

A11: Managing a Fine Line between Life Saving and Life Threatening: Experience of People undergoing Continuous Ambulatory Peritoneal Dialysis

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Background: People undergoing continuous ambulatory peritoneal dialysis (CAPD) face challenges to prevent life threatening complications, including maintaining appropriate dialysis techniques, food and water intake, and infection prevention. Understanding the experiences of people undergoing CAPD will augment how healthcare personnel can provide quality care to them and their caregivers.

Purpose: This qualitative study was intended to describe the experience of people undergoing CAPD.

Methods: Seven people undergoing CAPD were purposively recruited from one sub district in Lampang province, Thailand. Data were collected using individual in-depth interviews and analyzed using constant comparative analysis.

Results: People undergoing CAPD were 57 to 66 years old. They were categorized into 3 groups based on their experience in undergoing CAPD; 1) CAPD is life saving. This theme consists of strict and continuous practice; 2) CAPD is life threatening. This theme consists of recognizing abnormal signs and symptoms and timely solving the problems; 3) Undergoing CAPD requires support. This theme consists of active learning and support from family members and healthcare personnel.

Conclusion and Recommendations: The results revealed that people undergoing CAPD experienced CAPD as a fine line between lifesaving and life threatening. To manage CAPD as a lifesaving procedure, its characteristics include strictly and continuously following protocol, recognizing and timely managing abnormal signs and symptoms, active learning, and receiving help from family members and healthcare personnel. Recommendations could be made to provide guidelines for improving the quality of care for people undergoing CAPD.

Keywords: *continuous ambulatory peritoneal dialysis (CAPD), life Saving, life threatening*

BACKGROUND

Data from the Ministry of Public Health Thailand revealed that in 2012 there were 280,221 people living with end-stage renal disease (ESRD) and 35,000 people underwent continuous ambulatory peritoneal dialysis (CAPD) in Thailand (National Social Security Office, 2014). As of November 2014, there were 259 people in Lampang Province receiving CAPD (Lampang Provincial Health Office, 2014) and 64 of them were admitted and are under the supervision of Lampang Hospital (Lampang Hospital, 2014).

CAPD is a treatment of ESRD that patients can self-administer at home. However, the most common complications found with this procedure were peritoneal infection and volume overload. Such problems are caused by inadequate training of the patients. Peritoneal infection is caused by contamination while changing the dialysate fluid. Volume overload is caused by improper water and food restriction and medication management. These resulted in readmission of the patients. Being experienced in doing CAPD is considered important to help the patients carry on with their lives. Having adequate training and strictly and continuously following the instructions will result in effective CAPD. In addition, support from caregivers and healthcare personnel is also essential in enhancing CAPD management of the patients. Understanding experiences of patients undergoing CAPD will augment how healthcare personnel can provide quality care to them and their caregivers.

OBJECTIVE

This qualitative study was intended to describe the experience of people undergoing CAPD.

METHODS

Ethical approval was given by Boromarajonani College of Nursing Nakhon Lampang. Written informed consent was obtained from participants of the study.

The participants of the study consisted of nine people undergoing CAPD, they were purposively recruited from two health promotion hospitals in Mueang district, Lampang province, Thailand.

Semi-structured, in-depth interviews were used for data collection. Each interview took approximately 45-60 minutes and each participant was interviewed once or twice. The data collection was terminated when data saturation was achieved. The researchers were trained for an in-depth interview and followed the data collection method to reduce discrepancies among them.

The researchers coordinated with the directors of two health promotion hospitals for the contact information of ESRD patients undergoing CAPD under their jurisdictions. The researchers then met with the participants to explain the objective of the study and the rights to participate or withdraw from the study which will not affect the healthcare services they receive. The participants who voluntarily participated in the study selected preferable dates and times of the interviews. After each interview the researchers summarized the information of the interview to confirm the understanding between the interviewer and the participant. Verbatim transcription of the data was conducted by the researchers.

Data analysis was done using constant comparative analysis method.

FINDINGS

Participants undergoing CAPD ranging from 57 to 66 years old were categorized into 3 groups based on their experience in undergoing CAPD; 1) CAPD is life saving. This theme consists of strict and continuous practice; 2) CAPD is life threatening. This theme consists of recognizing abnormal signs and symptoms and timely solving the problems; 3) Undergoing CAPD requires support. This theme consists of active learning and support from family members and healthcare personnel.

1. CAPD is life saving. This theme consists of strict and continuous practice.

Participants described CAPD as a way to save their lives. In doing so, the patients or their caregivers need to strictly and continuously follow what they have trained with and learned from their experiences and the healthcare personnel.

1.1 Strict Practice:

Participants expressed that they and their caregivers strictly following the advice in terms of correct steps of doing CAPD, appropriate diet, and water restriction to keep them away from complications.

"I clean the (catheter exit cite) wound every day ... take a shower every day to clean up, cover the wound from the water while taking a shower. I just live like this ... don't let the wound get wet... if I make it wet by getting into the pond or go to work, the wound will be exposed to dust then it could get infected. I clean the wound once a day after taking a shower"

"I eat vegetable most of the time. I can eat all kind of vegetables except the pickled lettuce, all pickled stuff that the doctor (nurse) doesn't allow me to eat"

"The doctor recommends me not to drink too much water ... about half a liter will do. I drink just a bit. I have had enough, I am scared, so I drink (water) this little. I bought gum to chew. That helps me from thirsty a little."

1.2 Continuous practice:

Participants described continuously doing CAPD every single day to make their lives normal like others and to prevent complications. They adjust CAPD cycles to suit their daily activities or vice versa. They assess and monitor signs and symptoms of CAPD complications regularly.

"I normally do it (CAPD) at six o'clock or five o'clock. I do it at five o'clock in the morning, noon, then six o'clock in the evening and ten o'clock at night. If I sometimes fall asleep I would do it at midnight or one o'clock in the morning when I wake up. If I have work in Chiang Mai (province) I would do it at four am. Then I drive to Chiang Mai at five am. When I am back at nine or ten am. I will do at again. Sometimes I stop on the way from Chiang Mai to buy stuff and I might arrive home at one pm, I would do it then. I would do things normally. I modify CAPD cycle to fit my life."

"I use a clean towel to wrap it in the first round, then I use the rubber pad to wrap cover the towel again. Tie them tightly. The doctor (nurse) said that keep the wound away from dust. Do not let the wound be exposed to dust. Do not let the wound get wet."

"The liquid that comes out must be clear. Clear, yellow, not cloudy. If it is cloudy or has sediment that means infection. The appearance of a bad wound is swollen or red."

If there is pus, it's infected. They (nurses) said if it's infected you would have a stomach ache. You can't wait, you have to go to the hospital immediately."

2. CAPD is life threatening. This theme consists of recognizing abnormal signs and symptoms and timely solving the problems.

Participants described while they are doing CAPD to save their lives, at the same time it can be life threatening. To prevent life threatening events the patients need to recognize abnormal signs and symptoms and timely solving the problems.

2.1 Recognizing abnormal signs and symptoms:

Participants need to recognize abnormal signs and symptoms that occur on their own. They can assess the abnormalities in many ways.

"When I let the water out from the stomach if its color is unclear the doctor said that it was infected."

"For example, today I know that after I have done four cycles I got 800 cc. profit so I can do another cycle. I can do a total of five cycles."

"I must observe at the back of my feet. If they are swollen when I press they will dent (putting her finger at the back of her foot)."

"The stomach will be hot and aching all over the area ... it hurts all over ... it hurts much. It hurts until I cannot walk ... have to go to the hospital and stay for two nights in the hospital."

"They said it was infected ... because I worked and it got dirty. They said that."

2.2 Timely solving the problems:

When the participants face the problems during CAPD they solve the problem immediately.

"If the water is cloudy I need to rush to the hospital. The doctor (nurse) told me to go get antibiotics. At the hospital I did it (CAPD) five cycles instead of four cycle as I usually do at home. The doctor (nurse) said four cycles are not enough to wash out the germ. When I got better and got back home I did it (CAPD) four cycles."

"If the water that come out is bloody I would put in three bags of dialysate and let the water out continuously until it's clear then I would go to the hospital."

3. Undergoing CAPD requires supports. This theme consists of active learning and support from family members and healthcare personnel.

Participants described to do CAPD effectively they need to be active learners and they require support from their family members and healthcare personnel.

3.1 Active learning:

Participants learn from their own experiences and from other people who undergo CAPD. They decode successful actions that can mitigate and solve the problems that occurred to use in the future.

"Eggs, you must eat 7-8 eggs a day. Eat only egg whites every single day. Don't eat egg yolks. Eat 2-3 egg whites each meal. It will help prevent swelling. If you have swollen feet, it will be better and resolved. You need to eat like this continuously."

"If I can do it (CAPD) five cycles for two days, the swelling at the back of my feet will disappear completely."

"I used to have an infection. Now if we clean it, it won't be infected. My hands need to be clean, the work area need to be clean. The area that I do CAPD... I have one table that I clean it with 70% alcohol. I wash my hands with liquid soap."

"I refrain from salty food. I change to eat meat, eggs, a lot of protein, and fruit."

3.2 Support from family members and healthcare personnel:

Receiving care from family members in terms of things, actions, money, and emotions and help from healthcare personnel in terms of knowledge, information, and encouragement support effective CAPD management of the patients:

"Now it's my son who bears the burden (taking care of me). He works nearby but if he needs to go work far from home he would send me the money. If he is home, he would provide me food."

"Mostly the illness impacts mental health but we try to encourage each other. Other people who have the same illness could get better. I think like this. The people who used to do CAPD told me that it is good. At the beginning it's hard to accept, I am scared of everything. But because I love my mother I want her to live with me. We encourage each other."

"My daughter has done it (CAPD) for me since the first day coming back home from the hospital. During these two months at home my daughter does it all. She is afraid that mom will die. My daughter takes very good care of me. My daughter was trained with the nurse then she teaches me. It took me two months to be able to do it by myself."

"Every one month the solution is delivered. It is delivered to my home by a car. If I have fifteen boxes left, I would call the Hemodialysis Center and they would put an order for us."

"The doctor (nurse) said that if the solution is cloudy I need to go to the eighth floor of the hospital. If the wound has pus or the solution is cloudy I need to go see the doctor (nurse) immediately."

"When my husband was sick, I went to be with him at the hospital. I helped him doing dialysis. He cannot do it by himself."

DISCUSSION

The findings revealed that people undergoing CAPD experienced CAPD as a fine line between lifesaving and life threatening. To manage CAPD as a lifesaving procedure, its characteristics include strictly and continuously following protocol, recognizing and timely managing abnormal signs and symptoms, active learning, and receiving help from family members and healthcare personnel.

These findings are congruent with the study of Panida Thiamchanya, Chomanad Wannapornsiri, and Duangporn Huntrakul (2011), that explored self-care of patients with peritonitis from continuous dialysis therapy and found that complication prevention included monitoring signs and symptoms of infection, wound care, and following up with the doctor as appointed. The causes of infections were not following the CAPD protocol, negligence and not strictly enough in cleaning the body and equipment, and not following the advice of doctors and nurses. In addition, the findings of this study are consistent with the results from the study of Boontai Sittipaisan (2010) on self-management behaviors of chronic kidney disease patients under responsibility of Hang Chat Hospital, Lampang Province. It was found that self-management behaviors i.e. medication compliance and self-care activities are at high levels. Similar to the study of Cattliya Ukati and Natanich Chantajirakhovit (2007) on self-care agency and quality of life of end stage renal disease patients undergoing CAPD that found high level of self-care ability and quality of life. This was due to being well prepared at pre-CAPD treatment and well trained and being experienced with CAPD protocol. The findings of the current study also are in accordance with the results from the study of experiences of family members who care for patients with chronic kidney disease undergoing CAPD (Thana Dharmakun, Pimsurang Suwanjareon, and Thaveesab Sabmak, 2013). It was found that family members of patients undergoing CAPD described the meaning of care as providing assistance to the patients and making them comfortable both physically and mentally and willingness to care for them until the end.

RECOMMENDATIONS

The findings of the current study suggest the necessity of guideline for improving the quality of care for people undergoing CAPD. The guideline should indicate the characteristics of CAPD management that include strictly and continuously following protocol, recognizing and timely managing abnormal signs and symptoms, active learning, and receiving help from family members and healthcare personnel.

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