still think so, and I thought this feeling would go away in a while. (A-2-15)

(3) The category 《joy of living》 included three concepts. They were performing [adjustment of moderate work] in support of the medical staff and family and living positively by exploring [the existence of purposes in life] . They also had [a sense of fulfillment of having to carry out the role] , enjoying the feeling of being alive with the confidence that they can still contribute.

[Adjustment of moderate work]

“I gradually realized that I cannot perform

household work properly after undergoing dialysis. Initially, I was so tired after coming back home that I could not keep up. I was depressed initially but then started trying to adapt to the situation by thinking about the use of time, such as preparing for dialysis the day before and doing cleaning and washing when I was feeling good. (G-3-12)

【The existence of purposes in life】

“It's true that what you can do is limited if you are on dialysis. I have been on dialysis for 30 years, but I still have a positive feeling. I had a negative feeling that I was a burden to my family, but the idea that I can still do something that pleases my family, even on dialysis has got rid of all the negative feeling. That's why I have tried to find and do things that I can do. I have been on dialysis with the same feeling.” (G-3-16)

“My friends invited me on trips and I was able to travel to many places. I also played golf and took a variety of lessons and classes with my husband. I have done many fun things.” (D-1-33)

【A sense of fulfillment of having to carry out the role】

“My company has appreciated me and I am trying to meet their expectations as long as my health condition allows. I have a feeling of resignation, but also a feeling of reward in my job.” (F-2-16)

(4) The category 《factors that support acceptance》 consisted of four concepts and influenced the 《belief to survive》 and 《joy of living》 categories.

【Exchange of information among patients】

“I have come to talk with other dialysis patients and had peace of mind by sharing the same feeling with them. We would always talk about our families. I enjoyed talking to them.” (I-1-12)

【Medical professionals who come together】

“I have heard that many people feel down and become unwilling to go on dialysis, but I have never felt down because doctors and nurses have taken good care of me.” (C-3-16)

“If you are on dialysis, you may not be able to go on trips so often. I was happy to hear that doctors were planning a recreation trip for patients. I appreciate their kind consideration for us. I have come to feel that doctors and nurses are working hard with us to protect our health, instead of struggling by myself.” (D-2-13)

【Family support】

“My mother took care of my children and did household work for me while I was on dialysis. She never blamed me or complained to me. I have come to think that I was doing dialysis to become healthy.” (D-1-33)

【Financial support】

“Now our medical cost is paid by the government and I am thankful for that. I wouldn't be alive if there was no financial support, because I wouldn't be able to pay the treatment bills.” (B-1-16)

Discussion

All the patients included in this study were considered to be depressed by a mood questionnaire at the point of interviewing. A previous study conducted by Okazaki²⁾ identified worsening of the underlying condition, shunt trouble, and the need for life-long maintenance dialysis as factors associated with depression. In addition to these factors, the present study also suggested that the conflict between 《pain of living》 and 《belief to survive》 may also be a trigger for depression. However, we did not fully investigate the process of the state of their depression, nor the relationships between those categories and depression. Our major focus was the process of maintenance of dialysis that allows depressed patients on maintenance hemodialysis to continue their life-long therapy. The process is considered to be the one thing that prevents them from giving up on life, encourages them to consider whatever they can do as a purpose in life, and allows them to acknowledge the value of their existence, that is, the value of living as a human being.

The patients in this study had complications, such as shunt trouble, fracture from fall, and cardiovascular bypass surgery. The concept of **【pain and frustration from recurrent complications】** appeared to reflect not only physical pain, but also frustration of wondering why this happens to me, as well as mental stress, given that most patients do not undergo surgery or other procedures at the same hospital in which they undergo dialysis, but are usually transferred to another hospital to undergo these procedures. Even in those pain and frustration, the present results suggest that the patients were trying to explore and practice

what they can do through [come to terms with the current situation] living with the fact that they were depressed.

The patients had the belief to survive and the attitude of not giving up on life. This was not only reflected in their attitude to keep their job. In order to accept the fact that they have to continue dialysis throughout life, they were also trying to stay positive in their daily life by not working overtime, selecting departments at work suitable for their condition, adjusting work load, and [adjustment of moderate work] , that is, doing things that they can do little by little to make their family happy, even slightly. In other words, while having conflicting feelings, the patients appeared to have had a sense of fulfillment by exploring and practicing what they can do and move forward by identifying the value of themselves, instead of giving up everything.

In a study on nursing for dialysis patients, Futaesaku¹²⁾ reported a high rating of dialysis technique/assistance, a low rating of explanation on examinations and self-management, and a low rating on room temperature control, noise control, response to patient complaints, anxiety, and worries, deepening of a relationship of trust with patients, and relationships with patient families. On the other hand, in the present study, the patients mentioned [medical professionals who come together] and [family support] . [Medical professionals who come together] suggested that patients had a sense of security whereby the medical professionals are by their side to provide lifestyle and total health management. This seems to be important for promoting a patient's will to continue therapy and to help convey specialized knowledge. [Family support] in daily activities, such as raising children, preparing meals, and water intake management, as well as talking to the patient attentively, promoted positive feelings and caused changes in their attitude towards the therapy. Such supports from family members who always stand by are essential, and the thoughtfulness of the family appears to help them continue their therapy and leads to [a sense of fulfillment of having to carry out the role] . Hashimoto¹³⁾ conducted a study to identify factors that affect the mental well-being of dialysis patients in their daily life and suggested the

need to improve social work supports in the outing of dialysis patients, including going to a dialysis clinic, communication between patients and medical staff, and social roles. Moreover, the patients in this study showed the [financial support] they were receiving. With reduced activities of daily living (ADL) due to advanced age and complications, the patients were worried about going to the hospital. Some mentioned that the care taxi service has become such a financial burden that they cannot live off their pension. As the survey conducted by the Japanese Society for Dialysis Therapy¹⁾ revealed an increasing number of elderly patients, the present study identified economic burden as an important issue that needs to be addressed.

Study limitations and future research issues

First, although our subjects were in a state of depression at the point of interviewing, we did not fully investigate the process of the state of their depression, nor the relationships between categories generated and depression. Moreover, our study design did not allow comparing depressed patients with non-depressed ones. Therefore we couldn't identify whether it is a specific result from depressed patients. Another approach to resolve this issue is needed in the near future. Second, we selected subjects who had been on maintenance hemodialysis for more than 3 years and who scored 40 points or more in the Japanese SDS. We excluded patients on hemodialysis from diabetic nephropathy. In this meaning, the result obtained in the present study cannot be applied to those patients with diabetic nephropathy. Third, this study was conducted with patients from a single institute. Future studies should involve a larger number of institutions and patients and take into consideration patient lifestyle. Fourth, the results tended to be influenced by our judgment.

Conclusion

1. A semi-structured interview of 10 depressed patients on maintenance hemodialysis therapy identified four categories that constituted the process of acceptance of dialysis, including 《belief to survive》 as the core category, 《pain of living》 , 《factors that support acceptance》 , and 《joy of living》 . This process helped them recognize the value of their existence.

2. For patients on maintenance hemodialysis, the reliable behavior of medical professionals, thoughtfulness and understanding of their family, and reduced economic burden have a significant impact on their acceptance of and willingness to continue the therapy.

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うつ状態にある血液透析患者の維持透析のプロセス

坂東紀代美, 長谷川雅美*

要 旨

本研究では、うつ状態にある維持血液透析患者が、透析人生を継続するためにどのように透析を受けとめ、維持してきたかを明らかにすることを目的とした。64名の維持血液透析患者に気分調査を行い、うつ状態で維持血液透析を3年以上行っている患者を対象とした。それらの条件に該当する対象者10名に対して、インタビューガイドに沿って半構成的に面接を実施した。『修正版グラウンデッド・セオリー・アプローチ』を用い、分析テーマを「うつ状態にある維持血液透析患者が透析人生を維持できるプロセス」とし分析した。その結果、うつ状態にある維持血液透析患者は透析人生を維持するために、透析からくる合併症や透析導入から続く通院治療による「生きる苦痛」をもつ半面、「生き抜く信念」により、人生をあきらめず、できることを生きがいとし、「生きる喜び」を感じ、自分自身の存在の価値を確認していくプロセスとして描かれた。さらには、維持血液透析患者にとって、透析を受容し継続を支える力として、医療従事者の信頼できる対応、家族の気配りと理解、経済的負担の軽減が大きく影響していることも示唆された。