ORIGINAL ARTICLE

The Exploration of Dietary Adherence among Haemodialysis Patients in Hospital Kulim, Kedah

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Abstract:

Non-adherence towards dietary restriction is a common phenomenon among patients due to multifactorial causes. Knowledge, socioeconomic status, social support, together with perceived attitude and perceived behaviour, are said among the factors affecting adherence. Noncompliance to dietary restriction can lead to adverse long-term effects including deterioration of the cardiovascular system, heart failure, hypertension, and pulmonary oedema. End stage renal disease (ESRD) patients are required to follow dietary regimen about haemodialysis treatment ensuring effective treatment. The dietary regimen includes fluid, sodium, potassium and phosphate restrictions. This study aimed to explore the understanding of haemodialysis diet, barriers to adhering dietary restriction and the appropriate methods of nutrition education to the patients. An exploratory study conducted with a total of ten participants from Hospital Kulim Dialysis Center. A semi-structured interview was conducted in an average of 60 minutes to 80 minutes each participant. Haemodialysis diet knowledge was fair in every participant as everyone able to describe each restriction briefly. Most common barriers to adhere are related to human behaviour which is resistant to change, lack of control and lack of awareness in adapting dietary restriction in daily intake. Healthcare professional should focus on motivating patients to adhere to dietary restrictions by conducting individual counselling as frequent as relevant to help the patient understand and cope with dietary modifications suitable with their capability.

Keywords: Haemodialysis, Dietary adherence, Dietary restriction, Barriers, Nutrition education

1. INTRODUCTION

Haemodialysis (HD) is a renal replacement therapy treatment which replaces the renal function to excrete waste, remove extra fluid and balances electrolytes. Dietary advice may include dietary allowance, dietary restriction and dietary recommendation given by medical personnel especially dietitian. Ministry of Health (2011) revealed more than 22,932 Malaysia residents receiving haemodialysis in 2010 as compared to the year 2001 only 7,837 and the number kept increasing by years.

Dietary is one of the components in treating chronic disease whereby the guidelines are given by clinical dietitian according to related disease in individuals. Difficulty in adhering to these following dietary recommendations are common, especially on sodium restriction of two gram to three gram per day, restriction of fluid to one litre to one and a half litre daily and restrict phosphorus intake to 800 to 1000 mg daily [1]. Patients with end stage renal disease (ESRD) often fail to follow prescribed dietary and fluid regimen, leading to further complications [2]. It is proven that poor adherence can be a serious risk to health and wellbeing of patients [3].

Dietary advice for haemodialysis patients may be difficult to maintain and will result in nutrition deficit with poor dietary quality if neglected. As reported in 2016 by Luis et al, 77% and 50% of patients consumed less than the recommended daily energy and protein, respectively. Only 22% consumed enough fibre and less than 50% met the requirements for vitamins and other micronutrients.

Adherence to dietary regime increases the effectiveness of renal replacement therapy (RRT) in a haemodialysis patient. On the contrary, non-adherence is when patients are unable to follow the dietary advice and leads to other condition that may worsen the health status. Patient understanding related to haemodialysis diet is explored in this study in identifying the adherence status. There are multifaceted factors that affect dietary adherence. Therefore, this study aims to determine the factors causing adherence and non-adherence in patients. The finding will help the patient, care-giver, medical personnel together in improving the compliance rate towards HD diet to ensure each patient practice the prescribed treatment for effectiveness. Further exploration on patient's suggestion on appropriate education method to improve the compliance rate towards HD diet were investigated. The results of this study will contribute to a better understanding of the barriers toward dietary adherence and non-adherence of HD patients in Kulim.

2. MATERIALS AND METHODS

2.1. Study design, sample and setting

This is an exploratory study of dietary adherence related to chronic kidney disease (CKD) patients prescribed with dialysis treatment. Ten patients selected from the dialysis center in Hospital Kulim. The target population was HD patients. Eligible patients were (1) those receiving HD at the dialysis centre in Hospital Kulim for at least three months and (2) those receiving thrice-weekly dialysis sessions (3) ranging in age from 18 years old with (4) ability to communicate in English and Malay language well. The excluded criteria included patients who have not received dialysis treatment more than three months, illiterate problem and patients who unable to communicate well with age below 18 years old and those with infectious disease.

2.2. Study instrument

Patients' Information. The form that was developed based on a literature review included socio-demographic (age, gender, marital status, education level, employment status, and the presence of a caregiver) and disease-related (comorbid conditions and time on HD). This act as additional information to be related with other questionnaires.

2.3. Data collection

The study was based on discussions with one-on-one interviews with patients, using a qualitative description approach [5]. Semi-structured interviews using interview guide developed and leading question were carried out. Both inductive and deductive approach were applied in expecting themes and generating new themes. This interview involved many open-ended questions. There were probes and prompts to tease out from the respondent various strands of their narrative to complete the story [6]. Questions are divided into sections as shown is Table 1. The semi-structured questions for the participants took 60 to 80 minutes to complete and investigated their knowledge related to dialysis diet and what they thought were the barriers in adhering to all the restrictions highlighted by the dietitians.

Table 1: Interview Guide

Discussion Topic	Examples of specific probes
Dietary restriction knowledge	What do you know about the food you can and cannot eat? Why do you think you have to limit the food you listed before? How much you are allowed to drink? Do you follow the dietary advices? How do you restrict these food intakes? What harm it may cause you if you do not limit the intake of food you cannot have? Have you ever experienced any medical complication due to non-compliance before?
Barriers to adhere dietary advice	What is the main reason not complying with dietary restrictions? Is it burdening to follow the dietary advices? Do you have any food that you cannot limit and why? What is the hardest restriction to follow and why? Do you prepare your own food or buy it outside? How do you think about food with less salt? Can you drink only 500mL every day? If no, why? How do you know about all these restrictions?
Educational Method	Have you met a dietitian before? What do you think about the session with dietitian? Are there any other way of gaining information regarding HD diet? Which of the education method do you find effective? Why? Which method do you think you can have good understanding?

2.4. Data analysis

The interviews were audio-recorded and transcribed verbatim, and those in Malay were translated into English. Transcripts were reviewed for accuracy in transcription. [7]. Data validation using triangulation method with involvement of other researchers. Other researchers help in interpreting the data. This process involved several distinct stages, beginning with familiarization with the data. Each researcher reviewed the interview and data. The findings were compared to develop a broader and deeper understanding. Data were separately analysed by few researchers to determine the major themes. Then themes from were compared with regard to the main objective of the study. Application of multiple approach to verify analysed data in order to increase the credibility and validity of the study [8]. Data was organized and classified into themes and development of relationship between themes using Atlas.ti software. With this software all data will be organized according to themes and clear vision about the deep exploration eventually come into conclusion.

3. RESULT

The most dominant theme we found about the adherence of dietary restriction was the challenges in adherence. We divided the results into four sub-themes (1) lacking in self-control, (2)' resistant to change, (3) lacking awareness towards dietary restriction and (4) social surrounding.

3.1. Lack of self-control

Self-control reflects how individual deals with ability to provide conscious limitation of impulses and behaviour as a result of overwhelming emotion. Most participants engage how the loss of control cause non-adherence behaviour.

"I always drink plain water and plain tea. But whenever I go to visit my relatives and the drink served can be milk tea or coffee or Milo which I should not drink, but I drink anyway." (Participant 4)

"Laksa is my favourite food so I cannot resist the gravy especially when my wife made it herself. I tend to repeat eating laksa from day to night. That is how much I love laksa" (Participant 6)

Few participants enjoyed eating favourite food regardless of the dietary restriction outlined by the physician and dietitian. Knowing the consequences of non-adherence behaviour do not change anything, because wants over control;

"I always have fast food cravings. Three times every month is compulsory. I eat out a lot that's why" (Participant 1)

"Gulai is my favourite dish cooked with coconut milk, I don't like any modification in my gulai, less salt is fine though but without coconut milk the taste is not as good, the

creamy taste is not there without it." (Participant 4)

3.2. Resistant to change

The behaviour of refusal to comply dietary restrictions may be significant in most patients as it is a phenomenon where a person stands on his or her opinion based on beliefs, faith, culture or lifestyle.

"I know that curry is high in phosphate because of the coconut milk and the spices used. But I love curry and cannot just stop liking it. I don't like that soup or watery food or whatever another dish" (Participant 9)

"I like it if my rice is added with a lot of gravy of the dish, like nasi kandar. Not every day, only when we have curry in the house. I have been eating that way for years. It is like a habit and hardly changed" (Participant 2)

"My new favourite food is spaghetti Bolognese, made from canned tomato. My wife made it herself and I really like it. This week my wife cooks for me two times by my request." (*Participant 6)*

"Every weekend I will have my breakfast outside with my wife, having roti canai and kuah dhal. Both Friday and Saturday. It's a routine so she does not have to cook in the morning" (Participant 9)

3.3. Lacking awareness

Awareness is a perception and show of concern towards thing well-informed in a particular condition. It is a powerful tool to help people change and by lacking awareness in practicing dietary restrictions related to HD patients, non-adherence behaviour occurs.

Few participants who are younger usually have no comorbidities, it means they only have (end stage renal disease) ESRD that requires dialysis. This condition somehow affects how serious they see themselves as a patient. Participants tend to let loose their dietary restriction with the thinking that they do not have diabetes or cardiovascular disease;

"I don't practice strict diet because I don't have diabetes and high blood pressure. I used to practice a very strict diet to the extend I can only eat rice and fish my body felt very week that I cannot even walk" (Participant 10)

"..as I said before I don't restrict my food, I eat everything but the quantity is smaller. I don't have much concern like other patient who has cardiovascular problem, diabetes, high blood pressure. Instead I have low blood pressure" (Participant 3)

Few participant spoke about how fluid restriction is very hard that most patients are lack of awareness. Related to the limited fluid intake not only about how much they drink but also how much water-containing food they eat;

"...if we have to limit 500mL fluid per day, say we eat three times daily and drink 200mL each time, it already exceeds the recommendation. Including fluid from food like curry, gulai or soup. It all should be counted. People are unaware about how much they can really drink" (Participant 3)

"...the hardest to follow is fluid restrictions, if it is too hard people tend to ignore the importance of restricting diet. They know but they ignore. Who would want to follow if it is burdening. In the end people just drink, not so much but still exceeds the recommendation." (Participant 5)

Supplements are provided according to the individualised dosage prescribed by the doctor according to specific needs and it is individualised. Most of the participants have problems with supplement taking. They tend to forget or left the supplement which they have to eat together with meal and this may affect bones health if prolonged.

"When I eat at home I never fail to take my phosphate binder because I put it on the dining table but when I eat outside, I have the tendencies to forget even though I bring the pills with me in my handbag. When I step out of the car I usually bring my phone and wallet. Happens all the time. That's why I always missed my pills" (Participant 10)

"I always bring my pills everywhere. But when it comes to kenduri, I forgot to take my pills or I did it on purpose. Because usually I eat the binders with meal meaning I spread the pills on my food, but I feel embarrassed to take it out and eat with the pills while everyone is looking…." (Participant 5)

3.4. Social surrounding

Social surrounding includes living environment, people living together and working condition that somehow might challenge the adherence rate of HD patients towards their dietary treatment.

Most participants have family members who take care of them whether it is a wife, sister, daughter or son. The people living together with ESRD patients that undergo dialysis three times weekly give significant effect in dietary practice.

"I live with my sister, she and i cook together almost every day when she is home after work. She reminds me a lot about how much I can eat and what I can or cannot eat. She warned me every time she saw me eating too much or buying too many foods. We used to have bananas on dining table but not anymore" (Participant 10)

"He helped a lot with almost everything. He brings me to dialysis center every time, he buys me food to eat while treatment, he waits at the center to accompany me and takes medicine for me I'm very thankful. I cook for the whole family and my children get used to it already. Most food tasteless because less salt added, less sugar for drinks, everything is plain. They have to follow, act of prevention, because they have family history they don't want to repeat" (Participant 8)

"My wife is not working because she takes care of me at home and to bring me here when I can't drive. She makes sure I drink Nepro and eat my meal with supplement and she cooks too. Pinch of salt in all my food, she sticks to that. Not to forget my kids are very helpful, they also seek for additional info about anything I can or cannot eat" (Participant 7)

While some have to take care of themselves. Few participant lives with people who do not involve much with their condition.

"I work on my own, I do a lot of stuff outside like gardening or harvesting from the orchard. So I spend a lot of time

outside. I bought food from outside and bring it home to eat. I usually eat at home so it will be more comfortable to eat with the supplement (phosphate)" (Participant 5)

"..Usually I cook my food, but recently we go out every night to have dinner outside. My husband is a workaholic he is busy and very supportive. But I take care of myself, even my daughter has not yet understood my condition so she cannot help much" (Participant 3)

"I'm a stay-home dad, my wife works and she has a very good position, my children are all boys. My wife sometimes cooks for me, sometimes I did since I have nothing much to do. But my children do not talk much about my condition. They don't nag or say anything about it, maybe because they don't know…" (Participant 4)

3.5. Dietary education

Dietary education can be delivered in many ways depending on medical provider on which to tackle first and which act as supporting agent. All participants favour to having personal session with their physician and dietitian to get to know better about their condition and treatment. One to one session seems to be very effective in helping the patients to comprehend on how everything works and two ways communication are possible when there is any question to ask or confusion on any topic.

4. DISCUSSION

This study was essentially based on the experiences of patients with chronic kidney disease (CKD) that undergone dialysis treatment three times weekly in complying with dietary treatment and advice given by medical provider. Comparisons have been made within the discussion with the participants regarding dietary knowledge of haemodialysis diet, challenges to compliance with dietary modifications and education method preferences prior to delivery.

Most participants showed sufficient knowledge about dietary restriction and advice related to haemodialysis patients. However, a study reported that 84%of haemodialysis patients had a low or moderate knowledge of haemodialysis restriction [9]. Fluid and salt restrictions knowledge were the most frequently discussed and potassium was the least. This may be due to the ability to comprehend among participants about the dietary-related-knowledge gained. They may have clearer view about how excessive fluid may react with the body and cause oedema while for salt it may cause increased blood pressure. Therefore, these had been the most discussed topic during the interview showing their comprehension about haemodialysis diet. Regardless of how deep the participants acknowledged about the restrictions, this does not promise compliance among the participants. Similarly, there was no association between compliance with dietary and fluid restrictions and knowledge of these restrictions [10].

Non-adherence towards fluid restriction is the most common among dialysis patients in Hospital Kulim, Kedah. Rambod et al (2010) proposed that educational level is associated with fluid adherence and can be improved throughout counselling techniques [25]. Throughout the interview session, relatable factor affecting the adherence behaviour is socio-demographic data regarding employment status and educational level. As only one third of the patients are compliance in controlling daily fluid intake and this may be related to low educational level. While unemployed or retired individuals were mostly adhering to the fluid restrictions due to more stay-home and resting hours. Low daily activity than working participants which may have more outdoor activity prior to work causing more perspiration and fluid loss causing frequent thirst and leads to more fluid intake specifically water.

Challenges to adhere dietary recommendation was deeply explored and few major barriers identified throughout the session with participants. Behaviour changes require all of these components which are willpower, knowledge, social motivation and social ability. Firstly, resistant to change dietary habit comparable with dietary recommended intake. Factors promoting resistant behaviour are individual routine that one may have it since years and unable to cut for example having breakfast outside with family on the weekends with no concern on monitoring the intake complying to dietary advice. Another plot is where participants unable to discard favourite food ingredients with high content of restricted element. Favourite food sometimes can be their usual food which means what they consume every day. The behaviour of resisting from following the restrictions may harm one's condition with further medical complication. Social surrounding is another major barrier to adherence comparing the participants with and without caretakers. Participants surrounded with supportive family more likely to adhere restrictions. Supportive acts come from food preparation, continual reminder and willingness to follow the same diet.

5. CONCLUSION

This study reveals a deeper understanding of patients' barriers and behaviours toward dietary restrictions and advice together with dietary education delivery to HD patient. It is clear that patients' behaviours toward dietary restriction affect compliance rate in which human resisting behaviour changes is one of the major barriers. Resistant to change cause participants to take food that high in restricted element due to ignorance of treatment and complication. Probably complication experienced by noncompliant participant did not hurt so much they can still bear and just eat what they usually do, no restriction. Lack of control due to food cravings and favourite food may occur in participants. Cravings may cause excessive intake when they have access to the food because of long term restriction. Lack of awareness is another factor leads to non-adherence. Awareness of food choices on which contains high sodium, potassium and phosphate should be avoided is very lacking due to no other food choices or food habits. While social surrounding significantly affect adherence towards dietary restriction related to caretaker behaviour and social support expressed by the family members and close friends.

REFERENCES

[1] Nanovic, Lisa. "Electrolytes and fluid management in hemodialysis and peritoneal dialysis." *Nutrition in clinical practice* 20.2 (2005): 192-201.

[2] Chan, Yoke Mun, Mohd Shariff Zalilah, and Sing Ziunn Hii. "Determinants of compliance behaviours among patients

undergoing hemodialysis in Malaysia." *PloS one* 7.8 (2012): e41362.

[3] Desroches, Sophie, et al. "Interventions to enhance adherence to dietary advice for preventing and managing chronic diseases in adults." *Cochrane Database of Systematic Reviews* 2 (2013).

[4] Luis, Desiree, et al. "Dietary quality and adherence to dietary recommendations in patients undergoing hemodialysis." *Journal of Renal Nutrition* 26.3 (2016): 190-195.

[5] Longhurst, R. "Interviews: in-depth and semi-structured. International Encyclopaedia of Human Geography." (2009): 580-584.

[6] Livesey, C. "Focused (Semi-structured) Interviews," *Sociol. Cent*. (2010): 1-4.

[7] Wilson, Virginia. "Research methods: triangulation." *Evidence based library and information practice* 9.1 (2014): 74-75.

[8] Hastings, S. L. "Triangulation," Encyclopedia of Research Design. (2010): 1538–1541.

[9] Montazeri, Rahele Sadat, and Nasrin Sharifi. "Evaluation of nutritional knowledge in terms of dietary sources of protein, phosphorous, potassium and fluids restriction in hemodialysis patients." *Jentashapir Journal of Health Research* 5.4 (2014).

[10] Durose, Claire Louise, et al. "Knowledge of dietary restrictions and the medical consequences of noncompliance by patients on hemodialysis are not predictive of dietary compliance." *Journal of the American Dietetic Association* 104.1 (2004): 35-41.

[11] Rambod, Masoume, et al. "Dietary and fluid adherence in Iranian hemodialysis patients." *The health care manager* 29.4 (2010): 359-364.