



Perception Towards Illness and Health Care System Among Chronic Kidney Patients with Hemodialysis

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Abstract

Chronic kidney disease is still a problem faced by the world of health in Indonesia. The high prevalence of chronic kidney disease has increased every year. The high number of cases of chronic kidney disease causes higher efforts to seek treatment for chronic kidney disease which is influenced by perceptions of disease and perceptions of the health service system. This study aims to determine the illness perception and perception of the service system in chronic kidney patients with hemodialysis at one of the district hospitals in Yogyakarta Province (hospital X). **Method:** The research method was analytic observational with a *cross-sectional* approach which was carried out at the hemodialysis polyclinic at hospital X in January-February 2023. The sampling technique used *Convenience sampling*. Data collection was carried out by direct interviews with respondents using a questionnaire. Data were analyzed using the *Kolmogorov-Smirnov test* and the *Chi-Square test*. **Result and discussion:** The research results obtained a total of 102 respondents. The percentage of respondents with a good illness perception was 66.67% and a good perception of the health service system was 90.19%. Based on the results of the study, it can be concluded that perceptions of disease and perceptions of the health service system for chronic kidney patients with hemodialysis at Hospital X tend to be good. **Conclusion:** The results of statistical tests showed that there was no relationship between gender, age, duration of chronic kidney disease, education level, and family income on perceptions of disease and perceptions of the health service system at Hospital X, Special Region of Yogyakarta.

Keywords: *chronic kidney disease, illness perception, perception of the health care system*

Introduction

The prevalence of the incidence of non-communicable diseases as shown from basic health research data (Risikesdas) in 2018 has increased, especially in chronic kidney disease. The incidence of chronic kidney failure in Indonesia is based on data from Risikesdas, (2018) which is 0.38% of the total population in Indonesia¹. The high rate of increase in chronic kidney disease is proportional to the increasing effort to seek treatment. This is influenced by the perception of the disease and also the perception of the health care system.

Chronic kidney patients experience many changes in their lives due to various symptoms and treatments. Treatment performed by chronic kidney patients consists of hemodialysis, diet, and routine medication. The number of courses of treatment that must be carried out by chronic kidney patients can affect the patient's perception of the disease. Illness perception has a very important role in carrying out treatment. The patient's perception of the disease is

the patient's belief in the disease, its symptoms, causes, effects caused by the disease, and its ability to live it². The problems that often arise in chronic kidney patients with hemodialysis are related to adherence in undergoing medical therapy. Several factors affect patient adherence to hemodialysis, one of which is the patient's perception of the disease^{3,2}.

Many health facilities are available around the community to be one of the considerations in choosing treatment. The quality of health services influences a person's decision to seek treatment. Service quality has a close relationship with the perception of the service system where patients will give positive or negative perceptions in accordance with the services they have received⁴.

Based on this background, it is necessary to conduct research on perceptions of disease and perceptions of the health care system in patients with chronic kidney disease on hemodialysis. The purpose of this study was to determine the illness perception

and the perception of the health care system in chronic kidney patients with hemodialysis at RSUD X.

Methods

The design of this research is descriptive observation research with a cross-sectional research design. The research was conducted in the Hemodialysis Room at one of the district hospitals in Yogyakarta Province (Hospital X) from January to February 2023. The sampling technique used was *Convenience sampling*. The total sample was determined using the Cochran formula. The estimated proportion of the population with chronic kidney disease is not known with certainty, so a value of $p = 50\%$ or 0.5 is used. The level of confidence used is 95% and a margin of error of 10%. The minimum number of samples required is 96 samples. Respondents who met the criteria were respondents who were interviewed by researchers. The research subjects were outpatient chronic kidney failure patients with hemodialysis who were *JKN* (National Health Insurance) participants at Hospital X in the Special Region of Yogyakarta. Inclusion criteria in this study were chronic kidney outpatient of *JKN* participants who went to Hospital X in the Special Region of Yogyakarta, patients diagnosed with chronic kidney disease with hemodialysis for ≥ 3 months, aged ≥ 18 years, patients in a stable condition able to communicate, understand and answer questions questionnaire well and willing to participate in this study with caution. The exclusion criteria for this study were patients with incomplete questionnaire data information. The research instrument used in this study was a perception questionnaire disease and the system of perception of health services in chronic kidney patients.

Data analysis using descriptive analysis, Normality test and Chi-Square test. Descriptive analysis was used to provide a concise and clear picture of sociodemographics, perceptions of disease and perceptions of the health care system. The data is presented in the form of tables, averages and proportion calculations. The normality test was carried out using the Kolmogorov-Smirnov method to find out whether the resulting data is in a normal distribution or not. The data is said to be normally distributed if the significance value (2-tailed) is > 0.05 . The Chi-Square test was used to determine the relationship between individual sociodemographics and perceptions of disease and perceptions of the healthcare system. significance value <0.05 then H_0 is rejected which means there is a relationship between the variables studied.

Results and Discussion

Patients Characteristics

Table 1 Characteristics of Chronic Kidney Patients with Hemodialysis at RSUD X

Characteristics	N	(%)
Gender (n=102)		
Male	59	57.8
Female	43	42.1
Age (n=102)		
<45	30	29.4
≥ 45	72	70.5
Illness Duration (n=102)		
<5 Years	77	75.5
≥ 5 Years	25	24.5
Education Level (n=102)		
Low	18	17.6
Middle	74	72.5
High	10	9.8
Family Income (n=84)		
<UMR	30	35.7
\geq UMR	54	64.2

A total of 102 chronic kidney disease patients on hemodialysis who met the inclusion criteria to participate in this study and were willing to participate. Results of Characteristic patients are shown in Table 1. Respondents consisted of 57.8% male patients and 42.1% female patients. Previous Research have stated that male patients have a higher chance of developing chronic kidney disease which can be caused by lifestyle patterns, including consuming coffee and smoking. Clinically, men risk experiencing chronic kidney failure 2 times as much as women. This is possible because women pay more attention to health and maintain a healthy lifestyle than men, so men are more susceptible to chronic kidney disease than women⁵. Other studies have found that most patients with chronic kidney disease with hemodialysis were men, this could be because men are more often affected by hypertension, diabetes mellitus, and obesity which are risk factors for chronic kidney disease⁶.

The majority of respondents aged >45 years were 72 people (70.5%) more than patients with respondents aged <45 years, namely 30 people (29.4%). Clinically, patients aged >60 years have a 2.2 times greater risk of experiencing chronic kidney failure compared to patients aged <60 years. it occurs because increasing age causes reduced kidney function and is associated with a decrease in the glomerular excretion rate and worsening tubular functioning⁵.

The level of education is dominated by respondents in the middle education category as much as 72.5%. Then respondents in the low education category were 17.6% and respondents in the higher education category were 9.8%. The level of

education affects individual behavior in improving health care, disease prevention, treatment-seeking behavior, and decision-making about an action or therapy that will and must be followed in their health treatment. The higher a person's education level, the more awareness in seeking and deciding on treatment and care for their health problems will also increase⁷.

Respondents with the highest duration of illness were in the category <5 years (75.5%) and the category >5 years (25%). According to research at the Ulin Hospital in Banjarmasin, the duration of

treatment for chronic kidney patients was dominated by patients with disease duration <5 years by 92.01% and >5 years by 7.99%⁸. Furthermore, patients with the highest level of income were patients with an income category >UMR in Yogyakarta city (64.2%) and patients with an income level <UMR (35.7%). Similar to the research conducted on patients undergoing therapy at Roemani Hospital Semarang, the average family income of chronic kidney patients per month is more than the minimum wage⁹.

Illness Perception

Tabel 2 Illness Perception

Question	Strongly Agree (%)	Agree	Disagree	Strongly Disagree	Total
1. Chronic kidney disease is caused by a family history of chronic kidney disease	0.00	29.4	70.5	0.00	100
2. Chronic kidney disease is caused due to the burden of thoughts, stress or difficulties in life	0.00	10.7	89.2	0.00	100
3. Chronic kidney disease is caused by increasing age	0.00	53.9	46	0.00	100
4. Chronic kidney disease caused by smoking	0.00	23.5	76.4	0.00	100
5. Chronic kidney disease is caused by excess body weight	0.00	7.8	92.1	0.00	100
6. Chronic kidney disease is caused by frequent consumption of cholesterol foods	0.00	59.8	40.1	0.00	100
7. Chronic kidney disease is caused by inactivity	0.00	28.4	71.5	0.00	100
8. Chronic kidney disease is caused by frequent consumption of foods with a high salt content	0.00	93.1	6.8	0.00	100
9. Chronic kidney disease requires routine and long-term treatment	0.00	100	0.00	0.00	100
10. Chronic kidney disease can be cured by supernatural powers	0.00	0.00	100	0.00	100

Illness perception is the understanding that individuals have regarding their illness. Illness perception can also be defined as a person's perception of the physiology of the disease, symptoms, and inability to functioning¹⁰. In this study, the illness perception consisted of a 10-point questionnaire with direct interviews with chronic kidney patients. The results of the illness perception are shown in Table 2.

Chronic kidney disease is caused by factors from family history who also suffer from chronic kidney disease. There were 29% of respondents agree that chronic kidney disease can be caused by families that also have a history of chronic kidney disease, but 71% of respondents disagree because they thought that chronic kidney disease had nothing to do with family factors, but chronic kidney disease was caused by other precipitating factors such as hypertension and diabetes mellitus which are precipitating factors for chronic kidney disease. Another study found similar results where only 2.2% of respondents had a family history as a cause of respondents developing chronic kidney disease¹¹. Other research states that a family history of chronic kidney disease can also increase the risk of chronic kidney disease by 2.58 times. The

factors of family history and age with chronic kidney disease are referred to as CKD susceptibility factors, which are factors that increase the susceptibility to developing CKD^{12,13}. Another study states different results, this study was conducted on the population of El Salvador which found the prevalence of risk factors for a family history of chronic kidney disease at 16.9%. When a family member has chronic kidney disease or undergoes hemodialysis, a person may be at greater risk of developing chronic kidney disease as well.

Based on the results of interviews, more than half of the respondents disagreed that chronic kidney disease is caused by a burden on the mind, stress, or difficulties and a small proportion agreed. A lot of burden of mind can trigger an increase in blood pressure which is likely to increase the patient's experience of hypertension which can trigger a person to develop chronic kidney disease. In addition, the cause of a lot of thoughts can be caused by busy work factors such as office workers whose work requires continuous sitting, causing the ureters in the kidneys to be pinched, heavy workers who work outside in hot rooms and cause sweating and are prone to dehydration. Dehydration can cause urine to

become more concentrated, which can lead to chronic kidney disease¹². The disease can be a cause of stress. The patient's illness causes demand to adapt, especially in patients with chronic diseases that require adjustment over a long period of time¹⁴. The same applies to chronic kidney disease who require routine hemodialysis for life. Previous research explained that there is a relationship between the length of hemodialysis and stress levels in patients with chronic kidney patients.

Chronic kidney disease is caused by increasing age. Based on the results of the study, there were 54% of respondents agreed, and 46% of respondents disagreed. Respondents who disagreed argue that increasing age cannot cause chronic kidney disease because many of them are still in their productive age and have experienced chronic kidney disease. This research is in line with the theory that chronic kidney disease can affect all ages according to the underlying etiology⁵. Other research also states although kidney disease is better known as a chronic disease that is mostly found in the elderly, chronic kidney disease can actually affect all ages and genders¹⁵. In contrast, other research state that with increasing age the risk of a person developing chronic kidney disease also increases¹³. Changes in kidney function along with age increase the susceptibility of the elderly to impaired renal function and renal failure, and changes in renal blood flow, glomerular filtration, and renal hygiene in renal failure increase the risk of treatment-related changes. The decline in kidney function begins when a person enters the age of 30 years and by the age of 60 years, kidney function decreases by 50% due to a reduced number of nephrons and the inability to regenerate¹¹. Clinically, patients aged >60 years have a 2.2 times greater risk of developing chronic kidney failure than patients aged <60 years⁵.

Chronic kidney disease is caused by smoking. A total of 24% of respondents agreed and 76% of respondents disagreed. Respondents who agreed were active smokers. Chronic kidney failure patients undergoing hemodialysis who have a history of smoking have a risk of developing chronic kidney failure 2 times greater than patients without a history of smoking⁵. Smoking is also associated with an increase in high blood pressure. Nicotine contained in cigarettes will cause an increase in blood pressure because the nicotine will be absorbed by small blood vessels in the lungs and circulated by blood vessels to the brain, the brain will react to nicotine by signaling the adrenal glands to release epinephrine (adrenaline)¹⁶. However, other studies say smoking is

not statistically proven as a risk factor for chronic kidney disease¹³.

Based on the results of the study, most respondents (92%) disagreed that being overweight causes chronic kidney disease, and 8% of respondents agreed that weight is one of the factors causing chronic kidney disease. Being overweight is closely related to the patient's lack of exercise and activity habits. Another study stated that lack of exercise is a risk factor for CKD where lack of exercise can increase the risk of increased blood pressure¹⁶. Similar to lack of exercise, the results stated that most respondents also disagreed that lack of activity was a contributing factor to chronic kidney disease. Respondents argued that they were very productive so that their chronic kidney disease did not occur due to a lack of activity, while a small proportion agreed that it was due to a lack of exercise and an unhealthy lifestyle.

Lifestyle is an important thing that must be considered, one of the lifestyles that must be considered is the food factor. The results showed that most of the respondents (60%) agreed and the rest (40%) disagreed that foods containing cholesterol can cause chronic kidney disease. The unhealthy lifestyle of a patient can lead to complications of other diseases such as hypertension and diabetes mellitus. Similar research states that obesity, cholesterol, and family history can increase the risk of chronic kidney disease¹⁷. This study is different from previous research which states that from statistical tests conducted, there is no significant relationship between cholesterol levels and the incidence of chronic kidney disease¹⁸. The results of the study further showed that as many as 93% of respondents agreed that another cause of chronic kidney disease was frequent consumption of foods with high salt content. The same thing was explained in other studies, namely as many as 60% of respondents were patients with a history of consuming foods with high salt content¹⁶.

Chronic kidney disease requires treatment for a long time. 100% of respondents chose to agree. Where subjects with the long-suffering from chronic kidney disease with hemodialysis for 10 years and the latest for 3 months. Chronic kidney disease is classified as a chronic disease that has characteristics that are permanent, incurable, and require long-term treatment and outpatient care¹⁹. The results of this study are the same as the results of other studies where the hemodialysis therapy process takes a long time which will affect various aspects of life²⁰. The last perception is that supernatural powers can cure chronic kidney disease. The results showed that all

respondents (100%) disagreed. This is related to the level of confidence of each individual. All respondents stated that they believed 100% in medical treatment as a form of effort for the respondent's recovery. The results of this study are inversely proportional to other studies which stated that a number of patients said their chronic kidney disease was caused by magical things and they underwent alternative treatments outside the hospital such as psychics, shamans, and healers²¹.

Based on the distribution of the answers listed in Table 2, an assessment and score categories were carried out. The results of the illness perception were categorized into 2 groups, namely good and bad. The Kolmogorov-Smirnov normality test was conducted on the illness perception score which aims to determine the cut-off point for categorization. The results of the normality test showed a p-value <0.05 indicating that the data was not normally distributed so the cut-off point based on the median value was 24. The assessment data and score categories can be seen in Table 3.

Table 3 Rating and categories of Illness perceptions

	Mean	SD	Min Score	Max Score	Median	Category		Good	Not good	%
						%	%			
Illness perception	24	1.10	22	26	24	68	66.67	34	33.37	

The results of the study consisted of 68 respondents (66.67%) with a score ≥ 24 included in the good category, and 34 respondents (33.37%) with a score <24 including in the bad category. The results of this study indicate that most of the respondents have a good understanding of chronic kidney disease. This research is in line with other research where chronic patients have a positive perception that by doing routine hemodialysis and following a diet suitable for chronic kidney disease, their condition will remain stable²². This is supported by similar research which states that patients have high expectations and are compliant in managing self-care²³.

The results of this study differ from other research which stated that most chronic kidney disease patients undergoing hemodialysis have a negative perception (50.4%) where the impact caused by disease and its treatment is very large and has a major influence on life². Many negative perceptions of disease can lead to increased morbidity and mortality, decreased quality of life, and patient non-compliance³. So that to improve patient perception of disease, support from family, social, and health workers is needed.

Perception of Health Care System

Table 4 Perceptions of the Health Service System

Question	Strongly Agree	Agree	Disagree	Strongly Disagree	Total	
					(%)	
1. It is difficult for me to go to the hospital because there is no companion to accompany me	0	5.88	94.11	0	100	
2. It is difficult for me to go to the hospital because there is no transportation	0	2.94	97.05	0	100	
3. It is difficult for me to go to the hospital because it is far from home	0	0.9	99.01	0	100	
4. It is difficult for me to go to the hospital because the queues are long and the procedures are long	0	0	100	0	100	
5. I routinely treat CKD at the hospital every month	2.9	97.05	0	0	100	
6. I believe in the CKD medicines provided by the hospital	5.8	94.1	0	0	100	
7. Health services at the hospital are provided properly	12.7	87.2	0	0	100	
8. I trust the medical staff at the hospital	11.7	88.2	0	0	100	
9. Medical staff provide complete information about my CKD	8.8	91.1	0	0	100	
10. Medical staff at the hospital provide complete information about drugs	8.8	91.1	0	0	100	

The perception of the health care system with chronic kidney disease patients in this study consisted of ten questionnaire questions. Respondents' answers can be seen in Table 4. Most of the respondents went to the hospital without being accompanied by their families because their conditions were stable and some needed assistance from their families. Chronic kidney patients who experience physical weakness are unable to visit health facilities on their own so they need the help of

others, this causes chronic kidney patients to become dependent on²⁴. Most of the respondents disagreed that they had difficulty going to the hospital due to transportation constraints. Based on the research results, it is known that several means of transportation used by respondents to go to the hospital include private vehicles, public transportation, and free ambulances. So that respondents have no difficulty accessing health facilities. The results of another research state that

chronic kidney patients use transportation such as motorbikes (83.2%) and private cars (35.6%) as a means of transportation to the hospital¹⁰.

Most of the respondents did not find it difficult to go to the hospital because of the long distance from home and a few others found it difficult to go to the hospital. Based on the results of field observations, the majority of respondents live in the city of Yogyakarta and the most distant respondents live in Gunung Kidul Regency. Distance can affect the frequency of visits to health facilities, the closer the residence is to the health facility, the greater the number of visits to the health facility²⁵.

Respondents who live far from the hospital usually have difficulty going to the hospital due to transportation reasons and high costs. In using health services, sometimes long distances can also cause other factors such as economic factors or transportation costs which become obstacles for respondents, especially poor respondents who live far from health facilities²⁶.

All respondents stated that they had no difficulty going to the hospital because of the long queues and lengthy procedures. This is because the majority of respondents are permanent patients of the hospital. With the frequency of hemodialysis 2x a week and control 1x a month, the respondents were used to the flow of treatment.

The majority of respondents stated that they were willing to go to the hospital regularly every month. Every month the respondent has a routine control schedule 1x to the internal medicine polyclinic and the frequency of hemodialysis 2x a week. Most

respondents (94.1%) stated that they trusted the medicines provided by the hospital. In line with previous research, the dependence and hope of chronic kidney patients to get a cure lie in hemodialysis and consuming drugs provided by health facilities regularly²¹. In addition to having a high level of trust in the medicines provided by the hospital, the majority of respondents agreed that health services at the hospital were provided well (87.2%), respondents could trust the health workers at the hospital (88.2%) and health workers provided a complete explanation of chronic kidney disease (91.1%) and complete information about drugs (91.1%). This research is the same as previous research where service quality and consumer experience simultaneously have a significant effect on customer satisfaction. The patient's experience in obtaining health services will give a special impression to the patient which impression can have an impact on the next visits. Service quality is closely related to patient satisfaction so patients will have positive or negative perceptions according to the service experience the patients getting⁴.

Based on the distribution of the answers listed in Table 4, then an assessment and score category are carried out. The results of the perception of the health service system are categorized into 2 groups, namely good and poor. The results of the normality test show a p-value (<0.05) which indicates that the data is not normally distributed so the cut-off point is based on the median value of 30. Assessment data and score categories can be seen in Table 5.

Table 5 Rating and categories of perceptions of the health care system

	Mean	SD	Min Score	Max Score	Median	Category			
						Good	%	Not Good	%
Perception of health care system	30.41	1.47	30	36	30	92	90.19	10	9.80

The results of the research were that 92 respondents (90.19%) with scores ≥ 30 were included in the good category and as many as 10 respondents (9.80%) with scores < 30 were included in the bad category. Based on the results of this study, it shows that most respondents have a perception of the health service system in the very good category. This is in line with previous research which stated that service quality has a significant positive effect on hospital patient satisfaction²⁷. Health services can be said to be successful if they are able to provide patients satisfaction, where for patients the influencing factor in choosing a health facility is the quality of service. Perceptions of good health services can increase public interest in utilizing services from

health. In contrast to previous studies, most patient perceptions of the services of Harapan dan Doa Hospital in Bengkulu City were not good, this was influenced by several factors such as age, gender, education, and work. patient perception of the quality of the service system⁴.

The correlation between sociodemographics with perceptions of disease and the health care system was analyzed using the Chi-Square test. Based on the results of the Chi-square test listed in Table 5, the significance values for all variables were obtained, namely (> 0.05). The results of statistical tests showed that there was no significant relationship between sociodemographics, which in this case included gender, age, length of illness, level of education, and

family income on illness perception and the health care system.

Table 6 Chi-Square Test Results

Characteristics	Illness Perception			Perception of the Healthcare system		
	Good	Not good	Sig.	Good	Not Good	Sig.
Gender						
Male	41	18	0.478	53	6	0.884
Female	27	16		39	4	
Age						
<45	21	9		29	1	
≥45	47	25	0.645	63	9	0.156
Illness duration						
<5 years	49	27		69	7	
>5 years	19	7	0.422	23	3	0.730
Education						
Low	12	6		16	2	
Middle	35	19		46	8	
High	21	9	0.890	30	0	0.089
Family Income						
<UMR	18	12		26	4	
≥UMR	39	15	0.250	49	5	0.563

This study is different from previous studies where there is an influence between the variables age, gender, education, and occupation on patient perceptions of the quality of hospital services⁴. Other research states that there is a relationship between age and patient perception, while other variables such as gender, education, occupation, and income have no relationship to patient perception²⁸. The level of education was dominated by respondents with a secondary education level which illustrated that in general respondents were able to understand information related to chronic kidney disease. The Income level variable affects the compliance of chronic kidney failure patients undergoing hemodialysis²⁶. In addition, other studies state that there is a relationship between age and patient perceptions of service quality but did not find a relationship between gender and education level in perceptions of service quality²⁹. The service quality has a close relationship with patient satisfaction, so positive and negative perceptions will arise according to the experience obtained⁴.

Improving patient illness perceptions requires family, social, and health worker support so the findings in this study are expected to be useful for health service providers to be able to provide even better service quality in the future.

This study has limitations in data collection which was carried out in one hospital only so the number of samples studied was limited.

Conclusions

Illness perceptions and perceptions of the health care system in patients with chronic kidney disease with hemodialysis at one of the district hospitals in

Yogyakarta Province are categorized as good. Sociodemographics of patients including gender, age, duration of chronic kidney disease experienced, level of education, and family acceptance had no relationship to illness perceptions and perceptions of the service system at the hospital.

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Ethical Consideration

This study received ethical approval from the Hospital Health Research Ethics Committee No.41/KEPK/RSUD/XII/2022.

Authors' Contributions

DE, TMA designed the study; NAG carried out the data collection; NAG, DE, and TMA analyzed the data; NAG, DE, TMA, and VQT wrote and review the manuscript; and all authors read and approved the final version of the manuscript.

Competing Interests

The Author states that there is no competing interest in conducting this research.

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