



Self-caring in Islamic culture of Muslim persons with ESRD and hemodialysis: An ethnographic study[☆]



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Received 4 October 2018; accepted 14 November 2018

Available online 4 February 2019

KEYWORDS

Ethnography;
Muslims;
Hemodialysis;
Qualitative;
Self-caring

Abstract

Objective: Culture and religion may influence self-caring of persons with End Stage Renal Disease on hemodialysis therefore the study aimed to explore self-caring in an Islamic culture of Muslim persons living with End Stage Renal Disease undergoing hemodialysis.

Method: This study is a qualitative ethnographic study. Purposive sample of 4 females and 8 males of Muslims on hemodialysis aged between 31 and 62 years old and length of undergoing hemodialysis between 11 months and 9 years 3 months were recruited by using several inclusion criteria. The inclusion criteria were being diagnosed 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. Exclusion criteria applied in this study were hemodialysis persons with severe hyperventilation and edema, and loss of consciousness. Data were collected by using in-depth interviews, participant observation, and field note takings. Data analysis used the ethnosing data analysis method.

Results: Findings of the study revealed four categories that reflect meanings of and how informants care for themselves and how Islamic teachings and cultural values influences them. The categories emerged from the study are meaning of self-caring, actions in self-caring, Islamic influences to self-caring living and cultural influences to self-caring living.

Conclusions: Muslims on hemodialysis performed any activities or actions that reflected their efforts to perform their self-caring in order to survive or be healthy based on their own perspective. Islamic teachings were used as guidance in selecting treatments and performing their self-caring. Family members, nurses and other healthcare professionals should consider Islamic teachings in assisting and delivering care for Muslims on hemodialysis.

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[☆] Peer-review of abstracts of the articles is under the responsibility of the Scientific Committee of Riau International Nursing Conference 2018. Full-text and the content of it is under responsibility of authors of the article.

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Introduction

Hemodialysis as one of the Renal Replacement Therapies (RRT) is widely used for persons with acute or irreversible renal failure and fluid and electrolyte imbalance.¹ End Stage Renal Disease (ESRD) is one of major public health problems throughout the world. In Indonesia, there are approximately 70,000 patients diagnosed with ESRD every year and less than 5% of them undergo hemodialysis treatment.² As a chronic and terminal illness, ESRD affects the daily lives of patients and families as they confront changes in health status, lifestyles and roles.

Culture and religion may influence self-caring of persons with ESRD on hemodialysis. Culture is the learned, adaptive, shared ways of people with identifiable patterns, symbols, material and immaterial.³ Furthermore, cultural beliefs, values, and meanings often guide the thought and behavior of people in diverse cultures. Experiences of living with ESRD and hemodialysis have been studied by researchers and the meanings of this are diverse and expressed in various ways, 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.⁴⁻⁷ How persons undergoing hemodialysis treatment perform self-caring under the influence of their cultures and religions, particularly the Islamic culture are not known clearly and have not yet been studied. Research questions of this study were 'How do Muslim persons with ESRD on hemodialysis care for themselves?' and 'How does Islam and culture influence self-caring of Muslim persons with ESRD on hemodialysis?'

Method

The study was aimed to explore self-caring in an Islamic culture of Muslim persons living with ESRD undergoing hemodialysis in Pekanbaru, Indonesia. The study was an ethnographic study and employed the ethnosing research method. Informants of this study were recruited by using purposive sampling on the basis of several inclusion criteria. The inclusion criteria have been diagnosed ESRD, have known the diagnosis, have been undergoing hemodialysis at least 6 months, Muslim, and never change treatment to peritoneal analysis or renal transplantation. Exclusion criteria applied in this study were hemodialysis persons with severe hyperventilation, severe edema, and loss of consciousness. All informants were recruited in Pekanbaru, Indonesia. Data were collected by using interview, observation, and review of available documents. In collecting and recording data, the principal author used Personal Information Form to collect baseline characteristics of informants, interview guide, observation guide, field notes, camera, and audio-tape recorder. Camera and audio-tape recorder were used to take pictures or record interviews and conversation. Each interview was recorded and transcribed verbatim. Data were analyzed by using the ethnosing data analysis. There are four phases of the ethnosing data analysis.³ Trustworthiness of the study was highly maintained by employing criteria related to ethnosing. 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, Thailand.

Results

There were 12 informants recruited for the study, 4 females and 8 males aged between 31 and 62 years old. Length of undergoing hemodialysis of all informants is between 11 months and 9 years 3 months. Characteristics of the informants are shown in Table 1. Four categories with several themes emerged from this study. The categories are as follows:

1. Meaning of self-caring

Category meaning of self-caring reflect the aims of performing self-caring of informants. Themes under this category are surviving, for my family and being healthy. Surviving was mentioned by some informants to indicate their wish to be still alive even though it was torturous to live with terminal disease and rely on the hemodialysis machine, as a female informant said "...oh, yes, of course, because I still want to be alive..." and another said "I want to have a longer life, to be still alive." A male informant reflected that she still wanted to be alive by saying "I do not want to die yet..." For my family was expressed by some informants as their wish and the reason was to maintain ability to perform self-caring, as a male informant said "I do everything for my children, I want to see their success in life", and a female informant said "...for my family. My children still need me." Being healthy reflects ability to perform any activities in their lives, as one said "...being healthy, I can do my activities, can do anything..." and another said "For being healthy. If not healthy, how can you do your activities? Right? You can do nothing..." Being healthy also reflects the value of healthy itself, as one said "Healthy is expensive. It has high value. Being healthy is comfortable, not healthy is not comfortable" and another said "If you have much money but you are not healthy, you will feel your money is useless..."

2. Actions in self-caring

Category actions in self-caring depicts activities which they did to care for themselves, what they did when they had health problem or how they dealt with problems emerged in their lives. There are six themes under this category; controlling drinking and eating, taking a rest, massaging themselves, using wheelchair, asking for family help and seeking medical treatments. Controlling drinking and eating reflect informants' effort to restrict fluid intake and reduce accumulation of toxin in their body, as one said "...restricting drinking, eating, and everything that can make my body worse..." and another informant said "Controlling eating and drinking, especially drinking should be restricted". Taking a rest was selected as one way to deal with weakness, disease, or pain of informants, as a male informant said "...take a rest or sleep, to avoid triggering pain" and a female informant said "I take a rest and decrease my activities while I feel pain in my heart." Taking a rest was an effective way when they had weakness,

Table 1 Characteristics of the informants.

No.	Initial	Gender	Age (yo)	Marital status	Occupation	Education	Length of undergoing hemodialysis
1	EA	Female	50	Married	Civil servant	Diploma	1 year 9 months
2	R	Male	54	Married	Civil servant	Senior high school	9 years 3 months
3	S	Male	59	Married	Retired	Bachelor	2 years 2 months
4	M	Male	62	Married	Retired	Bachelor	6 years 1 month
5	H	Female	46	Married	Housewife	Diploma	5 years 2 months
6	L	Male	31	Married	Civil servant	Bachelor	2 years 8 months
7	E	Female	37	Married	Housewife	Senior high school	2 years
8	I	Male	32	Married	Entrepreneur	Senior high school	1 year 4 months
9	EF	Female	36	Married	Government officer	Bachelor	4 years 3 months
10	A	Male	49	Married	Entrepreneur	Elementary school	7 years
11	SJ	Male	56	Married	Civil servant	Bachelor	1 year
12	SH	Male	47	Married	Lawyer	Bachelor	11 months

as one said "...taking a rest to reduce weakness". Massaging themselves reflecting their effort to gain comfort or reduce pain, as one said "...massaging my foot to reduce pain..." and another informant said "sometimes while pain occurs, I massage my foot..." Using wheelchair was raised by some informants to ease the performance of some activities, as a male informant said "I use wheelchair when I go outside my home or to hospital" and another male said "...I use wheelchair if I'm not strong enough or sometimes I do walking exercise also".

The theme asking for family help depicts informants' way to be able to perform their activities, as one said "When I feel weak, I ask my wife to drive, or ask her to provide meal for me", and another said "Asking for my wife or my children to hold me to the restroom when my left leg feel weak". Seeking medical treatment was performed to deal with health problem that was not able to be cared for by themselves. One informant said "Seeing a cardiologist to check my heart that sometimes feel hurt" or "...go to see physician to ask medication for my stomachache".

3. Islamic influences to self-caring living

Category Islamic influences to self-caring living used to describe any influences of Islamic teachings in informants' life and their self-caring. Giving spirit, encouraging continuity of fighting, and creating serenity are themes under this category. Theme giving spirit describes effect of prayer (*shalat*) to informants, as one said "...After prayer I feel like I have spiritual uplift. Spirit will help me to perform my activities." Encouraging continuity of fighting was intended to express effect of Islamic teaching to the informant in seeking proper treatment for their illness. A female informant said "In Islam, we have to keep fighting to be healthy, to seek medication..." and a male informant also said "Islamic teaching makes me believe that if I select appropriate treatment, I will be healed". Creating serenity reflects effect of Islamic activities in informants' life that influences their self-caring. An informant said "By performing prayer, I feel peaceful, serene. There is mental tranquility" and a female informant said "If I cannot sleep, usually I perform *dzikir*. It makes me feel calm, peaceful..." These effects of Islamic teaching are very useful for informants in performing their

daily activities and caring for themselves, as one said "...by listening to Islamic talk makes me feel peaceful, and Islamic teachings drive me to do any effort to deal with my problem, and I'll never give up".

4. Cultural influences to self-caring living

Category cultural influences to self-caring living reflect influences from culture to self-caring living of informants. The influences can be shown through events, actions or activities which are based on elements in culture, such as social and traditional values. Themes under this category are support from society and adding options for treatment. Theme support from society was referred as the visit or support from social or religious group, as one said "...religious group in the mosque came to give support to me" and another said "my colleagues in my office and my community came to visit me, and I was happy... Feeling happy could enhance my spirit to perform my activities".

Adding options for treatment was described by informants as how culture provides traditional therapies or treatments that are available for any illnesses and influence informants in choosing treatment for their illness. These therapies or methods are transferred inter generationally and as legacy in particular culture. One said "my friends suggested me to take traditional therapy. Then I went to somewhere to take traditional medication called *bedah ayam* (chicken surgery). The therapist slaughtered a chicken and performed something to the dead chicken to remove illness from my body..." Another expressed his experience in taking traditional therapy by saying "I went to a village to meet a therapist, and the therapist massaged me and asked me to drink tamarind extract. He said that it was good for my body..." Even though many traditional and inherited therapies available, but the evidence of these are still doubtful and even not proven, as an informant said "I had tried many therapies from many cultures, went to many cities to take many therapies, but I got nothing. No therapy could heal my body. I still believe that hemodialysis is the only appropriate treatment for me".

Discussion

The informants in this study performed any activities or actions that reflects their effort to maintain their physical functioning as inseparable part in self-caring, such as restrict fluid intake, control food intake, take a rest or sleep while they feel weak, use massage or wheelchair and ask for help from family members if needed. In relation to Islam, illness is believed as atonement of their sins and this is an event to cleanse and purify physical, spiritual, mental and emotional aspects of the sick body.⁸ Illness is not considered as a punishment from God, but it is a way to increase patience. Islam encourages every Muslim to seek proper treatment because every disease has its remedy, as Prophet Muhammad said that there is no disease that *Allah* (God) has created, except that he also has created its remedy.⁹ Islam also teaches every Muslim to maintain their health, such as eat and drink moderately, as mentioned in Qur'an that Muslims should eat and drink, but avoid excess.¹⁰ Islam is concerned with not only physical aspect, but also psychological aspect of Muslim. Patience or *Sabar* and prayer or *Shalat* are the best way to face any problems in life, as *Allah* (God) encourage Muslim to seek Allah's help with patient perseverance and prayer.

Social support play important role in enhancing social interactions that will impact on health and well-being of the persons on hemodialysis. A study found that social support was positively correlated with physical health functioning, psychological and spirituality in Muslim on hemodialysis.¹¹

Islam has guided Muslims how to view health, illness and death, how to select treatments, what should be done and prohibited in gaining care from caregivers and undergoing treatments, and other related activities.¹²

Health care professionals should be sensitive to culture and religion of persons on hemodialysis. Considering culture and religion is needed in planning and implementing care for Muslims living with ESRD on hemodialysis. Further study is needed with separated gender and age, and different setting to explore more on impact of the age and gender differences in self-caring since age and gender are considered as important factors influencing living with ESRD and hemodialysis, as well as reflect differences in strength, ability, and responding to health problems. This study is a qualitative study which is the number of informants is slight and

generalization into larger setting or community is also limited. Also, informants do not represent all existing cultures in Indonesia. Studies in other cultures and settings may be required.

Conclusion

Muslims living with ESRD and hemodialysis perform any efforts to survive and maintain their self-caring. Physical and social functioning is important for Muslim persons on hemodialysis social support, including family-related social support and religiosity play an important role in enhancing their functioning and satisfaction of their life. Informants more consider Islamic teachings in selecting cultural or traditional treatments for their illness.

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