

MEANING OF LIVING WITH END STAGE RENAL DISEASE AND HEMODIALYSIS OF MUSLIMS IN PEKANBARU, INDONESIA: A QUALITATIVE STUDY

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ABSTRACT

This study aimed to explore meaning of living with End Stage Renal Disease undergoing hemodialysis of Muslims in Pekanbaru, Indonesia. This study was an ethnographic study conducted in Pekanbaru, Indonesia. 4 females and 8 males Muslims on hemodialysis were recruited using purposive sampling. The inclusion criteria were Muslims, being diagnosed with End Stage Renal Disease and having known the diagnosis, having been undergoing hemodialysis at least 6 months, and never change treatment to peritoneal analysis or renal transplantation. Data were collected using in-depth interviews, participant observation and documentation of field note. Data analysis used the ethn nursing data analysis method. Findings of the study revealed 3 categories; (1) restricted life, (2) life is struggle, and (3) reminder to God. Results of this study suggest nurses and other healthcare professionals should understand principles of religions and cultures in their community to help them provide culturally congruent care for their patients.

Keywords: *End Stage Renal Disease, Ethnography, Hemodialysis, Meanings, Muslims.*

INTRODUCTION

End Stage Renal Disease (ESRD) is one of major public health problems in the world. Approximately 70,000 patients diagnosed with ESRD every year and around 5% of them undergoing hemodialysis treatment in Indonesia (Endang, 2005). ESRD affects the daily activities of patients and families and influence their health status, lifestyles and roles. Persons with ESRD undergoing hemodialysis experience lifestyle changes that affect the individual's social and psychological functioning and present a challenge for the hospital team (Parker and Smith 2010).

Indonesia is a Muslim majority country. Many cultures or ethnicity exist in Indonesia. Muslims are influenced by Islamic values in living with the sufferings due to the illness. Leininger and McFarland (2002) described that cultural beliefs, values, and meanings often guide the thought and behavior of people in diverse cultures. Religious beliefs may also

influence a perception of causes of an illness, its severity, and the choice of treatment.

Experiences of living with ESRD and hemodialysis have been studied by researchers and the meanings of this are various such as accepting their life conditions, struggling to survive, developing strategies to improve their quality of life, being vulnerable, having mistrust, dependence, and feeling restricted in their lives (Clarkson and Robinson 2010; Molzahn *et al.* 2008; Richard and Engebretson 2008; Al-Arabi 2006; Hagen *et al.* 2004). The meanings of living with the illness in a particular religion particularly the Islamic culture are not known clearly. It is beneficial to know how Muslims gain meanings under influence of their way of life in living with their sufferings. Research question of this study was

'What were meanings of living with ESRD on hemodialysis of Muslims in Pekanbaru, Indonesia?'

METHODS

The study was aimed to explore meanings of living with ESRD undergoing hemodialysis of Muslims in Pekanbaru, Indonesia. This research was an ethnographic study. Ethnonursing research method was used as research methodology and data analysis method. According to Leininger and McFarland (2002) the method was designed to explore care and health knowledge related to areas such as social structure and environmental factors, and cultural life. Ethnonursing is focused on exploring knowledge and practices of informant's world of knowing and experiencing life related to care, health, well-being and illness.

Informants in the study were recruited by using purposive sampling employing several inclusion criteria. The inclusion criteria included patient with ESRD, having known the diagnosis, having been undergoing hemodialysis at least for 6 months, Muslim, and having never changed treatment to peritoneal analysis or renal transplantation.

All informants were recruited in Pekanbaru, Indonesia, where the majority of population are Muslims accounting for 85.0% of the total population (Central Bureau of Statistic of Indonesia 2011). Data were collected in 2012 using interview, participant observation, and field note collection. The principal author conducted semi-structured interviews and conversation with informants during data collection. In collecting and recording data, the researcher used Personal Information Form to collect baseline characteristics of the informants, interview guide, observation guide, field notes, camera, and audio-tape recorder.

Each interview was recorded and transcribed verbatim. Data were transcribed in Indonesian and analyzed by principal author since this is his first language. The data were translated into English and back-translated to ensure accuracy of interpretation. Data collected were analyzed using the ethnonursing data analysis. There are four phases of the ethnonursing data analysis according to Leininger and McFarland (2002); collecting and documenting raw data, identification and categorization of descriptors and components, pattern and contextual analysis, and presenting themes, research findings and recommendations.

The principal author performed all phases of the study and co-authors reviewed process and results of all phases. Trustworthiness of the study was highly

maintained by employing criteria related to ethnonursing as proposed by Leininger and McFarland (2002). The criteria are credibility, confirmability, auditability, and transferability. Methods used to enhance credibility of the findings were prolonged engagement, persistent observation, triangulation, and member checking. Confirmability was performed by restating the ideas or findings from what has been heard, seen, and experienced with informants. All data were recorded and documented appropriately. Each step of the research process was explained clearly and carried out under supervision of co-authors and they performed an audit to confirm the raw data and each step of the data collection process. Regarding transferability, quotations, commentaries, and stories were added to enrich the report and understanding of the context of experience. The authors described detailed information about all phases of the study. Readers may make decisions to apply or transfer the results to another, but with respect to similar situation, context, or culture (Leininger and McFarland, 2002).

Ethical consideration was highly maintained during the study. Ethical approval was granted by the ethics committee of the Faculty of Nursing, Prince of Songkla University and by local hospital as a starting point where the informants were recruited. Informed consent was ensured so that patients knew the details of the research project and there was no harmful risk in the study. All data gathered in the study were kept confidential. The anonymity of the informants was protected by giving each informant a code number.

RESULTS

Twelve informants were recruited for the study, 4 females and 8 males aged between 31 to 62 years old. Duration of undergoing hemodialysis of all informants was between 11 months to 9 years 3 months.

Table 1. Characteristics of the Informants (n=12)

No	Gender	Age (yo)	Marital Status	Occupation	Education	Length of undergoing hemodialysis
K1	Female	50	Married	Civil servant	Diploma	1 year 9 months
K2	Male	54	Married	Civil servant	Senior high school	9 years 3 months
K3	Male	59	Married	Retired	Bachelor	2 years 2 months
K4	Male	62	Married	Retired	Bachelor	6 years 1 month
K5	Female	46	Married	Housewife	Diploma	5 years 2 months
K6	Male	31	Married	Civil servant	Bachelor	2 years 8 months
K7	Female	37	Married	Housewife	Senior high school	2 years
K8	Male	32	Married	Entrepreneur	Senior high school	1 year 4 months
K9	Female	36	Married	Government officer	Bachelor	4 years 3 months
K10	Male	49	Married	Entrepreneur	Elementary school	7 years
K11	Male	56	Married	Civil servant	Bachelor	1 year
K12	Male	47	Married	Lawyer	Bachelor	11 months

Three categories emerged which reflected the meaning of living with End Stage Renal Disease undergoing hemodialysis; (1) restricted life, (2) life is struggle, and (3) reminder to God.

1.1 Restricted Life

Informants in this study had been undergoing hemodialysis for years. End stage renal disease made them come to the hemodialysis center twice a week and sometimes more than that if their condition worsened. They had to lie down for 4 to 5 hours during hemodialysis. The illness made them stick to the machine. Furthermore, this condition and health problems due to the illness restricted their lives. Themes emerged under this category were; (1) relying on the machine, (2) limited energy, and (3) limited travelling.

1.1.1 Relying on the Machine

Coming to the hemodialysis center and undergoing hemodialysis twice a week made informants' lives restricted. Four informants explicitly expressed that they were dependent on the treatment. Their life was so close and tied to the machine. The machine was important for their life. It replaced renal function to remove toxins and fluid excessive in the body. The informants relied on the machine. The researcher observed the informants in the hemodialysis center during data collection. All of them followed their hemodialysis schedules strictly. They came to the hemodialysis center on time. Some of them even had come and sat on the bed that they usually used before nurses started to work. They sat and talked to each other while waiting for nurses to begin to work. They were dependent on the treatment. However, relying on the machine had restricted their lives, as one informant said:

“Every Tuesday and Friday I have to go to the hospital for undergoing hemodialysis. I have traveled back and forth to the hemodialysis center twice a week, every month, for several years at the scheduled time. My life really relies on the hemodialysis”. (K2)

1.1.2 Limited Energy

Limited energy was perceived by all informants. The disease affected the renal function and consequently led to insufficiency of energy, possibly due to poor nutrients and oxygen intake. The energy was needed to perform their activities. Having less energy caused restricted activities and life. Food and water control was needed to deal with the illness and

health problems related to waste product and water accumulation. Observation results showed that some informants looked weak and fatigue particularly when they experienced blown. Two informants, a male and female looked lean, bony and weak. They performed less activity and walked slowly. However, the informants needed to know how to balance the food they took in order to produce sufficient energy for surviving. An informant reported that he had limited energy and it influenced his ability to perform activities.

“Currently I feel weak and a lack of energy, so I cannot perform activities easily like what I did prior to suffering from the illness. Now I cannot walk far. I only can walk around my home, if I walk more than that I will get blown and fatigue. My body does not allow me to perform more activities. I have limited energy.” (K11)

1.1.3 Limited Traveling

Limitation in travelling was a result of limited energy and strict hemodialysis schedule. Undergoing hemodialysis twice a week or more limited their time to travel. They did not feel free because of the tight schedule of the treatment. During data collection, several informants did not travel to other cities or provinces. They just stayed at home or went to office, or went to hospital for undergoing hemodialysis. An informant thought that she could not travel far from her home for several days because she had to strictly follow their hemodialysis schedule, twice a week. The strict schedule limited her life, as she said:

“I cannot travel anywhere, probably only can go around this city. Undergoing hemodialysis makes me like this.” (K1)

Another informant stated how his life was limited by hemodialysis schedule.

“My life is scheduled now. What in my mind now is Tuesday and Friday go to the hospital to undergo hemodialysis. I do not feel free to travel, always remember Tuesday and Friday” (K6)

1.2 Life is Struggle

Living with ESRD and hemodialysis was not easy for this informants. They had to face and deal with many health problems and other problems in their lives. The informants had to cope with accumulation of toxin and water in their bodies and health problems emerged due to this accumulation. Even though the hemodialysis treatment which they obtained was free but they still needed to earn money for their daily lives.

Some of them faced financial problems. The researcher had observed their homes and daily lives and found that three informants lived in a smaller house and had lesser furniture comparing to those of other informants. They did not have a car, and their spouses were required to work for earning money. Economic level of the three informants was lower than those of other informants. Themes emerged under this category were: (1) struggling with toxin and water accumulation and (2) struggling with income earning.

1.2.1 Struggling with Toxin and Water Accumulation

Some informants used the word “*Racun*” to indicate metabolic wastes which could not be removed. Thus they were accumulated in their bodies. “*Racun*” or toxins and water accumulation were concerns of the informants because these caused many physical complaints which they experienced. The informants were struggling with accumulation of the toxin and water in their bodies. The struggle was solved through various ways, such as restricted diet and water intake, and undergoing hemodialysis. Undergoing hemodialysis regularly based on schedule was an important way to remove the toxins and water accumulation. An informant expressed his struggle through this statement:

“Racun-racun” (toxins) and water are not removed by the kidney and then accumulated in my body. These cause physical complaints which I am experiencing now. I need to minimize the accumulation of toxin and water. Undergoing hemodialysis is one way to reduce the toxin and water in my body. I am still striving for reducing the toxin and water accumulation.” (K11)

1.2.2 Struggling with Income Earning

Financial difficulty had been perceived by three informants. Prior to suffering from the illness, the informants worked hard to earn money. But since the illness occurred and reduced their strength and ability to work, thus they earned less. They were struggling with maintaining the job to bring in income to the family. Their spouses who did not work previously were required to work to compensate for loosing income earned by the informants. During data observation, the researcher observed that the wives of the informants took the informants' role as a backbone of their families. The wives were very busy with their works and their duty to care for their husbands. A male informant said how his wife helped him to earn money:

“My wife replaces my role to distribute the newspapers

to my customers. I also sell goods and snacks in my small shop to increase our family income. I am not an officer so I do not get monthly salary. I and my wife have to work to earn money. We need money for our daily lives.” (K8)

Another male informant told how the illness affected his economic level.

“I did not work since I suffered from the illness and underwent hemodialysis. Now my family relied only on my wife's salary. She works as a school teacher. This illness affects my family financial status. Much money has been spent to pay for the treatments.” (K11)

1.3 Reminder to God

Muslims believe that suffering from the illness is a way to remind “*Allah*” (God). The informants in this study considered the illness as a reminder to “*Allah*” (God). They perceived that the illness as a way to get closer to Allah. The illness was also perceived as a way to test how high their “*Iman*” (Faith in God) was. Some essential components of “*Iman*” of the informants such as “*Sabar*” (patience), “*Tawakkal*” (resignation), and “*Syukur*” (grateful to God) of the informants were tested by *Allah* through having sufferings due to the illness. The emergence of the illness might increase the components of *Iman* (Faith in God) of the informants. Themes emerged related to this category were: (1) getting closer to God, (2) accepting the illness as God's will, (3) facing God's will through being patient with the illness, and (4) being thankful to God for His goodness.

1.3.1 Getting Closer to God

The illness was perceived as a reminder to get closer to *Allah*. By having the illness, the informants realized that God called them to perform more Islamic teachings in order to get closer to God. Getting closer meant closer in term of spiritual relationship with God which was reflected through becoming more religious in their lives by performing more Islamic teachings. The researcher observed that some informants were more religious through doing “*Dzikir*” (remembrance of God) using “*Tasbih*” (prayer beads) while they were undergoing hemodialysis and even in their homes. They read Islamic books during undergoing hemodialysis. In an informant's home, the researcher saw many Islamic books in front of the informant's mattress. When the researcher visited his home, he also saw the informant watching Islamic lectures on television. An informant said:

"I feel this illness makes me get closer to Allah (God). Through this illness, I am reminded and encouraged to be closer to Allah (God). Perhaps Allah wants to remind me to worship him more." (K3)

1.3.2 Accepting the Illness as God's Will

ESRD and hemodialysis had enhanced "Tawakkal" or "berserah diri" (acceptance) of the informants in this study. All informants used the words to express how they responded to the illness related to their belief in Allah (God). Furthermore, "Tawakkal" also meant accepting anything that Allah (God) gave to the informants. The informants usually mentioned "Sabar" and "Tawakkal" altogether. It indicated that the words had essential meanings in informants' lives. Acceptance was reflected through acceptance of their condition, submitting their fate only to Allah (God), and other positive attitudes in facing their problems, such as having positive thinking related to the illness and God's will. According to observation result, all informants had good acceptance. All informants explicitly expressed their acceptance of their current condition. They also had submitted their fate and lives only to Allah (God). An informant explicitly expressed his acceptance, happiness and positive thinking in the current life by saying:

"Previously, I could not accept the illness. I wondered why I got the illness. Now I have removed all negative thinking, and I can accept my current condition. I feel happy. Whatever happens to me, I submit my fate and "berserah diri" (resignation) to Allah (God)."(K3)

Another informant expressed her acceptance through the statement:

"Prior to having this illness I might have less "Sabar" (patience) and "berserah diri" (resignation), but now I have more patience and can accept the illness more. I believe that Allah gives this illness to me to test my patience and resignation. Allah probably wants me to show him how high my "Iman" (Faith in God)." (K9)

1.3.3 Facing God's Will Through Being Patient with the Illness

The word "Sabar" (patience) were mentioned by the informants to represent their religious beliefs in facing "Kehendak Allah" (God's will). Having the illness was considered as one of God's will in their lives. The informants also considered "Sabar" as an essential element in dealing with their health problems. "Sabar" was reflected by informants through their attitude in avoiding lament, regret, or blame others as cause of the

illness. During observation the researcher saw all informants had good patience. They seemed to have good understanding on "Sabar" in Islam. They did not regret or blame others or themselves. They also never expressed their regret due to the illness. An informant stated:

"I have to face this illness with Sabar (patience). The illness is "kehendak Allah" (God's will). As a Muslim, I need to be "bersabar" (being patient) in dealing with my problems. All that happens in my life should be faced with Sabar." (K11)

1.3.4 Being Thankful to God for His Goodness

The word "Syukur" was used by the informants to indicate gratitude to God. Thank God was expressed by some informants to show their "rasa syukur kepada Allah" (gratitude to God). Basically, "Syukur" is performed not only through utterance, but also through action. Utterance of "Syukur" is reflected by saying *Alhamdulillah* (All praise be to Allah). "Syukur" in action is indicated through maintaining or taking care of things which God give to Muslims, such as body, children, property, or other things. However, "Syukur" should be performed in any condition and anytime to indicate that Muslims thank God for anything that God gives to them. In this study, all informants realized the importance of "Syukur" in their lives. They mentioned "Alhamdulillah" to express the gratitude to God. Three informants expressed their gratitude to God for what God had given to them in their lives. Two of them said:

"Alhamdulillah (All praise be to Allah) I am still healthy, I mean that still be able to communicate with others as usual."(K3)

"You know, this is my real life. Even though living with this condition, I still enjoy and grateful for all God has given to me...Alhamdulillah (All praise be to Allah)."(K3)

DISCUSSION

Informants in this study expressed various meanings of living with the illness and hemodialysis. The various meanings might be due to diverse backgrounds of the informants. Demographic data showed that the informants came from different genders, education, and age ranges. However, variations in ethnicity, age, gender, level of education, occupation, and length of undergoing hemodialysis contributed to meaning of living with the illness and hemodialysis of the informants. A study by Duddu, Isaac, and Chaturvedi (2006) had reported that

different ethnic groups and gender differed in their perceptions of disease impacts and meanings.

The category of restricted life reflected how the illness and hemodialysis limited the informants' lives. Health problems and sufferings which they experienced and restriction in their lives as a result of undergoing hemodialysis throughout the life. Living with regular visit twice a week to hemodialysis center made the informants tie to the center. They could not stay far from the hemodialysis machine since it was an essential part of their lives. They felt limitation to travel far due to their reliance on hemodialysis. When they were suffering from problems related to the illness such as fluid excess in their body which cause blown up body structure, or any physical complaints caused by toxin accumulations in their body, the machine became very important for them. The machine helped them remove excess fluid and toxins in their body caused by ESRD. They also perceived limited energy due to the illness since they needed to limit diet and water consumptions to reduce fluid and toxins accumulations in the body. The illness caused limited energy among these patients. ESRD and undergoing hemodialysis made their lives more restricted. However, restrictions in life were commonly perceived by hemodialysis patients (Clarkson and Robinson 2010; Al-Arabi 2006; Sadala and Lorencon 2006; Polascheck 2003).

This category of life and struggle used to show that their lives were not easy and they needed to struggle in dealing with many sufferings. Informants in this study needed to struggle in living with the illness and undergoing hemodialysis. It was focused on struggling with toxin and water accumulation and struggling with earning. Toxin and water accumulation also caused emergence of many health problems which caused changes in physical strength. The health problems impacted on inability to perform their daily activities and roles normally. However, John and Thomas (2013) reported that the physical changes experienced by hemodialysis patients impacted on lowering ability to perform roles and daily activities.

The theme of struggling with income earning reflected another concern in the struggle. For all informants, undergoing hemodiaysis was free, but they had to spend more money for treating other chronic health problems that never disappeared from their lives. They needed money to buy some medications which might not be covered by their insurances. They also needed money to take other treatments or therapies

such as herbals or ritual which they thought could help them to deal with their health problems. They needed more money for transportation from their homes to the hospital and vice versa twice a week. Furthermore, not all informants lived with adequate economic status. For those living with financial limitation, they had to struggle to deal with the economic crisis. A study by Small (2010) also reported financial constraints since even though insurance covered hemodialysis treatment, but patients still needed money for other expenses related to the illness, such as medication and treatment expenses or transportations expenses. The male informants with financial limitation had physical limitation to struggle in earning money and involvement of their wives to earn money was considered important for them. However, Al-Sayyari and Shabeen (2011) had confirmed that suffering from ESRD and hemodialysis also affected finances and work of the patients with the illness.

In relation to category of reminder to God, this study revealed the religious meanings of living with hemodialysis. Reminder to God indicated that the informants gained spiritual impacts of suffering from the illness. The illness made them became closer to God and more patient. The illness also promoted recognition to God and reminded them to be more "*Bersyukur*" (grateful to God). In Islam, Muslims believe that suffering from an illness is also a chance to get closer to God. Getting closer to *Allah* means performing worship more frequently. Time during suffering from the illness is also a chance for Muslims to evaluate themselves and increase their level of *Iman* (faith in God). In this study, informants performed Islamic teachings such as "*Shalat*" (prayer), '*Do'a*' (supplication), read Qur'an, "*Dzikir*" (remembrance of God), and other Islamic activities more to get closer to God. Results of this study corresponded with several studies which linked suffering from sickness to increased religious beliefs which were not only in Islam (Zeilani and Seymour 2010; Yousefi *et al.* 2009) but also in Christian (Barrio *et al.* 2004). In this study several informants had realized the importance of performing more worship either in better or worse situation (Elliott *et al.*, 2012). Their study revealed the importance of religious practices in managing their daily lives and dialysis.

The theme facing God's will through being patient with the illness showed that ESRD and hemodialysis caused the informants to have patience in facing problems in their lives. In Islam, Muslims should be

patient in facing problems in the life because patience is a way to ask for help from Allah when Muslims have problems. As mentioned in Qur'an "Oh you who have believed, seek help through patience and prayer. Indeed, Allah is with the patient" (Qur'an, 2:152). Furthermore, *Allah* will not be charged beyond Muslims capacity and every Muslim may not be desperate in the life. According to Qur'an "Allah does not charge a soul beyond its capacity" (Qur'an, 2:286) and "Oh my sons, go and search Yusuf and his brother, and do not lose hope in the mercy of Allah. Indeed, no one despairs of relief from Allah except the disbelieving people" (Qur'an, 12:87).

The themes accepting the illness as God's will and being thankful to God for His goodness reflected that suffering from the illness and hemodialysis created spiritual encouragement for the informants to enhance their resignation and to be more grateful to *Allah* (God). Muslims believe that their lives and all occurrences in the world are totally regulated by *Allah* (God). Accepting all occurrences in the life, relying only on God, and submitting fate to God which are performed by informants reflected their resignation to the God. The resignation was also reflected "*Iman*" (faith in God), as described in Qur'an "Say: Nothing will happen to us except what Allah has decreed for us. He is the protector, and upon Allah let the believers rely"

(Qur'an, 9:51). Thank God or "*Syukur*" (grateful to God) which expressed by informant was important in the life. As God's creation, Muslims should always be grateful because *Allah* will give more favors if Muslims are grateful, and Muslims will obtain severe punishment if they are not thankful, as mentioned in Qur'an "And remember when your Lord proclaimed: If you are grateful, I will surely support you (in favor), but if you are thankless, my punishment is severe" (Qur'an, 14:7).

CONCLUSION AND IMPLICATION

The meanings of Muslims and living with ESRD and hemodialysis represent restriction in life and struggle experienced by them in dealing with problems in their lives. Hemodialysis and the illness also reminded them about relationship with God, as well as patience and being thankful to God. In delivering caring for hemodialysis patients, nurses need to understand principles of religions and cultures, especially religions and cultures that exist in their community. This understanding is needed to provide culturally competent care for the patients. Nurses can use the findings to develop guideline of practice in hemodialysis center for their patients. Findings of this study can be used as a basis to conduct further research aimed to make an appropriate model for culturally sensitive nursing care for Muslims on hemodialysis.

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