

The Role and Function of Family in Improving the Quality of Patients' Life: Managing Nutrition During Hemodialysis in Medan, Indonesia

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Abstract— Hemodialysis patients experience physiological and psychological deterioration in bodily functions due to their chronic disease. Therefore, the family has a key role in overcoming this to improve the patient's quality of life. The design used in this study is qualitative and quantitative, which aims to decide the quality of life of hemodialysis patients and determine the family's role and function in nutritional monitoring in the city of Medan. Respondents in this study were hemodialysis patients whom their families accompanied. The number of respondents was eleven patients and forty-four patient families using the purposive sampling technique. Inclusion criteria for patients undergoing routine hemodialysis, undergoing hemodialysis for more than 6 months, while undergoing hemodialysis accompanied by their nuclear family, the nuclear family directly treats the patient. The results showed that forty-four people or 68.20% of respondents had an excellent quality of life, 81.80% of the patient's family had a good role and function. Two themes were found in the role and function of the family in monitoring the patient's nutrition, namely: (1) meeting the patient's needs so that the patient's condition was stable and (2) being support for patients undergoing hemodialysis. The family is the closest person who is the companion, caring for and providing support to patients to improve the welfare of life.

Keywords— Nutritional status; renal dialysis; quality of life; nuclear family; chronic disease.

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I. INTRODUCTION

Hemodialysis is the best treatment used to treat advanced for end-stage renal disease. Hemodialysis treatment indication has been kidney failure and broadened to other pathological conditions, such as refractory heart failure, anasarca hepatic disease, and acute intoxication. In Indonesia, the main cause is hypertension. In addition, many are caused by Diabetes Mellitus, Glomerulopathy, and others. Hemodialysis functions to cleanse the blood by removing blood from the body and putting it to the dialyzer to do diffusion and osmosis after clean blood is returned to the bloodstream in the body [1].

New patients undergoing Hemodialysis in Indonesia continue to increase from year to year. According to data from the Indonesian Renal Registry in 2015, there were 30,554 active patients, all patients both new patients in 2015 and old patients from the previous year who were still undergoing routine hemodialysis and were still alive until Dec 31, 2015. This has increased from 2014. In 2014 11,689 active patients

were undergoing Hemodialysis. In 2015 the number of active patients in North Sumatra was 1236 people [2].

Patients often complain of insomnia, joint pain, skinching, and muscle cramps while undergoing hemodialysis. Another complication felt by patients when undergoing Hemodialysis is interradiation hypertension, hypotension, vascular access problems, chills, headaches, nausea and vomiting, itching, and others [3]. It can impair patients' quality of life. This hemodialysis therapy indirectly affects patients' quality of life such as physical, psychological, spiritual, socioeconomic status and dynamics in family forums [4].

Quality of life requires optimal attention and is important for patients with chronic kidney disease. Chronic disease conditions make patients feel frustrated, so they need help to adapt to the disease while undergoing maximum care throughout their lives [5]. The patients' quality of life with hemodialysis therapy is still a problem that attracts the attention of health professionals.

Optimal patients' quality of life is a necessary issue that must be considered in providing comprehensive nursing services. Patients can survive with the help of hemodialysis

machines, but still, leave many critical issues resulting from hemodialysis therapy.

The current development of hemodialysis therapy has made it easy to do hemodialysis at home, but many patients still need help from another health team [6]. The family is the best source of care for patients with hemodialysis and has a basic role in managing and improving the patients' quality of life with hemodialysis. The quality of care provided by the family will increase patients' quality of life with hemodialysis [7].

The family has an important function in improving the health of family members, especially in terms of physical, psychological, social, and environmental aspects. If these four aspects not good, it will result in a decline in the health of family members [8]. Family support is an important factor needed by family members who experience illness, family support can prevent or reduce patient stress levels because decreasing stress levels can optimize health conditions and improve the quality of life of patients [9].

Research that has been done previously discusses the relationship of family support with improving the quality of life of patients with chronic kidney failure. Researchers have not found research that outlines the role and function of the family in improving patients' quality of life by managing nutrition in patients in aspects of patient care, especially in the city of Medan. Therefore, researchers are interested in seeing how the family's role and function improve patients' quality of life by managing nutrition in caring for family members who undergo hemodialysis therapy in the city of Medan.

II. MATERIALS AND METHOD

A. Research Design

This type of research uses quantitative and qualitative. Quantitative data is presented with a descriptive design, and logical rationalization presents qualitative data. The research design was conducted to explore further how the role and function of the family in improving the quality of life of hemodialysis patients by managing nutrition. The assessment of the patient's quality of life uses quantitative data, while the roles and functions of the family are presented in the form of quantitative and qualitative data.

The number of samples for quantitative research is 44 respondents and qualitative data is obtained from 11 participants. The sample was selected using purposive sampling with the inclusion criteria of routine hemodialysis patients, undergoing hemodialysis for more than 6 months, while undergoing hemodialysis with the nuclear family, the nuclear family directly treats the patient. The research location is a hospital in Medan, Indonesia.

B. Research Instrument

This instrument used was a family role and function questionnaire and a quality of life (QOL) questionnaire for hemodialysis patients measured by WHOQOL-BREF [10]. This questionnaire consists of twenty-six statement items, there are 5 choices of answers with Likert scale techniques, which are very bad, bad, mediocre, good and very good. Items 1 and 2 assess the individual's perceptions of quality of life and health, the other items are categorized into physical, psychological, social, and environmental domains. Questionnaire contains a systematic statement to show the

quality of life of hemodialysis patients. This index assumes that each answer category has the same intensity. The quality-of-life instrument was modified using the literature to answer complaints or complications that were felt during hemodialysis. The highest total instrument value is 130 divided into 3 intervals: low, medium, and high.

The role and function of the family instrument in caring for sick family members in terms of needs, expectations, actions taken and constraints in fulfilling nutrition for sick family members, namely patients undergoing hemodialysis.

The instrument uses closed questions containing true and false answers. Choosing the correct answer gets the point of one and picking the wrong answer gets zero point. The highest answer is 20 and the lowest answer is 1. The total score added above 50% is correct, so the role and function of the family in caring for sick family members is categorized as good. If the correct answer is less than 50%, it is categorized as bad.

The validity test value of the questionnaire on the role and function of the family in caring for sick family members was $r = 0.87$ and the value of the questionnaire for the quality of life of hemodialysis patients was $r = 0.88$. The value of the reliability test of the role and function of the family using Cronbach alpha was 0.78 and the value of the quality-of-life reliability test for hemodialysis patients used Cronbach alpha was 0.79.

C. Data Collection

This research was conducted from February to June 2018. The number of respondents was forty-four hemodialysis patients with his/her families. The data collection procedure is that the researcher submits a permit application to conduct research from the head of the research institute at the initial stage. Then the researchers conducted an ethical test at the ethics committee of the nursing faculty of the Universitas Sumatera Utara Number 1333 / III / SP / 2018. The researcher applied for a research permit at the Medan City Hospital. Then the researchers conducted research in the hemodialysis installation of the Medan City Hospital.

Researchers met with respondents to be used as research samples. The researcher determined the respondent according to the inclusion criteria, after figuring out the respondent the researcher gave a family role and function questionnaire to the patient's family and conducted an interview related to the function and role of the family with 3 questions. Then the researcher gave a questionnaire to the patient about the quality of life of the hemodialysis patient.

III. RESULTS AND DISCUSSION

A. Demographic data

Most the patient's family characteristics are elderly adults, female gender, junior high school education, married status, Batak ethnicity, unemployment status, income IDR <2,750,000, the family that accompanies the patient is a spouse. Information can be seen in Table I.

TABLE I
CHARACTERISTIC OF FAMILY PATIENTS

Characteristic	f	%
Age:		
Late teenager	6	13.6
Early adult	8	18.2
Late Adult	9	20.5
Early elderly	15	34.1
Late elderly	4	9.1
Old	2	4.5
Gender:		
Male	11	25.0
Female	33	75.0
Education:		
No school	5	11.4
Elementary School	7	15.9
Junior High School	19	43.2
Senior High School	13	29.5
Bachelor	5	11.4
Marital Status:		
Married	37	84.1
Widow	1	2.3
No married	6	13.6
Ethnic:		
Batak	29	65.9
Jawa	8	18.2
Minang	7	15.9
Occupational:		
Government employee	4	9
Farmer	3	6.8
No work	25	56.8
Private employee	12	27.3
Income:		
IDR<2.750.000	40	90.9
IDR>2.750.000	4	9.1
Patient Relationship:		
Child	12	27.3
Spouse	28	63.6
Other	4	9.1

The characteristics of most hemodialysis patients are early elderly, male gender, high school education, married status, Batak ethnicity, unemployment, duration of hemodialysis >3 years, undergoing hemodialysis twice a week, income IDR<2,750,000. Information can be seen in Table II.

TABLE II
CHARACTERISTIC OF HEMODIALYSIS PATIENT

Characteristic	f	%
Age:		
Late teenager	2	4.5
Early adult	3	6.8
Late Adult	5	11.4
Early elderly	18	40.9
Late elderly	16	36.3
Gender		
Male	36	81.8
Female	8	18.2
Education		
No school	1	2.3
Elementary School	8	18.2
Junior High School	7	15.9
Senior High School	15	34.1
Bachelor	13	29.5
Marital Status		
Married	42	95.5
Widow	1	2.3

Not married	1	2.3
Ethnic		
Batak	22	50.0
Jawa	8	18.2
Minang	1	2.3
Melayu	1	2.3
Other	12	27.3
Occupation		
Work	15	34.1
No work	29	65.9
Length of Undergoing HD		
Less than 6 months	11	25.0
6 months - 1 year	8	18.2
1 - 3 years	12	27.3
More than 3 years	13	29.5
Hemodialysis Schedule		
Once a week	1	2.3
Twice a week	43	97.7
Income		
IDR< 2.750.000	35	79.5
IDR> 2.750.000	9	20.5

B. The Role and Function of The Family in Caring for the Patient

Based on the frequency distribution of the roles and functions of hemodialysis patients' families in treating patients from psychological aspects, physiological aspects, spiritual aspects, and social aspects, 36 (81.8%) had good roles and functions, and only 8 (18.2%) which is in the bad category. There are five family functions: affective function, social function, reproductive function, economic function, and health care function. Psychological, physiological, spiritual, and social aspects are part of one of the family functions, namely the function of the family in providing health care. The health care function carried out by the family, besides fulfilling the provision of food, clothing, housing, and health care for family members, also aims to prevent the occurrence of illness in one family member.

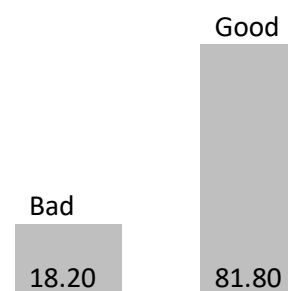


Fig. 1 The role and function of the family in caring for the patient

Frequency distribution data for the role and function of the family in treating hemodialysis patients in terms of 4 aspects obtained data that is the role and function of family members in treating patients from psychological aspects of 42 respondents (95%), physiological aspects of 38 respondents (86%), spiritual aspects of 32 respondents (73%) and social aspects 26 respondents (59%).

The role and function of the family caring for the patient based on psychological aspects obtained 42 respondents (95%) performed a good role. Patients undergoing hemodialysis require motivation and support from the family to go about their daily lives, especially undergoing routine hemodialysis therapy. This change results in changes in

conditions within the family, thus affecting interactions between family members in dealing with healthy or sick conditions [11].

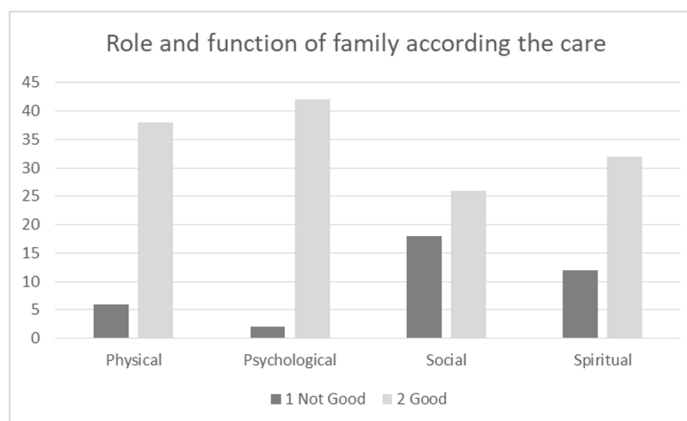


Fig. 2 Role and function of family according the caring

Playing the role and function of the family also has some obstacles, so they have not been able to play their role in caring for sick family members fully. Constraints that the family may face are changes in the patient's lifestyle, especially in eating arrangements, should provide more funds and time to accompany the patient to visit the dialysis center, change the role of the patient while at home and meet all patient dependencies [12].

Demographic data results obtained the most ethnic groups, namely the Batak ethnic group by 25 respondents (65.9%). The Batak tribe has a habit, if there are family members who are sick then other family members will provide encouragement by providing wages and ulos cloth [13]. Provision of wages and ulos cloth aims to increase the enthusiasm & willingness of patients to be healthy and show the family's hope and desire to care for and pray for the health of patients. This habit makes the patient's enthusiasm for health that begins to decline becomes stronger. The habits that exist in the culture of a tribe can cause an increase in the spirit of healthy living, handling complaints that arise, how to treat patients, seek help and care for patients and makes patients more valued and loved.

Demographic data results obtained that the family members of patients who accompanied the most patients during hemodialysis were spouse of 28 people (63.6%). Support from spouse can further improve the quality of life of patients. Family support is the attitude, actions and family acceptance of the patient's illness. The family also functions as a system that can feel sick family members as part of the family, so that sick family members feel supported, and the family is always ready to provide assistance if needed. Family support can be in the form of verbal and non-verbal support such as advice, help, attitude or behavior, attendance and things that can provide emotional support for patients provided by people who are close to the patient or from his social environment. Family support is closely related to improving the quality of life of patients. Quality of life is something that is felt by patients who present in the inability, limitations, symptoms and psychosocial nature of an individual's life both in the context of the cultural environment and its value in carrying out its roles and functions. The presence of the closest person

can help the individual's overall perception of happiness and satisfaction in life and the environment in which he lives for the better [11].

The family is the closest environment to the patient, including hemodialysis patients. The family plays an important role when the patient experiences physical and psychological changes such as insomnia, and anxiety about the disease, boredom to undergo hemodialysis therapy throughout his life and a long-time therapy takes 4-5 hours for each visit to the dialysis center. Quality of life for hemodialysis patients can be caused by various factors such as health management, economy, family support, and others. Patients who have to undergo hemodialysis are mostly caused by hypertension and diabetes mellitus, but there are still many other causes. Respondents in this study were mostly caused by hypertension. Patients with chronic kidney failure who have a history of hypertension, diabetes or polycystic kidney disease experience a gradual physical decline, so they do not feel complaints due to their deteriorating health [14]. Patients undergoing hemodialysis often have several complaints. Based on researchers' results, the most frequent complaints are weakness, difficulty sleeping, and dizziness, shortness, and itching. This complaint will affect the quality of life of patients. Therefore, the role of the family is needed in helping to overcome this and strengthen the patient in hemodialysis [1].

The results of the study amounted to 13.9% of respondents stated experiencing physical limitations during hemodialysis. Families always assisted in meeting their needs and actively participating in helping respondents during hemodialysis. Reduced physical abilities during hemodialysis can be caused by body fatigue. This results in respondents being unable to carry out activities to meet their daily needs. This is in line with research conducted by Xhulia et al. [6] that assistance from the family is very important in meeting patient needs. Help from the family can improve patients' quality of life [6]. Diseases suffered by one family member will affect other family members. This condition also results in disruption of family interactions

C. Quality of Life of Hemodialysis Patient

The frequency distribution of the quality of life of hemodialysis patients based on the complaints or complications during the hemodialysis was as much as 2.3% in the low category, 68.2% in the medium category and 29.5% in the high category. The quality of life of hemodialysis patients can be seen from the length of time the patient undergoes hemodialysis [15]. Normal laboratory values and coexistence with family can improve the quality of life for hemodialysis patients. Coexistence can increase the role of the family, so that patients comply with dialysis treatment, drug therapy, and diet. Social support such as family and friend support have a significant value as an important tool for improving quality of life, adherence to therapy and social relationships for hemodialysis patients [16]. The patient's age also influences the patient's quality of life at illness and education. The younger the patient's age, the better the quality of life and the higher the level of education, the better the quality of life [17]. The higher level of education makes it easier for patients to receive health education from health workers. Nurses have long periods of time with patients.

Nurses have a role in teaching patients how to carry out health management to improve their quality of life. Health education has significant value in improving the quality of life of hemodialysis patients through increasing awareness and reducing misunderstandings in dealing with the disease. The quality of life of hemodialysis patients is a measure of the success of dialysis therapy [18].

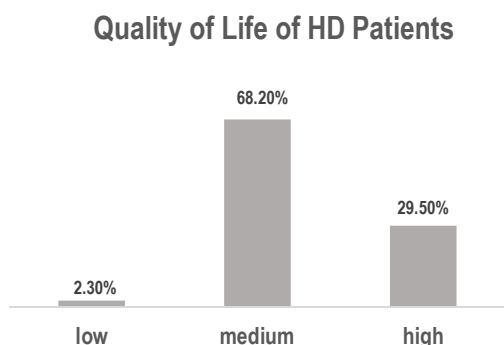


Fig.3 Quality of Life of Hemodialysis Patient

Based on this study, it was found that complaints in patients during hemodialysis were as follows:

- 1.4% of patients were sleepy
- 13.9 patients felt weak
- 4.2% of patients complained of cramps
- 1.4% of patients complained of thirst
- 1.4% of patients complained of anxiety
- 8.3% of patients complained of itching
- 2.8% of patients complained of having problems with defecation and urination
- 1.4% of patients complained of fever
- 1.4% of patients complained of boredom
- 1.4% of patients complained of dry lips
- 1.4% of patients complained of coughing
- 11.4% of patients had no complaints
- 12.5% of patients complained of insomnia
- 8.3% of patients complained of shortness of breath.
- 5.6% of patients complained of double-lumen pain
- 12.5% of patients complained of a headache
- 1.4% of patients complained of vomiting
- 5.6% of patients complained of nausea
- 1.4% of patients complained of hemodialysis machine off
- 2.8% patients complained of shivering.

The results showed that the quality of life of hemodialysis patients in Medan was moderate at 68.2%. This study is not in line with the Tel and Tel studies [19], which states that the quality of life of hemodialysis patients is in a low category. This shows that the patient has adapted sufficiently to the hemodialysis process so that he can maintain his quality of life. This study is different from Winata [11], which states that patients' quality of life at the Kasih Ibu Hospital in Surakarta in the good category at 63%. Rustandi *et al* [20] study also found that the quality of life of more than a few patients with Chronic Kidney Disease (CKD) who underwent Hemodialysis at RSUD dr. M. Yunus Bengkulu in the high category [20]. Winata states that the quality of life of patients with chronic renal failure is influenced by family support and adequate hemodialysis processes [11]. This study also found that the quality of life of respondents who were still moderate

could be related to low socioeconomic status. Socioeconomic status is an important factor related to improving the quality of life of patients with chronic kidney failure [21]. Improving the quality of life is an important and main parameter for determining the quality of nursing care in hemodialysis patients [22].

This study obtained data of male respondents was as much as 81.8% compared to the number of female respondents. Based on several studies revealed that the level of quality of life in women and men differ. Namely, the quality of life of men is better than women [21] [22]. This may be because women have several duties and responsibilities to their families that they cannot avoid [23], [24]. Hemodialysis requires frequent hospital visits or dialysis centers, especially twice a week, which causes patients' lifestyle changes and causes fatigue in patients.

Rustandi *et al* [20] said that age could affect the quality of life of hemodialysis patients. This influence is mainly on the physical component, where patients under the age of 65 have better physical nursing abilities [20]. Older patients more easily accept disease conditions than younger age because younger patients still perceive that they are young and have stable health conditions [14].

D. Role and Function of Family with Qualitative Approach

The first participant is a woman aged 52 years, the second participant is a woman aged 42 years, the third participant is a woman aged 55 years, the fourth participant is a male age 40 years, the fifth participant is a male age 45 years, the sixth participant is a woman aged 50 years, the fourth participant is a male participant aged 40 years. Seven women aged 40 years, the eight male participants aged 45 years, the nine female participants aged 48 years, the ten female participants aged 42 years and the eleven male participants aged 48 years.

There were 2 themes emerged from this study, namely (1) Meeting the needs of patients so that the patient's condition is stable, and (2) Being a supporter for patients Undergoing Hemodialysis. Meeting the needs of patients, especially in controlling food and helping patients in their daily lives are obtained from the family. Family can be a supporter of patients undergoing hemodialysis therapy so that the patient's health can continue to be stable.

1) *Theme 1: Meeting the needs of patients so that the patient's condition is stable.* Families who have family members undergoing hemodialysis in this case the family plays a role in fulfilling the patient's basic needs, especially nutrition. The family has the view that changes that occur in patients require family assistance such as monitoring nutrition, fluids and health. The role and function of a good family against nutritional diseases can support a good life, while the role and function that are not good enough to cause the patient to suffer.

"All activities are assisted and accompanied by me, the patient can't do anything ... let alone eat ... lazy to eat ... how does red blood go up" (P1)

"Eh ... daily activities can still be done, but those who are hard to do must be assisted ... especially eating if they are not paid attention to ... like stealing food ..." (P9)

"We never leave our children alone; we always support each other in turn especially the food must be in accordance with current conditions ... " (P7)

Eatin....is not a problem.....father likes to steal if not controlled..we will give food as the doctor said...if father eats wrong, the next day he will be short of breath...we'll see he really- really sick (P2)

"This grandfather is chatty everything must be helped even though if we weren't there we could be independent he like sulking and don't want to eat" (P10)

"... Parents must be taken care of properly. They are old it's a shame if they don't pay attention to their eating" (P4).

2) *Theme 2: Being a supporter of patients undergoing Hemodialysis.* In undergoing hemodialysis, the majority of patients are accompanied by their families. The family is the closest person to the patient and has a bond in a familial relationship as wife/husband and child. The family says they always help family members in all their basic needs.

"Is it permissible if you are sick to be given supported, you know ... especially when you are healthy, this father likes to help people ... good people, you know, son" (P2)

we take care of everything, we give support to calm our parents' hearts....if it's healthy we are also happy, it's good for your health, brother.....eh...he like to help people, good with employees (P6)

"...who else encourages my husband, so who is it, bro?" (P3)

"I woke up my mother early in the morning to remind of today's hemodialysis schedule..." (P5)

Hemodialysis schedule has become our routine, you know, our time is definitely there for mom..... so that our beauty mom is healthy, you know, brother..... (P8)

"... I always strengthen my father, if my father can definitely undergo hemodialysis. Many can hemodialysis, why not sir, I said ... yes ma'am ... "(P11)

Patients who undergo hemodialysis often experience health problems both physically and psychologically. This often affects the fulfillment of daily needs so that the family is very instrumental in meeting the needs of patients so that the patient's condition is stable. Meeting these needs, especially in the diet. Based on the results of interviews with respondents, the family must be able to provide food according to the diet of patients with chronic kidney failure and remind patients to obey the patient's diet. Patients also revealed that the family's main role is to be able to treat the patient at any time [11].

The family can be support for patients Undergoing Hemodialysis. This is because Hemodialysis can cause boredom due to undergoing therapy for a long time and for life. The role of family members as friends is the most appropriate thing for patients. Being a friend is the most statement from the patient's family in triggering the patient's enthusiasm to continue Hemodialysis [5].

Meeting the dietary needs of patients with chronic kidney failure can increase with social support from the environment or health workers, and family support to increase patient motivation. The family is able to be a counselor for patients to stick to the diet and undergo treatment and help patients deal with any complaints that occur due to illness. Respondents also expressed that the family's role and function are a reminder for patients to adhere to the diet during

hemodialysis. This is in line with Ahrari's opinion, in 2014 that the family is an important part of the health team. The family plays its role and function well is one of the most effective ways to improve patient adherence to treatments and improve patients' quality of life [11].

Families who carry out their roles and function well when patients are hospitalized can provide information and nutrition according to patient needs to improve quality of life and minimize complications [25]. This is consistent with the findings by Isenberg and Trisolini [25] that states that the primary source and guide of patients in managing nutrition is information, information that is done by the family and the role in providing nutrition must be carried out properly and throughout the patient's life [26]. Families need this information in the management of patients with hemodialysis. This can improve the quality of life of hemodialysis patients. The role of the family is expected as a regulator of nutrition by paying attention to things that can be consumed and that cannot be consumed as well as the number of limits that can be consumed.

IV. CONCLUSION

The results of the study concluded that the quality of life of patients undergoing Hemodialysis was good. Good quality of life can be influenced by family support, economic factors, stress control, and adaptation to the disease. The role and function of the family in this study are in a good category, especially in the physical care category but in the social care category it is still not good. The results of further exploration of the role and function of the family in nutrition monitoring are: (1) Meeting the patient's needs so that the patient's condition is stable, and (2) Being a supporter for patients Undergoing Hemodialysis. So, it is important for nurses, especially hemodialysis nurses who more often meet with patients to assess and support patients to improve their quality of life by involving the family as a supporter during hemodialysis and serves to help meet the needs of patients. This research can be useful for nursing implementation, especially for dialysis nurses. Dialysis nurses can improve patients' quality of life by providing knowledge to patients' families about fulfilling nutrition that requires the role of the family. This research is expected to be material for nursing education, especially family nursing. The role and function of the family are needed for hemodialysis patients to improve their quality of life. In this research, follow up is needed to make the family multidisciplinary health professional. Therefore, further research is needed on developing family role models for the stability of the patient's condition, especially the fulfillment of the patient's nutrition.

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