

Research on the structure of home-based nursing care provided by family caregivers responsible for dialysis patients requiring nursing care

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Research on the structure of home-based nursing care provided by family caregivers responsible for dialysis patients requiring nursing care

Kazumi Hayashi, Michiko Inagaki*

Abstract

The purpose of this study was to clarify the structure of home-based nursing care provided by family members responsible for dialysis patients requiring nursing care from the viewpoint of nursing care conditions, caregiver awareness, and the influence of care on the lives of family caregivers. The subjects of this study were 22 family caregivers in Ishikawa Prefecture responsible for dialysis outpatients requiring nursing care receiving treatment at 10 dialysis centers. Semi-structured interviews were carried out and analyzed by the Modified Grounded Theory Approach (M-GTA). As a result, we extracted 18 concept names and nine categories. Three stages were found in the nursing care process; namely, <commitment to dialysis nursing care>, <organizing a nursing care system/ learning the points of treatment>, <adjusting to nursing care and lifestyle>, and these stages were categorized as the *process of learning home-based nursing care*. Caregivers always concentrated on <<providing nursing care considering the patient's limited life expectancy>>, which was central to the stage of <organizing a nursing care system/ learning the points of treatment> and influenced approaches to nursing care, which consisted of a <shift of lifestyle>, <adjustment of lifestyle in accordance with the dialysis schedule>, and <learning the points of dialysis nursing care>. Results suggested the necessity of developing nursing care methods in accordance with the stages of the learning process in order to enable family caregivers responsible for dialysis patients requiring nursing care to provide continual support that fits comfortably into their family life.

Key words

Dialysis patients requiring nursing care, Elderly dialysis patients, Family caregivers, Home-based nursing care, Process of learning nursing care

Introduction

1. Current condition of dialysis patients requiring nursing care in Japan

The increased use of dialysis in elderly patients in Japan has significantly increased the average life expectancy of these patients, and the number of elderly dialysis patients has been growing. However, various social issues relating to elderly dialysis patients have been identified, including a

lowering of the activity of daily living (ADL), sensory organ and gait disorders, and care for patients who have difficulty going to hospitals due to complications that arise after the initiation of dialysis¹⁾. Furthermore, elderly dialysis patients also undergo mental and psychological changes along with aging and the lowering of physical ability. It is reported that physical and social conditions caused by the initiation of dialysis

Doctor Course, Division of Health Science; Kanazawa University Graduate School Science

* Graduate Course of Nursing Science, Division of Health Science; Graduate School of Medical Science, Kanazawa University

including a sense of loss and limitations on daily activity are related to organic brain damage^{2,3}. The Japanese Society for Dialysis Therapy⁴ carried out a survey on the granting of nursing care insurance to dialysis patients in 2002 after the implementation of nursing care insurance; however, there have been no surveys targeting the lifestyle of dialysis patients requiring nursing care until now.

2. Condition of dialysis patients requiring nursing care in Ishikawa Prefecture

The authors carried out a survey on the condition of dialysis patients requiring nursing care in Ishikawa Prefecture in 2006⁵. The dialysis patients requiring nursing care targeted by this survey are defined as individuals certified as requiring nursing care and those who require nursing care by family members for assistance related to dialysis therapy. There are 40 dialysis treatment centers in Ishikawa Prefecture. The prefecture was separated into four healthcare and welfare blocks for this survey due to differences in healthcare conditions between urban areas and rural areas. As a result, each block showed that 11.4 to 19.1% of the total number of dialysis patients had impaired migration, and 5–10% exhibited symptoms of dementia/communication disorders. A total of 81.0 to 90.5% of the patients were receiving outpatient care. Less than 2% of the patients were visiting dialysis centers from other facilities, including medical facilities. Among outpatients, 10.8 to 28.2% received assistance from family members for hospital visits. The survey revealed that it is difficult for facilities other than dialysis centers to treat dialysis patients in Ishikawa Prefecture, forcing many dialysis patients requiring nursing care and patients with functional disorders to utilize home-care services and family support transportation to and from specialized dialysis centers for treatment.

3. Review of documents concerning family members responsible for dialysis patients requiring nursing care.

Dialysis patients require continuous monitoring

of their medical condition in accordance with treatment protocol, including dietary management, for the care of impaired renal function in addition to the need for ongoing outpatient treatment that takes place twice to three times weekly. Such tasks are normally assigned to individual patients as self-care related to dialysis treatment. When dialysis patients develop conditions requiring nursing care, that is, when patients find it increasingly difficult to carrying out tasks related to self-care, it is impossible for them to continue dialysis treatment without family involvement. Strauss⁶ asked, “What happens in the home is mostly over the horizon, is partly or completely invisible to physicians and other health personnel. . . . The illness impact on the family (especially the spouse or parent) is often the key factor in how successful is trajectory management.” It is considered to be of significant importance for healthcare professionals to clarify the tasks to be carried out by family members responsible for patients receiving home-based nursing care.

Some longitudinal studies have been carried out, including a study on the structuring of nursing care ability of family caregivers for patients with dementia and the clarification of levels of capability⁷, research on nursing care experience from the viewpoint of career development and role acquisition based on the idea of adjustment and development^{8,9}, a clarification of a general outline of nursing care for cerebrovascular disease¹⁰, and a clarification of the learning stages of nursing care experience¹¹.

There is insufficient research on the families of dialysis patients, and no methodology to support such families has as yet been established. Watanabe et al.¹² examined family stress in coping with dialysis and examined support for families. Hiramatsu¹³ and Mizutsuki¹⁴ described the meaning of support as end stage to cope with the concerns of families of elderly dialysis patients dependent on medical care. In consideration of the above, family members responsible for patients requiring nursing care develop nursing care abilities through the continual experience of nursing care. Furthermore, while the family

members of dialysis patients receiving life-prolonging treatment due to dependence on medical care were required to provide continual nursing care related to treatment as well as daily physical care, procedures for such care have not yet been clarified.

4. Purpose and meaning of this study

The purpose of this study was to clarify the structure of nursing care provided by family members responsible for dialysis patients requiring nursing care in the context of their continual home-based care and from the viewpoint of nursing care conditions, caregiver awareness, and the influence of care on the lives of family caregivers. Such clarification makes it possible to indicate care models for dialysis patients who require nursing care and who receive home-based. It also contributes to the development of family support.

Method

1. Subjects

The subjects of this study were 22 caregivers at 10 dialysis centers in Ishikawa Prefecture. Subject background is shown in Table 1.

Dialysis patients developed conditions requiring nursing or had existing conditions requiring nursing care at the time dialysis was initiated. Conditions requiring nursing care included gait disorder, complications of diabetes, cerebrovascular disease and dementia. Such conditions made it

difficult for patients to carry out the self-care required for their dialysis treatment.

The authors explained the purpose of this study to the persons in charge of nursing care at each dialysis center prior to a preliminary survey and asked their cooperation in selecting interview candidates. The condition for inclusion was that the participant be a family member responsible for dialysis patients requiring nursing care (hereinafter referred to as “caregiver”) living with and caring for the patient.

2. Data collection

Interviews were carried out between August, 2006 and May, 2007. The interview was semi-structured and carried out following the interview guide. The content of the interview included items related to the course between the initiation of dialysis and the present condition; the reasons for initiating nursing care and the procedures that were followed; the content, difficulties and evolution of nursing care; and the influence of nursing care on the life of the caregiver. Subjects were free to answer as they deemed appropriate.

The contents of the interviews were recorded on tape, and observations were entered in a field notebook. Seventeen subjects were interviewed once, four were interviewed twice, and one subject was interviewed four times. The length of the interviews was between 40 and 160 minutes.

Table 1. Subject outline

Family caregivers			Dialysis patients requiring nursing care				
Age	Gender	Relationship	Age	Complications (including overlapping diseases)	Period of time for home-based nursing care	History of dialysis	Patient's degree of care need
Individuals in their 30's: 1	Male: 3 Female: 19	Wife: 9	Between 60 and 69: 5	Gait disorder: 6	Less than 1 year: 4	Less than 1 year: 3	Patients at 1st degree of care need: 4
Individuals in their 40's: 1		Daughter: 5	Between 70 and 79: 6	Complication of diabetes: 6	1 year or more—less than 3 years: 2	1 year or more—less than 3 years: 4	Patients at 2nd degree of care need: 5
Individuals in their 50's: 7		Daughter-in-law: 5	Between 80 and 89: 10	Cerebrovascular disease: 4	3 year or more—less than 5 years: 9	3 year or more—less than 5 years: 4	Patients at 3rd degree of care need: 4
Individuals in their 60's: 9		Son: 2	90 or older: 1	Dementia: 8	5 year or more—less than 10 years: 4	5 year or more—less than 10 years: 6	Patients at 4th degree of care need: 2
Individuals in their 70's: 4		Husband: 1	(Average: 77.6 years of age)		10 years or more: 3	10 years or more: 5	Patients at 5th degree of care need: 2
							Patients without care need certification: 4 Unknown: 1

3. Data analysis

Data analysis was carried out in compliance with the Modified Grounded Theory Approach (M-GTA)^{15,16} propounded by Kinoshita. First, we created a verbatim record based on the recordings of interviews and written observations. In the creation of the verbatim record, we focused on content that revealed the nursing care provided, the degree of awareness expressed by caregivers, and nursing care that seemed to influence the caregivers' lives to create definitions. We summarized the content of the definitions to derive concept names. We created worksheets by thoroughly reading each case to identify concept names, definitions, examples and theoretical descriptions. When creating worksheets, we confirmed that similar examples of cases did not exist in other areas of the subject's data or in other subjects' data. Contrasting phenomena were examined when found. By the comparison of similarities and the contrast of differences, we confirmed that concept names and definitions matched the data, and noted the theoretical descriptions that were revealed.

We also examined categories and category relationships to clarify structures related to the

learning of nursing care for dialysis patients requiring nursing care. In order to monitor the validity of data analysis, instructors provided continual supervision of the analyses being carried out.

4. Ethical considerations

After a thorough verbal and written explanation of the purpose of this study to the persons in charge of nursing care at each dialysis center, we asked their cooperation in selecting interview candidates. The authors provided a verbal and written explanation of the purpose of this study and ethical considerations to interview candidates introduced by the persons in charge of dialysis nursing care. Interviews were carried out after obtaining consent. This study was reviewed and approved by the Medical Ethics Committee, Kanazawa University Graduate School of Medical Science.

Results

1. The process of learning home-based nursing care experienced by family caregivers responsible for dialysis patients requiring nursing care (Fig.1)

We extracted 18 concept names and nine

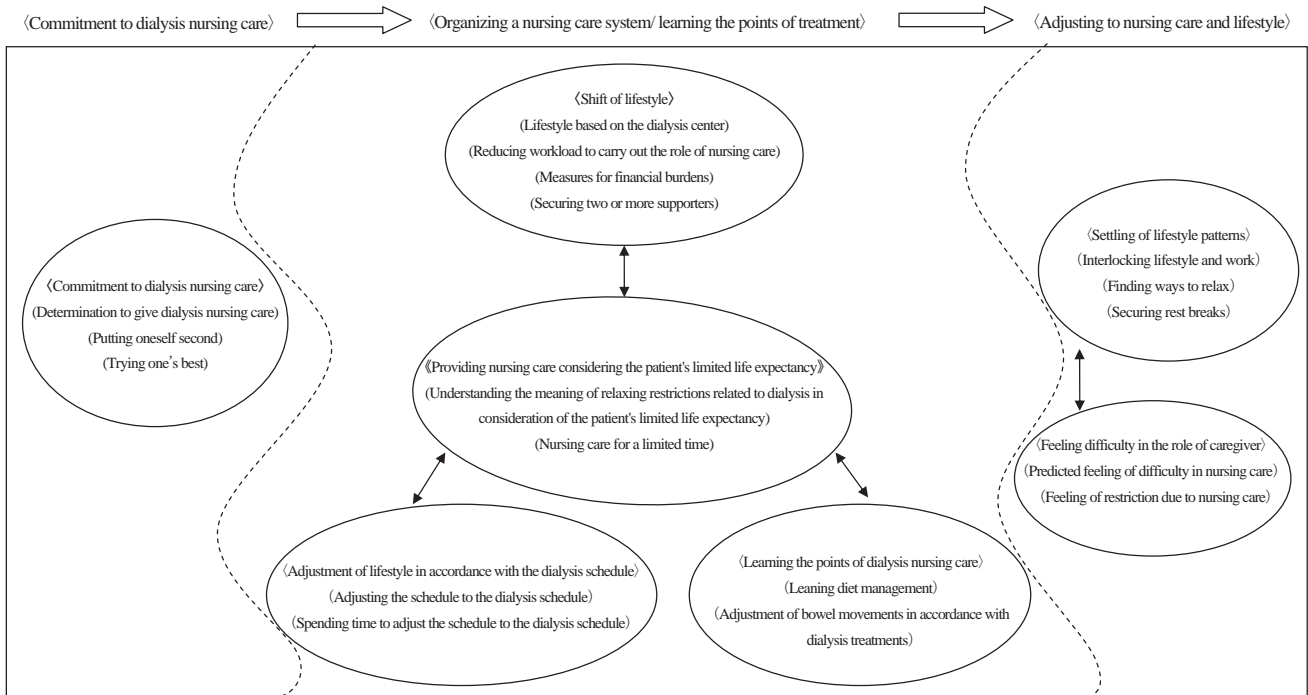


Fig. 1 The process of learning home-based nursing care experienced by family caregivers responsible for dialysis patients requiring nursing care

< > Category
 << >> Core-category
 () Concept
 ↔ Categories interacting with each other
 → Flow of the nursing care process

categories. An overview of the processes follows: Concept names are indicated by (), definitions are indicated by { }, category names are indicated by < >, and core-categories are indicated by 《 》 within sentences.

Three stages were found in the nursing care process; namely, <commitment to dialysis nursing care>, <organizing a nursing care system/ learning the points of treatment>, <adjusting to nursing care and lifestyle>. Through these stages, caregivers learned effective approaches through experience; therefore, we categorized these stages as *the process of learning home-based nursing care*.

The beginning of the stages described above was the point at which caregivers began their <commitment to dialysis nursing care> due to the development of conditions in the patient that require nursing care; therefore, this stage was so designated. In the next stage, <organizing a nursing care system/ learning the points of treatment>, caregiver efforts were divided into four components; namely, 《providing nursing care considering the patient's limited life expectancy》, <shift of lifestyle>, <adjustment of lifestyle in accordance with the dialysis schedule>, and <learning the points of dialysis nursing care>. The activity in these categories took place in a concurrent or complex manner depending on each family's situation. Caregivers always concentrated on 《providing nursing care considering the patient's limited life expectancy》, which was central to these four categories and influenced approaches to nursing care, which consisted of a <shift of lifestyle>, <adjustment of lifestyle in accordance with the dialysis schedule>, and <learning the points of dialysis nursing care>. Finally, the process entered the stage of <adjusting to nursing care and life>, and showed a <settling of lifestyle patterns>. Caregivers in this stage, however, maintained an awareness of <feeling difficulty in the role of caregiver>.

2. Explanation of the extracted categories and concepts (Table 2-1, 2-2)

1) <Commitment to dialysis nursing care>:

(Determination to give dialysis nursing care), (Putting oneself second), (Trying one's best)

All caregivers in this study started nursing care or increased their commitment to nursing care to a higher degree than before from the time they began assisting with hospital visits due to the development of conditions requiring nursing care in the patient. This included three concepts.

(Determination to give dialysis nursing care) was defined as the caregiver's {decision to make a deeper commitment due to the impossibility of responding to the situation with the assistance and commitment up to the present}. It was found that this was accomplished by (putting oneself second) and (trying one's best), once the commitment to nursing care was made. (Putting oneself second) was based on {feeling the need to give priority to the patient in providing nursing care}, and (trying one's best) was based on {feeling the need to provide nursing care as much as possible while not being sure how much support could be given to patients}. Both show the responsibility individuals felt in their role as caregivers; however, the former perceives the role of nursing care as *things to do/ things that have to be done*, and the latter perceives the role of nursing care as *providing nursing care because it can be provided* or *providing nursing care as much as possible*.

2) 《Providing nursing care considering the patient's limited life expectancy》: (Understanding the meaning of relaxing restrictions related to dialysis in consideration of the patient's limited life expectancy), (Nursing care for a limited time)

《Providing nursing care considering the patient's limited life expectancy》 were perceived as approaches to providing dialysis nursing care in consideration of the patient's limited life expectancy, and designated as a core-category in the stage of <organizing a nursing care system/ learning the points of treatment>.

The category of 《providing nursing care considering the patient's limited life expectancy》 included two concepts: (Understanding the meaning of relaxing restrictions related to dialysis in consideration of the patient's limited life expectancy), which means {caregivers understanding

Table 2-1. List of concepts and categories

Category	Concept name	Definition	Example
Commitment to dialysis nursing care	Determination to give dialysis nursing care	Caregiver's decision to make a deeper commitment due to the impossibility of responding to the situation with the assistance and commitment up to the present	<ul style="list-style-type: none"> • My mother gradually became weaker, and we were asked by the hospital to take care of her. I had been working until that time, so my husband took her to the hospital in the morning before he went to work, and I went to pick her up during my lunch break. So my situation became stressful and I became restless. When I went back to work and people mentioned that it was very busy, I felt bad about being gone during lunch. I was also exhausted at night, and my daughter even mentioned to my husband, "Dad, mom will be sick if she keeps doing this." The following year, I quit work. The doctor told us that my mother may not live long. My mother helped me to take care of my children very well, so that I decided to show my gratitude by returning her care. (Three other similar cases)
	Putting oneself second	Feeling the need to give priority to the patient in providing nursing care	<ul style="list-style-type: none"> • Our family life revolves around dialysis. *cut* This is not something we are made to do, but something we should do because a member of our family is ill and it is a matter of course to take care of our kin. If we feel that we cannot do this all by ourselves, we can ask the hospital for help. (Two other similar cases)
	Trying one's best	Feeling the need to provide nursing care as much as possible while not being sure how much support could be given to patients	<ul style="list-style-type: none"> • I really would like to do whatever I can. My mother-in-law is going to a day-service every Friday to take a bath. If she becomes weaker, I am not sure what we can do. Right now, she is taking care of herself as much as she can, and my father-in-law also helps her. (Two other similar cases)
Providing nursing care considering the patient's limited life expectancy	Understanding the meaning of relaxing restrictions related to dialysis in consideration of the patient's limited life expectancy	Caregivers understanding the meaning of not enforcing severe limitations in consideration of the patient's limited life expectancy	<ul style="list-style-type: none"> • When we visit the hospital for dialysis treatment, I am always asked about many things, such as what kind of food I am cooking. I am not sure if I am getting better at nursing care or not. *cut* I felt sorry for him. He cannot do this and that ... and I came to wonder why I had to follow so many restrictions for such an old guy. I was told that he couldn't have soup, only the stuff we mix into it. But it's difficult to eat without the soup, right? Finally, he couldn't go shopping by himself and his weight gradually dropped and he stopped drinking water. I felt so sorry for him. • Maybe my mother's age is a big factor. She is already over 80 years old, so I feel that I do not want to put restrictions on her life. If my mother were a little younger, maybe, I would think more about what to do to help her to live longer. (Two other similar cases)
	Nursing care for a limited time	Feeling that nursing care for dialysis patients could be done because the physical condition of the patient tends to worsen, limiting the period of nursing care to a few years	<ul style="list-style-type: none"> • One of the neighborhood wives told me that a patient over 80 years of age gets weaker because of dialysis; the treatment is very hard for the patient, so it will probably only be for a year or so; and when the patient gets weaker, he won't be able to handle the dialysis treatment, either. So, I thought I could try if it were only for a few years and decided to commit to the treatment for him. But, he developed dementia and it was just so hard. (Two other similar cases)
Shift of lifestyle	Lifestyle based on the dialysis center	Caregivers and patients changing their lifestyles to center on the dialysis center in order to make continued treatment possible for dialysis patients requiring nursing care	<ul style="list-style-type: none"> • I live in xxx town, which is far from my mother's home. My mother had taken care of her house by herself, but I decided to come here to take care of her. My older sister is sick and cannot take care of mom, and I am the only girl in my family. My brothers also live far from here and their wives are also working, so they cannot take care of mom in terms of time. I am from this area and many of our relatives are still here. • I have two brothers, and we talked together. My oldest brother lives apart from the family because of work. If our parents were to require dialysis treatment, somebody would have to give them a ride to and from the hospital. So, my parents, both dialysis patients, rent an apartment near the hospital in the town where I (their youngest daughter) live. Individuals who live in underpopulated areas have a hard time. (Two other similar cases)
	Reducing workload to carry out the role of nursing care	Working caregivers needing to reduce their workload (including changing/ cancelling business appointments) in order to continue providing dialysis nursing care	<ul style="list-style-type: none"> • I reduced my work to 70%. It took two years to do so. I have clients, and I know it is kind of selfish to say, but this is the situation. I also adjusted my business schedule to accommodate the dialysis schedule. While I am at the hospital for dialysis treatment, I cannot accept orders from my clients. So, I asked them to understand my situation. • I am on the sales staff so I can adjust my schedule easily. But, that does not mean that I can juggle the work and care. I actually cannot work in the afternoon. *cut* Now I can somehow manage to take time off, but if my work hours were fixed, like from 8:00 am to 5:00 pm, I would be out. Even now, work is tough as it is. (Another similar case)
	Measures for financial burdens	Implementing measures for financial burdens regarding dialysis treatment and nursing care	<ul style="list-style-type: none"> • Financially, it is difficult to afford because my mother receives only 30,000 yen per month as a pension. So, we sisters help mom out financially. The meals after dialysis treatment, which used to be free of charge, have to be paid for. The medical cost has become 2,500 yen from 5,000 yen. We have to pay about 10,000 yen to the hospital every month. My sisters contribute about 30,000 yen for living expenses. (Three other similar cases)
	Securing two or more supporters	Securing the assistance of relatives to continue providing nursing care	<ul style="list-style-type: none"> • Because I am a self-employed, I can adjust my schedule to help out with dialysis treatment. It is probably impossible for regular business men to adjust their schedule to the treatment. My son and I, two key persons, are ready to help. (Three other similar cases)

Table 2-2. List of Concepts and Categories

Category	Concept name	Definition	Example
Learning the points of dialysis nursing care	Learning diet management	Caregivers learning their own diet management in the process of involvement in the diet management of dialysis patients requiring nursing care	<ul style="list-style-type: none"> • Meals for dialysis treatment were a hassle. It was too difficult for me. I was told that the food I prepared had a high proportion of phosphorus and kalium, but it was difficult to make it better. When we visited the hospital the next time, they told me that the proportion of phosphorus was high. Then, I tried to reduce the phosphorus, and they said that the kalium was high. I tried my best for a year. I cooked separate meals for my mother. She complained that I made her eat such food. She gradually ate less and less. She told me that she was only lying in bed, so she didn't get hungry at all. So, finally I felt that my mother should be able to eat anything she wanted to. • I did not know about dialysis treatment at all, so I was not a good helper. My mother weighed 37kg, and then dropped to 33kg, which is the base weight. I had given her a bottle with 300ml of water every day, but since the last visit, I was surprised to hear that she had been told not to drink any water even when she takes her medicine, but to take medicine by mixing it into her rice. I am not making any special meals for her. I'm serving the same meals that we eat and giving her just a little bit. *cut* I know this is not the best way, but I do this way because I guess this is the only way to keep her alive. (Seven other similar cases)
	Adjustment of bowel movements in accordance with dialysis treatments	Caregivers carrying out adjustment of bowel movement so that the patient would have a bowel movement on days other than dialysis treatment days to avoid a bowel movement during dialysis treatment	<ul style="list-style-type: none"> • The nurse always tells us to use good diapers so that there won't be any problems when my mother has bowel incontinence, and I always give her extra diapers. I also control the stool conditions for dialysis treatment. Mom uses two kinds of medicine to soften her stool. I do not give her powdered rhubarb when she visits day care for her bath or receives dialysis treatment. But it is difficult because she worries about incontinence. (Two other similar cases)
Adjustment of lifestyle in accordance with the dialysis schedule	Adjusting the schedule to the dialysis schedule	Caregivers adjusting the living activities in accordance with the dialysis schedule	<ul style="list-style-type: none"> • On the day for dialysis treatment, I have to get up at 6:30 am and eat breakfast by a certain time. I give my mother a ride to go to the hospital in the morning, and my son goes to pick her up. (Seven other similar cases)
	Spending time to adjust the schedule to the dialysis schedule	Caregivers spending time at the hospital and other places during the dialysis treatments for patients	<ul style="list-style-type: none"> • I visit the hospital with my father three times a week. After bringing him to the hospital, I sometimes go home by bus, chat with other dialysis patients' families here (at the dialysis center), or go shopping at department stores near the hospital to wait for him. (Two other similar cases)
Settling of lifestyle patterns	Interlocking life and work	Life of caregivers becoming less stressful by interlocking life and work	<ul style="list-style-type: none"> • Support for dialysis patients is not easy at all. Everything works centering on the dialysis treatment. It took two years for us to settle down this pattern, which is the sharing roles and reducing work. (Another similar case)
	Finding ways to relax	Caregivers participating in fun activities utilizing spare time between nursing care	<ul style="list-style-type: none"> • My lifestyle has settled down. (How long did it take for you? Was there anything that helped you settle down?) After we started visiting a regional salon. Finally I could feel that this is something to live for. (Two other similar cases)
	Securing rest breaks	Caregivers perceiving dialysis treatment as the only time that could be used freely, relieved from responsibility for the patient while he/she was being cared for by healthcare professionals	<ul style="list-style-type: none"> • When my mother is taken care of by nurses during dialysis treatment, I can be alone. Reading newspapers at the hospital cafeteria or visiting a hot spring relieves my stress. (Two other similar cases)
Feeling difficulty in the role of caregiver	Predicted feeling of difficulty in nursing care	Feeling that it would be very difficult if the burden of nursing care were to become greater in the future	<ul style="list-style-type: none"> • Many people mentioned that even though the time spent for dialysis treatment support is short at the beginning, it would increase to three times a week and take four hours each time. I was wondering when it would happen to me. When the treatment starts being every other day, it is unbelievably difficult, isn't it? With treatment twice a week, I had two days in between the treatments, but ... *cut* ... when it starts being three times a week, I just wondered how many more years I will have to do this. (Two other similar cases)
	Feeling of restriction due to nursing care	Feeling that caregivers are bound by continual nursing care without rest or relief	<ul style="list-style-type: none"> • I visited a hot spring with my sister for a night and two days, but I could not relax. I always thought about being called out for my father. This is such a disease, isn't it? • I feel that I am bound to support my mother. I do not need to worry about my mother because I am always with her. *cut* Even if I go on a trip and ask somebody to take care of her, I will always be worried about her. I've been doing this for more than three years all by myself. So, I know I can't relax on a trip because I am always thinking about her. (Another similar case)

the meaning of not enforcing severe limitations in consideration of the patient's limited life expectancy}; and (Nursing care for a limited time), which consisted of the {feeling that nursing care

for dialysis patients could be done because the physical condition of the patient tends to worsen, limiting the period of nursing care to a few years}.

3) **〈Shift of lifestyle〉: (Lifestyle based on the dialysis center), (Reducing workload to carry out the role of nursing care), (Measures for financial burdens), (Securing two or more supporters)**

The category of **〈shift of lifestyle〉** was created based on the perception that each of the four concepts involved a change in the caregiver's lifestyle to provide dialysis nursing care.

Caregivers changed their place of residence closer to the dialysis center (life based on the dialysis center) in order to make continued treatment possible for patients requiring nursing care. On the other hand, there were some cases in which the patient and his/her spouse moved closer to the residence of their child/caregiver. In such cases, too, residence was determined in relation to the dialysis center in the area. Middle aged caregivers, individuals who were also at the stage of their lives in which they had important responsibilities at work, tried to adjust their work environment (reducing workload) in order to provide transportation to and from the dialysis center in accordance with the dialysis schedule. Caregiver families attempted to implement (measures for financial burdens), including the cost of transportation to and from the dialysis centers twice or three times per week and the cost of nursing care, in order to make the continuation of dialysis and nursing care possible. Furthermore, caregivers attempted to secure the assistance of relatives in nursing care (securing two or more supporters) and for consultation.

4) **〈Learning the points of dialysis nursing care〉 : (Learning diet management), (Adjustment of bowel movements in accordance with dialysis treatments)**

The category of **〈learning the points of dialysis nursing care〉** included two concepts; (Learning diet management) meant that caregivers who had learned diet management at the hospital and who at first had followed instructions for diet management came to understand through experience that it was possible to serve the same meals as the family ate by reducing the amount and learning to check the physical reaction of the patient rather than

insisting on serving dialysis meals. Furthermore, caregivers carried out (adjustment of bowel movement in accordance with dialysis treatments). This meant that {caregivers arranged it so the patient would have a bowel movement on days other than dialysis treatment days to avoid a bowel movement during dialysis treatment}. Many patients were administered lapactic to induce bowel movements. Caregivers recognized that if the patient moved his/her bowels during dialysis, it would cause trouble for healthcare professionals, and took the appropriate action.

5) **〈Adjustment of lifestyle in accordance with the dialysis schedule〉: (Adjusting the schedule to the dialysis schedule), (Spending time to adjust the schedule to the dialysis schedule)**

The category of **〈adjustment of lifestyle in accordance with the dialysis schedule〉** included two concepts; (adjusting the schedule to the dialysis schedule) and (spending time to adjust the schedule to the dialysis schedule), which entailed caregivers adjusting their schedule to the dialysis patient's schedule, and caregivers attempted to adjust their schedule to the patient's and the dialysis schedule.

6) **〈Settling of lifestyle patterns〉: (Interlocking lifestyle and work), (Finding ways to relax), (Securing rest breaks)**

The category of **〈settling of lifestyle patterns〉** related to the stability of the psychophysical condition of dialysis patients requiring nursing care. When the psychophysical condition of patients became stable, social resources were provided and the life of the caregivers became less stressful. Three concepts were extracted based on the perception of caregivers that their lives became less stressful.

Caregivers could (reduce workload) by a **〈shift of lifestyle〉** and coordinate their work and role as caregiver, which is the condition of (interlocking life and work), and could (find ways to relax) including {participation in fun activities utilizing spare time between nursing care}. The support of care managers and other family members, and the experience of being able to take a break, even for a short time, made caregivers feel that they could

Table 3. Stages of nursing care in this study and compatibility with the existing research

	Stages of nursing care in this study	Miyae (2004)	Nogawa (2000)	Sodei (1990)
Stages	3	4	4	5
Contents (Characteristics)	1. Commitment to dialysis nursing care 2. Organizing a nursing care system/ learning the points of treatment – 3. Adjusting to nursing care and lifestyle – –	1. Stage of confusion 2. Stage of establishing a nursing care structure 3. Stage of improving the quality of nursing care 4. Stage of becoming aware of the improvement of nursing care ability – –	1. Initial phase (adjustment to the role of caregiver) – – 2. Middle phase (re-commitment to the role of caregiver) 3. Late phase (settling into the caregiver lifestyle) 4. Terminal care phase	1. Confusion stage 2. Shock stage – 3. Stability stage 4. Overload stage 5. End stage
Subjects	Caregivers responsible for dialysis patients requiring nursing care	Caregivers responsible for elderly patients with dementia	Caregivers responsible for elderly patients with chronic and incurable diseases	Caregivers responsible for patients with cerebrovascular disease

Numbers attached to the stages in existing research indicate the order of the nursing care stage shifts.

continue nursing care. Caregivers perceived dialysis treatment at this stage as the {only time that could be used freely, relieved from responsibility for the patient while he/she was being cared for by healthcare professionals} and as (secured break time) while schedule adjustments may have been required.

7) <Feeling difficulty in the role of caregiver>:
 (Predicted feeling of difficulty in nursing care),
 (Feeling of restriction due to nursing care)

Caregivers experienced <feeling difficulty in the role of caregiver> even at the stage in which dialysis nursing care had settled down. This stage included two concepts; (predicted feeling of difficulty in nursing care) and a (feeling of restriction due to nursing care). The (predicted feeling of difficulty in nursing care) was defined as the {feeling that it would be very difficult if the burden of nursing care were to become greater in the future}, and caregivers felt increasing difficulty by predicting that the number of dialysis treatments would increase from two to three times per week and that dementia would worsen in the near future. Furthermore, caregivers recognized the (feeling of restriction due to nursing care) which means that caregivers {feel that they are bound by continual nursing care without rest or relief}.

Discussion

1. Characteristics of the process of learning home-based nursing care experienced by family caregivers responsible for dialysis patients requiring nursing care

In order to clarify the characteristics of the process of learning home-based nursing care observed in this study, we carried out a comparative investigation utilizing the existing research (Table 3). The difference between the studies involved the period of nursing care; Nogawa^{8,9} and Sodei¹⁰ considered the period of nursing care until the last day of the patients, and this study, following Miyae⁷, considered the period of nursing care until the caregiver adjusted to the new lifestyle and nursing care. Miyae⁷ targeted caregivers responsible for elderly patients with dementia, Nogawa^{8,9} targeted caregivers responsible for elderly patients with various diseases, and Sodei¹⁰ targeted caregivers responsible for patients with cerebrovascular disease.

Miyae⁷ and Sodei¹⁰ defined the stage of starting the nursing care process as the *stage of confusion* and *confusion stage* which were stages representing the conflict over accepting the patients' condition and the hesitation in making the decision to continue nursing care because caregivers were unable to accept the changes in the condition of patients requiring nursing care. In the stage of starting nursing care in this study,

caregivers had less confusion and shock when patients developed conditions requiring nursing care, and decided to (commit to dialysis nursing care) because they understood that they couldn't handle the situation with the support and commitment they had given to date. On this point, it is assumed that caregivers had to handle the situation by shifting their approach to commit themselves rather than hesitating and allowing themselves to be confused because they felt that the continuation of dialysis treatment was essential to life of the patient.

《Organizing a nursing care system/ learning the points of treatment》in this study were equal to the stage of *establishing a nursing care structure* and *improving the quality of nursing care* described by Miyaue⁷⁾ and the *adjustment period for the role of nursing care* described by Nogawa^{8,9)}. However, in this study, caregivers were actively working on acquiring better methods from their experiences rather than adjusting themselves to the role of nursing care as time passed, as indicated in research by Nogawa^{8,9)}. This, as described above, is assumed to be created by caregivers who were responsible for dialysis patients requiring nursing care and who encountered the situations for which they had to develop skill in nursing care as a part of treatment to prolong life.

《Adjusting to nursing care and lifestyle》was dealt with in all the studies mentioned above⁷⁻¹⁰⁾, however, caregivers in this study perceived the dialysis treatment time as (secured rest break) in spite of their need to 《adjust lifestyle in accordance with the dialysis schedule》.

In consideration of the above, the process of learning home-based nursing care in this study was the characteristics of nursing care provided by caregivers, and showed the nursing care condition of dialysis patients requiring nursing care.

2. On 《providing nursing care considering the patient's limited life expectancy》

《Providing nursing care considering the patient's limited life expectancy》included (understanding the meaning of relaxing restrictions related to

dialysis in consideration of the patient's limited life expectancy), or evaluating restrictions in the patient's daily life in accordance with dialysis treatment and in consideration of the patient's limited life expectancy, and the recognition of (nursing care for a limited time), meaning that nursing care could be provided because the caregiver realized that it would be for a short period (a few years) rather than a life-long commitment. Such recognition was assumed to be included in the approaches to nursing care while promoting the process of learning dialysis nursing care. Caregivers always considered the patient's limited life expectancy and continued nursing care with a view to approaches and the period of nursing care to patients who required dialysis treatment and suffered physical decline due to aging.

Four approaches, 《providing nursing care considering the patient's limited life expectancy》, 《shift of lifestyle》, 《adjustment of lifestyle in accordance with the dialysis schedule》, and 《learning the points of dialysis nursing care》, in the stage of 《Organizing a nursing care system/ learning the points of treatment》, were acquired by caregivers themselves through trial and error in order to continue dialysis treatment.

The importance of a viewpoint-of-life model rather than medical-care model is proposed for nursing care for elderly patients^{17,18)} who are definitely nearing death, which is one perspective of nursing care designed to consider the patient's limited life expectancy by considering the present rather than the future in not causing the patient undue discomfort for the sake of treatment¹⁹⁾. It is necessary for dialysis patients requiring nursing care to continue dialysis treatment for the purpose of life extension; however, the physical, psychological and lifestyle burdens are significant for elderly patients. It can be assumed that caregivers became aware of 《providing nursing care considering the patient's limited life expectancy》by considering the remaining period and learning how much they should commit themselves to nursing care.

Hashimoto²⁰⁾ referred to the estimate of patient life expectancy, confirmation of patient desire,

evaluation of patient conditions (QOL), and the patient's future life environment at home as the essential in the medical care of elderly patients. It is believed important that dialysis nursing care be considered from the viewpoint of the elderly patient and family care in order to make it possible for the patient and the caregiver to continue a stable life (QOL).

3. Study limitations and future issues

Subjects in this study were individuals introduced by the persons in charge of dialysis nursing care who had agreed to cooperate with the survey. Therefore, it was assumed that these subjects were well-adapted caregivers who had a relatively good relationship with healthcare professionals and, accordingly, who worked positively on nursing care. There is a need to expand the range of sampling including unadapted cases to elaborate the theory. Furthermore, the degree of theoretical saturation needs to be increased regarding the process of learning dialysis nursing care clarified in this study and the specific theory about the requirements for the process, as well as the validity of the concept and category names.

Conclusion

This study was carried out to clarify the structure of home-based nursing care provided by family caregivers responsible for dialysis patients requiring nursing care from the viewpoint of conditions of nursing care, awareness, and influence on the lives of family caregivers utilizing qualitative study methods. The results of this study clarified the following:

- 1) In the process of continual home-based nursing care provided by family caregivers, three stages were extracted: *process of learning home-based nursing care*; <commitment to dialysis nursing care>, <organizing a nursing care system/ leaning the points of treatment>, and <adjusting to nursing care and lifestyle>.
- 2) Caregiver efforts included four components: <providing nursing care considering the patient's limited life expectancy>, <shift of lifestyle>, <adjustment of lifestyle in accordance with the dialysis schedule>, and <learning the points of dialysis nursing care>. Caregivers always concentrated on <providing nursing care considering the patient's limited life expectancy>, the component that was positioned at the heart of these four categories and influenced approaches to nursing care, consisting of <shift of lifestyle>, <adjustment of lifestyle in accordance with the dialysis schedule>, and <learning the points of dialysis nursing care>. Results suggested the necessity of developing nursing care methods in accordance with the stages of the learning process in order to enable family caregivers responsible for dialysis patients requiring nursing care to provide continual support as well as enabling the patients to continue dialysis treatment - comfortably in their family life.

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要介護透析患者にかかわる家族介護者の在宅ケアの構造に関する研究

林 一美, 稲垣美智子*

要 旨

本研究は、要介護透析患者にかかわる家族介護者の在宅介護の構造を、介護の様相、認識、家族介護者自身の生活への影響から明らかにすることを目的とした。対象は、石川県内に在住する10透析センターにおいて通院治療をしている要介護透析患者にかかわる家族介護者22名に、半構造的面接を実施し、修正版グランデット・セオリー・アプローチでデータ分析した。その結果、要介護透析患者にかかわる家族介護者の在宅介護の構造として18概念名と、9 カテゴリーを生成した。家族介護者の在宅介護継続の経過において、〈透析介護への自己投入〉、〈介護体制を整えていく・療養の要領をつかむ〉、〈介護と生活が落ち着く〉の3つの段階が見いだされ「在宅介護獲得プロセス」と命名した。介護者は常に「余命を意識した介護」という思いを抱えており、それが〈介護体制を整えていく・療養の要領をつかむ〉段階の中心部にあり、〈生活様式の転換〉、〈透析時間に合わせた生活時間の調整〉、〈透析介護に関する要領の体得〉である介護の取り組みに影響を与えていた。以上の結果から、要介護透析患者にかかわる家族介護者への透析看護の視点は、家族生活の営みの中で、家族が透析療養を無理なく継続して支え続けることが重要になること、および獲得プロセスの段階に応じたケア方法の開発が必要であることが示唆された。