

# The Grapple with Dialysis

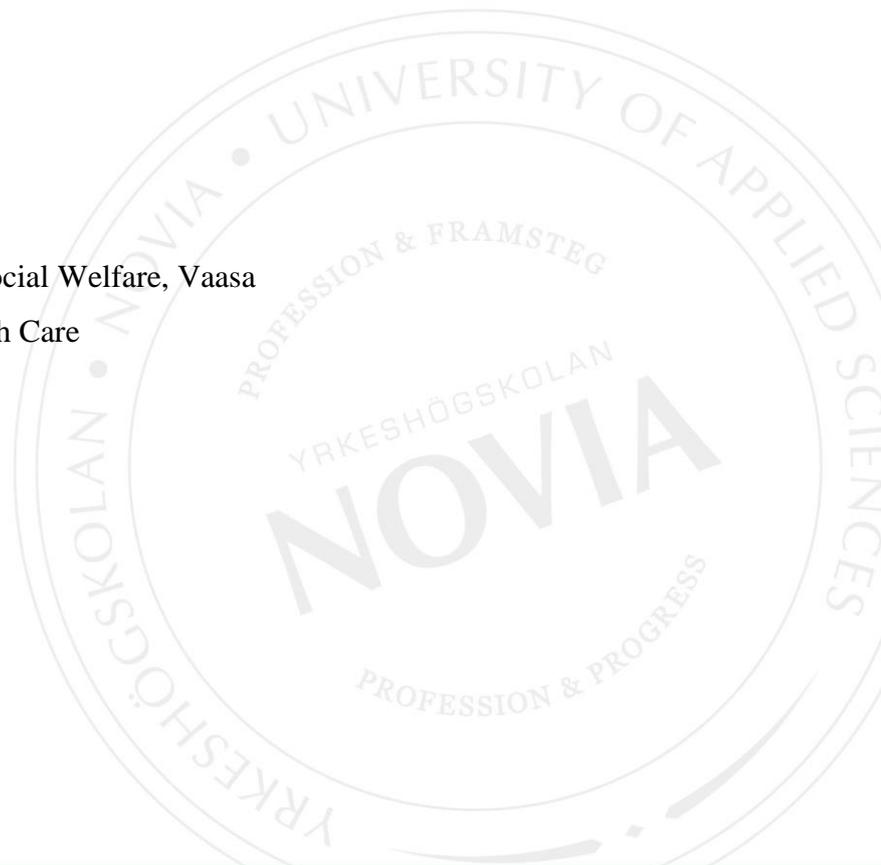
- a qualitative literature study on the experiences of adult dialysis patients.

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## **DEGREE THESIS**

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Appendices 1

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### **Abstract**

Dialysis is an important treatment for people who have end stage kidney disease, which is considered incurable. This study uses the qualitative method of research and reviews nine articles that all talk about life while on dialysis.

The study focuses on exploring the challenges and diversities that most adult dialysis patients face with every day. This will spread, gain information and knowledge to improve skills in assisting patients living with dialysis.

Taking into consideration Roy's adaptation (2009) model particularly the four human systems, which are physiologic, self-concept, and interdependence that relates to problems, and role concept that relates to changes that happens to the lives of all dialysis patients. The nine articles talk about the experiences of adult patients of dialysis that gain insight differently into their quality of life. The result shows there were four main categories found as answers to the aim of the study, which are physiologic, self-concept, interdependence and role concept. All four main categories have several subcategories that explain the challenges and diversities of a dialysis patient.

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Language: English

Key words: Dialysis, Haemodialysis, peritoneal dialysis, adult

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# 1 Introduction

Chronic kidney disease affects millions of people in the world and people who are affected by this disease mostly undergo dialysis to help supplement their impaired renal function and extend their life. When there is kidney failure for a person, it becomes a lifelong condition, and there is a need to prolong life. Dialysis serves as this lifesaving treatment for people who cannot do their normal activities before they needed dialysis. Although most information about dialysis seems to be very upbeat and optimistic, in reality, it is not as good for everyone and dialysis has never been an easy treatment even for the fittest people. Dialysis can be exhausting and stressful. An individual spends at least three days each week just to travel for treatment, getting the treatment and recovering from treatment. Adults who undergo dialysis treatment are forced into a plan they cannot control by themselves and spends as much as 18 hours in a week just to receive dialysis which does not include the travel to and from the place where they get treated (Wadd, King, Bennett, Grant 2011).

Adults living with dialysis are faced with a great challenge and responsibility to attend each dialysis session and to which every session takes time and effort. To be prescribed to undergo dialysis of any kind is a life-changing situation and it is very stressful involving a great deal of coping and monitoring which affects not only the physical but also the emotional and mental health of anyone. Each person's experience in living with dialysis is different and the first few weeks upon diagnosis and prescription is usually the hardest but in time patients would adjust to situations to which it is up to us nurses to help care for patients undergoing dialysis treatment.

Working in a dialysis facility for within a certain period and having a family member that is going through the same disease process inspired me to study the different challenges they are experiencing. By understanding which actions can be done to help dialysis patients, this serves as an important nursing responsibility that involves us, nurses to assist not only to the dialysis procedure by itself but also through helping patients deal effectively with the situation in this part of their life. I am studying at Novia University of Applied Sciences and I am on my final year.

## **2 Aim and problem definition**

This study focuses on exploring the challenges and diversities that most adult dialysis patient's face with every day. This will spread, gain information and knowledge to improve skills in assisting patients living with dialysis.

The problem definitions presented in this study are:

1. What are the challenges that adult dialysis patients experience?
2. What are the diversities that they need to face in the course of treatment process?

## **3 Background**

The Dialysis procedure dates back to the mid-20<sup>th</sup> century, which in 1943 Kolff invented the dialyzer or artificial kidney, he is the father of dialysis. Eventually, Kolff and Scribner would eventually contribute to what is now known as modern dialysis (Davita 2017). This chapter will discuss what dialysis is all about and what factors, concerns or challenging issues that affect dialysis patients.

### **3.1 What is Dialysis?**

Dialysis by principle is a treatment process that takes away waste products, corrects the electrolyte, water, and acid-base abnormalities that are needed when the kidneys fail to function. And also when the kidneys fail its primary function needs to be done artificially to which dialysis is a treatment where the blood and dialysate are passing through a semipermeable membrane. (Levy, Brown, Daley 2009).

### **3.2 Types of Dialysis**

There are two types of Dialysis; these are Haemodialysis and Peritoneal dialysis. Both these process filters the blood to remove creatine, urea, and other wastes as well as water but keeps the important parts of the blood like the red blood cells and the nutrients (Stein et al. 2002, p90).

#### **3.2.1 Haemodialysis**

This type of dialysis circulates the blood through an artificial disposable dialyzer. The Dialyzer is attached to a big dialysis machine, and the purpose of this machine is to pump

the blood and dialysate, which will pass to the artificial dialyzer that maximizes the diffusion process because the machine can pump more amounts of blood at a time. The haemodialysis machine can also monitor vital signs, blood chemistry and control the access flow and dialysis dosage (Levy, Brown, Daley 2009, p73). The duration of haemodialysis treatment depends on how well the status of the kidneys, the fluid weight gain in between treatments, the size of the patient and which type of artificial kidney they are using. The haemodialysis treatment lasts about three to four hours per session, and is done about three times per week (National kidney foundation 2017).

### **3.2.2 Peritoneal dialysis**

Peritoneal dialysis is dialysis which uses the part of the body called the peritoneum as a filter. A permanent catheter is placed through the lower abdominal wall into the peritoneal cavity, and then it is in the peritoneal cavity that the dialysis fluid is injected and then eventually drained after. Peritoneal dialysis can be done at home and does not require for patients to be in the hospital which allows doing more activities (Stein, et al. 2002, p91).

### **3.2.3 Types of dialysis access sites**

In Haemodialysis, a fistula is created through surgery, and these serve as the communication of the artery and vein inside an extremity to the dialysis machine. A direct communication is called a native arteriovenous fistula or AVFs (Sofocleous 2015). According to Fresenius, a fistula is considered as the first and ideal choice for haemodialysis access; this is because this method has the lowest chance of infection. This method is created by connecting one of the arteries to a vein under the skin of the upper lower arm. The Fistula is created at least 2 to 3 months before a person begins a dialysis to make time for it to develop and mature depending on the doctor's order. Another method is the use of a catheter attached to large vein in the neck. (Fresenius 2016).

## **3.3 Statistics**

There are many people around the world that are affected by chronic kidney disease, and nowadays it has become a worldwide health crisis (National Kidney Foundation 2015, 16). According to an article authored by Frellick, one in 10 people worldwide has Chronic Kidney Disease (Frellick 2017). The National Kidney Foundation states that 10% of the worldwide population is affected by chronic kidney disease. Over 2 million people at the moment need dialysis treatment to prolong their life, and that this number only represents 10% of the actual

number of people who needs dialysis to live (National Kidney Foundation 2015,1,3). Dialysis is important mainly because chronic kidney disease if left untreated will cause death. According to the Global Burden of Disease study in 2010 chronic kidney disease was the 18th cause of the total number of deaths in the world (National Kidney Foundation 2015: 2) and as of 2017, it rose to become the 15<sup>th</sup> cause of death with over 800 thousand deaths (World life Expectancy 2017). The World Health Organization estimates that the number of people that require dialysis treatment increases about 8% every year although almost 80% of the people who mostly receive dialysis treatment are in wealthy countries with good access to health care and consists of large populations of older adults (White et al. 2008).

Finland has a large number of aging population, in fact, according to the Finnish registry for kidney diseases since 2010. The elderly population poses a huge challenge because the older part of the population ranging from 65 years is expected to increase from 17.6%-26% in 2030 and the 20-64-year-old people will drop in numbers from 60%-52%. Having the larger older population increases the number of renal patients that might lead to having more people getting renal disease (Finnish Registry for kidney diseases 2010). As of 2015 there are on average 88 incidences of renal replacement therapy (RRT) patients for every million inhabitants living in Finland with 183.2 new RRT patients between the age of 45-64 years old and 129.2 between 65-74 years old (Finnish Registry for kidney diseases 2015, p 10)

### **3.4 Challenging issues or concerns of dialysis patients**

People who experienced dialysis are put through a stressful situation that involves challenges and concerns that will affect their overall health; there are several factors and concerns faced by every adult dialysis patient.

#### **3.4.1 Physical problems**

Pain in haemodialysis, is the pain that exist upon insertion of the needle going in but it would stop after that. Muscle cramps might also cause pain during haemodialysis most especially if there has been more fluid weight gain in between treatments. As for peritoneal dialysis, abdominal pain can mean as an infection called peritonitis. Pain might be felt at the end of a drain cycle for peritoneal dialysis (DaVita 2017).

The kidneys that does not filter the waste products from the bloodstream affects nutrition in a patient who goes through dialysis and body, which means the person, now will need to limit his or her fluid intake and have a big change in their diet and food plan since their

kidneys do not function as normal. A person on haemodialysis diet should avoid foods containing high amounts of sodium, phosphorous and potassium, all the while maintaining and limiting fluid intake (Davita 2017).

Anaemia is a common physical problem in which the kidney produce less hormone called erythropoietin, which is responsible for making red blood cells, without this hormone the red blood cell count in the body will drop, and then a person develops anaemia. In this case, the haemoglobin level must be regularly checked (Corr 2007, 25-26).

According to the Centers for disease control and prevention, adults who went through dialysis treatment have increased the risk of acquiring an infection most especially haemodialysis patients. The fact that Haemodialysis patients also have low immune systems the chance to get infection is high due to frequent visits to hospitals for their treatment (CDC 2017). For patients undergoing peritoneal dialysis, there is a risk of them acquiring Peritonitis (Kidney Research UK 2013).

According to the advisory group of the American society of nephrology, patients with the end-stage renal disease will have an average of about 11-12 medications per day and take an average of 17-25 doses (Pai, Cardone, Manley, et al. 2013). The most common of these medications consist of Erythropoietin which is a drug that helps to replenish red blood cells for the treatment of anaemia. Iron which is used for red blood cell production. Active vitamin D which is taken to prevent loss of bone minerals. Phosphorous binders get rid of phosphorus in the blood. B-complex vitamin and folic acid help bring back appetite and lower the rate of heart disease. Topical creams and antihistamines relieves itching and dry skin. And finally, vitamin E is said to prevent cramps (Lynn 2017).

According to Davita among the problems that usually cause disrupted sleep patterns can be sleep apnoea which causes breathing to be stopped or interrupted when in deep sleep which is usually accompanied by snoring, restless leg syndrome is a disorder wherein there is an uncontrollable sensation to move their legs. Inadequate dialysis clearance caused by a build of waste in blood because of the non-removal of waste from the blood (Davita 2017).

Sexual dysfunction occurs for patients with chronic renal disease and more to those with end stage renal disease in the form of erectile dysfunction for men and anovulation for women which serve as the most common symptoms. The symptoms of sexual dysfunction start early and are seldom improved after the dialysis treatment has started. Women who undergo haemodialysis are discouraged to have pregnancy (Mustafa & Schmidt 2015).

### **3.4.2 Psychological Problems**

The National Kidney Foundation states that in the start when an adult has a kidney problem there is less interest in sex because a person who undergoes through dialysis needs the energy to deal with physical and emotional stress. A person's emotion can also affect the sex life of a person mainly because having to go through dialysis treatment will induce stress, depression, nerves, fear of disability or death, marriage problems and more. (National Kidney Foundation 2017). When a person undergoes haemodialysis he or she can experience several negative human emotions, these are the feeling of hopelessness, numb, fear, overwhelmingness, sadness, resentment and anger (Fresenius 2016).

Depression is prevalent, and according to an article made by Heilman it has been called as the "common cold of mental health". Having kidney problems and undergoing dialysis treatment does not mean an adult will experience depression. Depression has many causes in the case of persons just recently diagnosed with chronic kidney disease this might lead to strong emotions on how their life is about to change which can bring up feelings of sadness and despair. (Heilman 2017).

According to Schatell compliance in dialysis if the patient does not comply with the treatment plan it just means that there has been a failure in promoting self-management or the patient is just exercising his or her right for refusal of care (Schatell 2014).

### **3.4.3 Social Problems**

Gerogianni and Babatsikou explain that the social lives of adult patients are significantly affected along with a change in daily routines and their ways of living (Gerogianni and Babatsikou, 2014a). More specifically psychological disorders may occur due to the negative effects to the professional, social and the economic status of patients, which also affects the families and the people around them (Gerogaianni & Babatsikou 2014b).

Adults who subjected to dialysis, in general, develop depression, non-cooperative behaviour, sexual dysfunction, and occupational and rehabilitation difficulties. These factors are why dialysis disturbs the quality of life of patients, which will interfere with their physical and social well-being (Rodrigues & Botti 2009, 529).

The families for adult dialysis patients of dialysis live every day with them through their experience of dialysis. This means that all the problems and successes come together for both the family and the patient regarding living with their condition. It does not matter which kind of dialysis treatment it is because the family who loves and lives with the patient who

is faced of prolonging his or her life with dialysis does not let the families escape from feeling the same turmoil, which the patient feels. (Faber 2017).

Work is an essential part of everyday life, an adult needs to work to earn money, and according to the national kidney foundation, many people with chronic kidney disease or kidney failure still work, go to school or have families (National kidney foundation 2017). There are no restrictions in working while undergoing dialysis treatment simply because dialysis treatment was designed to adults to work or live normal lives all except for the fact that they have to undergo a maintenance treatment they have to go through a few times a week (Davita 2017).

## 4 Theoretical Framework

The theory is the Adoption Model by Roy (2009). This theory gives an idea on how to provide care for patients with short, long-term or end-stage illnesses. According to her theory, the environment is composed of negative and positive stimuli that might harm or improve one's well-being. Roy's model sees a human individual as an "adaptive system" strives to maintain a balanced life when facing external or internal stimuli (Roy 2009).

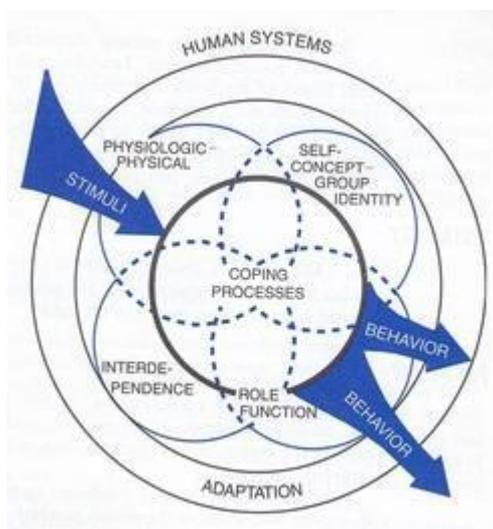


Figure 1. Representation of Human Adaptive Systems (Roy 2009).

Roy's theory is made up of 4 modes, and this is the theory of "Persons" as an Adaptive System. One adaptive response affects the other adaptation responses. **Physiological** response is the way how the physical body reacts to external or internal stimuli. **Self-concept** is how the individual sees oneself; it includes as well his or her beliefs and feelings. It is a mental or spiritual character of an individual. **Interdependence** refers to the relationship

between the person and the important people around them, i.e., family, friends, partner, and support systems. **Role function adaptive** is the persons who function in their society. This is how the persons behave towards another individual when they are faced with their own position in a unit of a functioning society (Roy 2009).

According to Roy these adaptations help to an individual attain an optimum quality of life as high as possible. The main goal of nursing is to help a person to adapt to these stressors. This enables an individual to find meaning and purpose in life and to become whole again as a person (Roy 2009).

## **5 Method**

This part of the study enables the readers to understand what the method was used and how the data was gathered and analysed in the search for answering the aims of the study. This section also mentioned the limitations of the study.

Qualitative and Quantitative research are the two ways on how to conduct a research study. Qualitative research tends to investigate the subject's perspective about the problem (Polit & Beck 2012). This is a subjective type of research; data collection in this type of research is done by informal interviews, or literature collection. It is a systematic review that is narrative in nature, the quality of assessment is done with inclusion and exclusion criteria's. (Polit & Beck 2010)

### **5.1 Ethical considerations**

Research goal is to gain information on how to prevent illness, promotion of health. Checking if right interventions are given to adult dialysis groups with individual needs, gaining knowledge on different coping skills that would be helpful on lowering the negative effects of certain health problems and for the improvement of the health system for future use (Brown 2013). However, despite all of these guidelines, nursing research has been reported to put harm on the target group due to not following the rules that on writing a particular research study (Brown 2013).

Qualitative research is more on subjective research, experiences, and emotions from the target group. The subjectivity of one's research has raised many controversies regarding the nature of truthfulness of the study since human feelings have inevitable biases both from researchers and from the target group point of view (Leung 2015).

Ethics according to Polit and Beck (2010) these are set of values in research procedure should comply, with accompanying professional obligation in conducting a research study. According to Mayer and Steneck (2014), there were three research misconduct namely, fabrication, falsification and plagiarism and two issues raised whether these are an intentional or un-intentional act (Mayer & Steneck. 2014, 120). Fabrication means making false interpretation and unrealistic results. Misappropriation means that altering useful information. Plagiarism a dishonest act that is very common in the academic environment. Words or ideas from another person without source giving acknowledgment to the author. (Merriam, 11th ed., 2003). Using exact words, copying and putting paragraphs and paraphrasing without citations are very common mistakes in nursing research (Macnee & McCabe 2008).

## **5.2 Data Collection**

To make sure that the accuracy of the study is observed, the following ways were done in choosing the articles for the study of interest. The opening of the search engine FINNA and going to the database CINAHL, EBSCO and PubMed were free of charge and the preferred language to be used in the course of choosing the articles in English. The selection of words that are relevant to the study has been done, and the keywords used were “dialysis,” “peritoneal dialysis,” haemodialysis,” dialysis experience,” dialysis care,” “nursing care for a dialysis patient.” There were several articles found in the search for this study, but the researcher chose only nine articles that are qualitative, published seven years ago 2010-2017 and were written in full English text.

Articles used were all qualitative, written in English text, published within the year 2010-2017. Articles that were excluded are quantitative research studies, research that was not written in English, materials that cannot be viewed in full text, and research materials published more than seven years ago.

Reading the articles chosen was a quite a big job but taking notes while reading was done to make sure important information are well remembered. Giving attention also to review the literature used was done. Peer review of the research papers or feedbacks to obtain views from others perspective to give the latest understanding of the issues that were read.

### **5.3 Literature Review**

A systematic review was chosen by the researcher in this study since the articles gathered were the focal point to answer the research questions (Polit & Beck 2010 p515). All material used in this study use the inclusion and exclusion criteria in to have a remarkable outcome in order not to lose important data.

According to O’Leary, keeping bibliographies literature that has relevance, accuracy and quality sources at the same time keeping the author and audience - background qualification of the writer or blogger is professional, and taking considerations about the audience whether for the public or particular group of people. Summarizing the important information whether it is a phrase, a sentence, and feed backing, the way researchers evaluate the or ask about the read data and the last one relevance where the correlation of between your study and the questions from the aims raised in your study must be observed while doing literature review (O’Leary 2010 pp 79-80).

### **5.4 Content Analysis**

Qualitative data analyses, explore, organize and attempts to describe patterns or connections from data gathered from different sources (O’Leary 2010). In this kind of analysis method it is quite confusing since it is large task that needs plenty of time, methods used may not be applicable to another study, combining patterns that are relevant to each other (O’Leary 2010) and there is no universal rule that guides the researcher in the conduction of such analysis (Polit Beck 2010 p463).

The method used on this study is Qualitative content analysis wherein the researcher analyses the content of articles to identify themes, patterns, interconnections of both by using and editing style analysis (Polit Beck 2010 p469). Content analysis is the process of organizing and integrating narrative, qualitative information according to emerging themes and concepts (Polit Beck 2010 p273). At this stage, the researcher of this study act as an interpreter who thoroughly read the articles develops segments and units to make a “category scheme” with reciprocates the codes that will help in sorting the information gathered and this is called editing analysis style (Polit Beck 2010 p273). Exploring the concepts was done wherein the researcher goes through each sentence and paragraphs to points out similarities and differences of the concepts presented on the data (O’leary 2010 p264). According to O’Leary once the articles are scrutinized the next step is to look for patterns in the text that

are applicable in looking for a suitable connection among various themes for related data (O'leary 2010 p265).

The data were deductively explored wherein it seeks for predetermined, while it develops a certain prediction from generalized assumptions. (Polit Beck 2010 p13).

## 6 Results:

This thesis was able to answer the questions: “What are the challenges that adult dialysis patients experience?” and “What are the diversities that they need to face in the course of treatment process?” The challenges and diversities that dialysis patients experience and face are plenty; dialysis is a life-changing situation which brings out many challenges. Using the qualitative content analysis, the author was able to acquire categories that discuss the lives of people with dialysis all of which shows different perspectives on how adult dialysis patients experience problems and face diversities in their life with dialysis. To answer the aim of this study, the nine articles were analysed to sort out all the stated challenges and all the stated diversities for each article. There are four main categories that the article idea can be defined respectively to which namely physiologic, self-concept, interdependent, and role function.

### 6.1 Literature Review of articles

The literature review of the nine articles can be found in Annex.

### 6.2 Challenges faced by an adult dialysis patient

To answer the first question of this study, challenges that were mentioned in the nine articles were categorized as **Physiologic, Self –concept, and Interdependent**.

#### 6.2.1 Physiologic

Under the first category, physiologic problems deals with the physical aspect of human individual, there were seven subcategories that were found, and they are: *Sexual dysfunction, low-self-esteem, bodily disorder, mortal/fragile self, preventing progression, physical pain, restricted life limitations and hard on body*

*Sexual dysfunction*

Patients undergoing haemodialysis can perform sexual activity but the desire, excitement, and interest of initiating of doing the act have significantly changed. The act itself causes them to be easily tired and often leads to shortness of breathing which most of them experience. According to DaVita person who undergoes through dialysis needs the energy to deal with physical and emotional stress (DaVita 2017). Physical changes in the body often affect sexual activity since bodily changes affect their partner's perception when they see this transition. Having a negative feeling about self has a relation between making love with their sexual partners (Frazao, Bezerra, et al. 2014). The changes in physical appearance make them feel "dirty" makes them not to do intimate activities with their partner (Calvey & Mee 2011). The feeling of impotence has also been raised by most dialysis patients since it is a life-long treatment (Viegas AC 2017).

#### *Low self-esteem*

Weight gain in haemodialysis causes a feeling of unattractiveness, which causes poor opinion about one's self-physical appearance. The feeling of failure to be independent, feeling of insecurity, feeling of regret, feeling of anxiousness, anger because of the personal situation are factors that contribute to patients esteem issues. Change in sexual drive affects one's perception about themselves, being not able to do an activity with their partners raises a lot of self-esteem issues as well (Frazao, Bezerra et al. 2014, p.218). Seeing their selves as a medical body when they CVC access protruding in their neck raises self-esteem issues (Calvey & Mee 2011). Having a swollen arm because of the fistula, which is a common access to every dialysis patients makes them feel different from any other people because of such change in their appearance (Fresenius 2016).

#### *Bodily disorder*

Being on dialysis treatment causes many physical changes. A damaged kidney causes swollen painless extremities, changes in urine output and difficulty in breathing (Viegas, et. al. 2017). A common problem of patients on dialysis is that of low haemoglobin level that carries oxygenated blood to different organs in the body such as lungs, these patients experiences fatigue and malaise when engaging physical activities (Corr 2007, 25-26). Some patients experienced blood in urine, sharp pain in the kidneys, feeling of cold followed by hot stated to be flu-like symptoms. During the treatment process, complications are inevitable some patients verbalized pain at the back and sometimes be mistaken as spinal pain (Viegas et al. 2017). Common bodily disorder is the swelling of the arms because of dialysis access site, veins are visible and protruding (Frazao, Bezerra, et al. 2014). These

limitations experienced by dialysis patients because of the sickness makes them feel they are handicapped such as preventing the use of arm, which has the access site. (Guerra-Guerrero 2014)

#### *Mortal/fragile self*

Mortality issues comes commonly when patients are diagnosed with life-threatening diseases. Undergoing dialysis has been just a medium to extend one's life. The absence of dialysis treatment puts them into realizing how delicate life is. Mortality comes together along with dependence on dialysis treatment; it sums up the life of dialysis patient. (Calvey 2011). A missed treatment means to face the consequence of life and death. (Corr 2007, 25-26). The existence of one's self is changed by the disease and disease treatment (Guerra-Guerrero 2014).

#### *Preventing progression*

Following religiously the scheduled treatment plan, which includes the dialysis sessions and medications. The dialysis patient eventually treats the treatment regime as something very important which means that missing any treatment regime could personally mean the difference between life and death. The only way to prevent dialysis complications is to be in the treatment together with medications itself. The adherence to diet is also important and can be a problem all foods should be within regulation (Guerra-Guerrero 2014). Nevertheless, dialysis patients face their diet with utmost importance. Also similar to the food intake, the liquid intake involves measuring exact amounts and setting liquid restrictions, which prevent patients from drinking too many liquids (Davita 2017).

#### *Physical pain*

Pain in dialysis can be experienced during and after the procedure, like needle cramps and pain during insertion of the needle (Bourbonnais, Tousignant 2012). Pain would exist upon insertion of the needle going in and it is the most common kind of pain that a dialysis patient are experiencing (DaVita 2017). Pain as part of physical changes in the body, which some experience back and joint pain (Frazao, Bezerra, et al. 2014).

#### *Restricted life limitations and hard body*

A restriction on ones usual activity due to life changing disease. A haemodialysis patient verbalized that they need to stop working since their body cannot cope up from the demands of their workplace at the same time the number hours that they needed to have that certain

treatment. Peritoneal dialysis patients said they were still able to work but complained of limited income since they would have less time to work because of scheduled treatment (Clarkson, Robinson 2010). Due to the span and frequency of treatment and the effects of the dialysis, patients tend to work less and financial status has always been affected (Frazao, 2014). Planning the week's activity leads to changes in their social, family life since they have to think about their three times a week treatment, which restricts them from having more productive activities (Guerra-Guerrero 2014). The hard body challenge involves physical impairments from dialysis, which can also go along with the mind and spirit per say to which these problems can cause loss of will and feeling of dread (Clarkson, Robinson 2010).

### **6.2.2 Self Concept**

Self-concept problems are the views that are more defined towards oneself or the individual. Under the category of self-concept, there were five subcategories: *Managing fear*, *Coping*, *Sense of fear*, *Feeling of loneliness*, *Liberty to captivity*,

#### *Managing fear*

A perception on how to deal fear is a big challenge for dialysis patients. Among the fears stated managing fear from bodily harm is very common, which deals with the fear of physical pain. The fear of the unknown shows the fear of not being sure of how patients would manage the lifelong treatment. Peritoneal dialysis patients verbalized the fear of making a mistake while performing the procedure at home and with that, they make sure someone is with them while they are on dialysis (Sauve, Vandyk, Bourbonnais 2016). A fear of impending death is a common fear shared by almost all dialysis patient, with these following scheduled treatment would save them from this situation (Guerra-Guerrero 2014).

#### *Coping*

Some dialysis patients when they undergo dialysis find their strengths and motivation through God and religion. Some of them find help in others who also is going through the same situation as they are experiencing (Clarkson, Robinson 2010). Dependence of dialysis machine has been their refuge in the treatment process, having the thought of that the machines manage them to live has been their way of thinking that they will still live their life as much as they can (Guerra-Guerrero 2014). Taking to someone with the same situation a dialysis support groups have established for these patients to find refuge from their sickness (Clarkson and Robinson 2010). ). Spiritual ideas is used as means of coping from the

stressors experienced by the participants they view their situation as a test of their faith whether they will give up or hold on with the situation they are in (Viegas et. al 2017).

### *Sense of fear*

The most common fear, was of the fear of the dialysis needle, the mere sight of the dialysis needle triggers the sense of fear. Frequent coming to dialysis ward for treatment accompanies fear since having a simple infection causes different complications for a dialysis patient. (Herlin, Wann-Hansson 2009). Fear of doing task that might risk the dialysis access, because if it happens the whole treatment would be in disorder (Jonasson, Gustafsson 2017). Dialysis patients finding themselves in uncertain situations and thinking about inevitable death and also the thought that dialysis patients lives depends on the dialysis machine (Calvey 2011).

### *Feeling of loneliness*

The dialysis patients shows lack of desire or inability to socialize because of avoidance of discussion about having a dialysis. Dialysis patients also find difficulty in finding friends because of fear of losing another partner because of the treatment; partner left because of dialysis treatment (Herlin, Wann-Hansson 2009). Being not able to do activities together with their family and the thought is not able to see their kids grow saddens them(Calvey & Mee 2011).

### *Liberty to Captivity*

The patient sees all the challenges they experience and thinks of it as barriers and limitations that prevents them from living their lives as they did before the start of the dialysis treatment (Jonasson, Gustafsson 2017). Patient sees their treatment as a transition from a good quality of life, to a life-changing situation whether from personal, family, social activities and financial situation to deterioration of life (Guerra-Guerrero 2014). The feeling of being imprisoned on the treatment since its restricting them from doing things aside from going to dialysis sessions (Viegas et. al 2017). The disease put a person to life drastic change, from family to economic factors (Gerogaianni & Babatsikou 2014b)

### 6.2.3 Interdependence

This category deals with social problems, which can either require or involve the family or members of the health team. Under the third category Interdependence, three subcategories emerged, and these were; *needing support*, *dependence on the caregiver*, and *emotional and social pain*.

#### *Needing support*

The family members are the first source of support among dialysis patients, which can help them, face all the challenges they have to go through (Clarkson, Robinson 2010). The patient lean on heavy reliance to nurses during dialysis treatment to provide emotional, functional and information support to the patient for them to understand the situation they are in and how important their treatment is (Sauve, Vandyk, Bourbonnais 2016).

#### *Dependence on caregiver*

The patient is concerned about their relationship with their caregiver. Spending a lot of time in the ward creates a “personal chemistry” between the patient and the caregiver. Most dialysis patient are not confident to be handled by a nurse that is different from the one they have already been used to (Herlin, Wann-Hansson 2009). Peritoneal dialysis patients preferred someone helping them while doing their treatment rather than doing alone ( Sauve, Vandyk, Bourbonnais 2016)

#### *Emotional & Social pain*

Emotional and social pain best describes as problems of isolation, which was the result of lack of time and losing time to self and people around because of lifestyle changes due to dialysis (Bourbonnais & Tousignant 2012). Having three times a week treatment makes hard for patients to find time for their friends and loves ones; it seems the treatment made them feel imprisoned, and the dialysis is just their life. The feeling of frustration, anger, aggressiveness, and depression has been a common initial reaction for someone who was diagnosed with the disease. (Viegas et. al 2017).

### 6.3 Diversities faced by an adult dialysis patient

To answer the second question, the articles that spoke about diversities from the nine articles fall under the category **Role function**.

### 6.3.1 Role function

These are the roles dialysis patient take to face the diversity that comes with dialysis treatment. The subcategories are *Learning to live with loss*, *Future self*, *Living with hope*, *Embracing the disease*, *Adjusting to the new life and, moving towards reconciliation*.

#### *Learning to live with loss*

Being left with no choice, patients need to accept their situation, the more they ran away from it by not going to the scheduled treatment puts their life in a more dangerous situation (Viegas et. al 2017). Change is what marks the entire transition of the dialysis patient from the time the disease is diagnosed to embracing the treatment as part of their weekly routine. This change involves the loss of health, kidney function, time, activities and body image that is caused by the disease (Sauve, Vandyk, Bourbonnais 2016).

#### *Future self*

The dialysis patient describes changes that might or never happen in the future and they accept this role to give an awareness of their uncertain future. Dialysis patients assuming this role is unsure about what their purpose would be in the future, or the belief that dialysis treatment would one day return their future to them in which the role of dialysis treatment is a lifeline that keeps them alive (Calvey & Mee 2011).

#### *Living with hope*

The dialysis patients' shows hope and that hope is an expression to which its role serves as a symbol that can liberate dialysis patients to allow them a normal life (Sauve, Vandyk, Bourbonnais 2016). Having a strong spiritual foundation and support from the people around them helps dialysis patient to find meaning in their lives (Clarkson and Robinson 2010). Dialysis patients express hope of getting a transplant to have their normal life back (Calvey 2011).

#### *Embracing the disease*

The role of embracing the disease shows acceptance within dialysis patients and their life situation. Seeing one's life divided into two stages of before and after, seeing the present phase with dialysis as something they must fight every day to embrace the disease and treatment (Guerra-Guerrero et al. 2014). Some dialysis patient just says to accept their situation with confidence while moving on with their lives (Viegas AC 2017) the fact that

they cannot change their situation and left them without a choice makes them feel just to move on and deal with the changes (Viegas AC 2017).

#### *Adjusting to the new life*

Dialysis patients learn to adjust to a new life to which this is the approach in accepting treatment and accepting and coming into terms with their situation considering both the inner and outer possibilities and not trying to escape or judge them. Regardless how hard or horrible the situation is, acceptance means to want to move further in life despite the changes (Jonasson & Gustafsson 2017). Family, social, psychological factors greatly affects how a dialysis patient adapts to the situation when adjusting to diversities in their lives (Viegas et al. 2017).

#### *Moving towards reconciliation*

The dialysis patients who have moved on to their new roles and obtain the feeling of gratitude and acceptance of their new situations experience a more stable existence but does not mean they are accepting of the illness. It is here where new ideas are made and how this can lead dialysis patients to new goals and new relations (Jonasson & Gustafsson 2017). When patient find the usefulness of the treatment then they start to appreciate how important it is to follow their weekly dialysis schedule (Viegas et al. 2017). Dialysis patient involve faith in God to which the patient with dialysis accepts their condition as a hurdle sent by God and that it is their destiny (Viegas et al. 2017).

## **7 Discussion**

This part of the study is where the data findings from the articles gathered are used to which background and framework altogether utilized to analyse an outcome that will mirror the aim of this research. This study aims to focus on exploring the challenges and diversities that most adult dialysis patients face with every day in hopes to spread, gain information and knowledge to improve nursing skills in assisting patients living with dialysis. Using systematic qualitative review, the results have been analysed to form a conceptual model that would base my findings that would most ideally represent the things learned.

## 7.1 Discussion of results

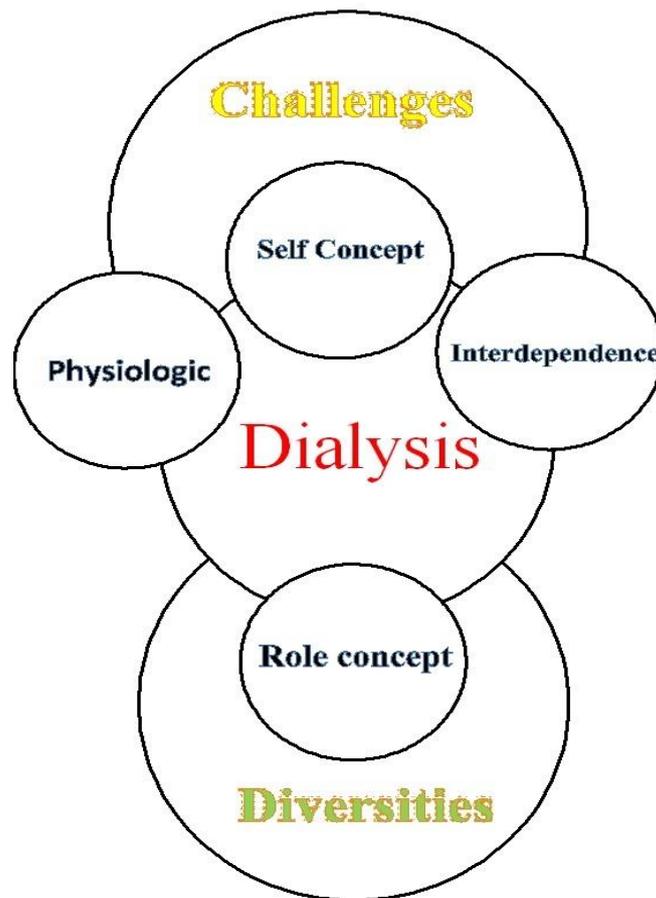


Figure 2. Dialysis in relation to theoretical framework used

Inspired by Roy's Adaptation model and her Diagrammatic representation of human adaptive systems figure 2 shows how dialysis is in the life of an adult individual.

Tracing back to the background of this study, the adult dialysis patients experience so many problems. Chronic renal disease throughout the span of treatment causes pain (DaVita 2017), the social life can affect the family and the significant other (Gerogaianni & Babatsikou 2014), the patients nutrition which involves dietary and fluid intake (Davita 2017), side effects like anaemia, disorders that can affect sleeping (Corr 2007), negative human emotions (Fresenius 2016), mental issues like depression (Heilman 2017), financial issues like employment (Davita 2017) and income source (Fresenius 2016), compliance with the treatment (Schatell 2014), medications (Pai, Cardone, Manley, et al. 2013), and infections (CDC 2017). All of these problems affect the lives of dialysis patients suffering from renal disorders.

Based on the categories in result, dialysis becomes the centre of the lives of anyone diagnosed with the chronic renal disease, which puts it at the centre of this diagram. Also

based on the aim of this study, a person that goes through dialysis experience face two main concepts in their lives, and these are the challenges and diversities. To state the fact that we are all human beings the result of this study takes into account the four human systems or person systems under Roy's adaptation model (2009). The human systems taken into account are physiologic, self-concept, role function, and interdependence.

The challenges that an adult dialysis patient experience according to this study that is divided into three of the four human adaptive systems of Roy, which are considered as the main subcategories under challenges. The first challenge that dialysis patients experience deals with the physical. Under the Physiologic category, the themes that were discussed in the articles explains that dialysis can cause *sexual dysfunction, low self-esteem, bodily disorder, preventing progression, physical pain, restricted life limitations and hard body challenges*. The second subcategory under the problems dialysis patients experience is about self-concept, which deals with the challenges that dialysis patients face through themselves to which these involve *having a sense of fear, managing fear, coping, feeling of loneliness and having a concept of liberty to captivity*. The third subcategory is *interdependence*, which are challenges that involve relying on others namely needing support, dependence on the caregiver and emotional and social pain.

Dialysis patients also face diversities during the span of their life along with renal disease and this takes into consideration the last of the four human systems of Roy that is the Role functions. In Roy's model (2009), adaptation is stated; to which in this study's model adaptation is synonymous and can lead to diversity and these diversities, play a significant role to which dialysis patients according to the articles read seem to adapt to face the diversities happening in their lives. The diversities found in this study deals with *learning to live with loss, living with hope, the future self, embracing the disease, adjusting to the new life and moving towards reconciliation*.

In Roy's model, all of the patient behaviour is the result of stimuli that goes through the coping process that contains the human subsystems to which the behaviour is adapted once a stimulus is applied (figure 1). In this study which is a literature review, only aims to know what are the problems and changes in the life of dialysis patients. This gives a structure model (figure 3) of correlation that takes into account some elements from the Roy adaptation model that shows how challenges and diversities are connected and interrelated together in the lives of dialysis patients.

## **7.2 Discussion of Method**

This part of the study contains the open-ended exchange of ideas for further thinking, learning and problem solving, understanding or appreciation exists. The study shows multiple points of view that respond to the author of this study and her ideas in an effort to help build knowledge, understanding, or interpretation of the matter at hand (O'leary 2010).

### **7.2.1 Critical Review**

The study is critically reviewed mostly by two sources. The first using the qualitative analysis style mentioned by Polit and Beck (2010) to which this study practices editing analysis wherein the data in the articles has been analysed carefully to acquire segments of knowledge about each in order to use those segments and units to form a scheme that will eventually become a category scheme to where a structure was formed which connect the categories (Polit & Beck 2010).

Based on Roy's (2013 p .357) adaptation model-based research: global view this study answers several questions on how, where, and by whom are the nursing concerns managed, how do these health concerns reach a status of being important and the relative value of nursing research.

Qualitative research has been continuously questioned about the "soundness" and how appropriate the methods used to arrive at a particular conclusion since it is based on gathered personal opinions. According to Golafshani, there has always been a continuous conflict between the validity and reliability of qualitative research studies (Golafshani 2003, 600). Validity and reliability both these words as terms are questionable with regards to their applicability in this kind of research process (Golafshani 2003, 601).

The reliability of this study is determined by how accurate and consistent the data collected for this research is (Polit & Beck 2010). Although a qualitative study can be different with regards to the fact that each of these nine articles chosen for this study may have different personal opinions about the subject, though this may be true it just shows how different authors have different experiences and reactions and interpretations. Despite all of this, the data found among all the articles and the use of this study is consistent, to which they talk about the challenges and diversities of dialysis patients. Also in this study, the nine articles are considered too small for this study to be a valid source material, but all things considered, this research proves to show some results. The more evidence that can be gathered on what

the topic of the study is supposed to be discussing the more people will be confident of the validity of a study (Polit & Beck 2010, p380).

In a qualitative study, research is mostly from the collection of personal opinions in which the statements very common both on the part of the researchers part and subject of the study (Golafshani 2003, 601). Some of the ways to make sure that credibility of such qualitative study is being observed is to recognize statements that might change the result of the study. Carefully record data, to ensure information gathered are precise and clear. Observing resemblance and variations of other studies to make sure that all aspects of the study are well defined, using simple and exact terms in the formulation the study and making sure to use a certain method that assures the data presented are right for the particular study (Golafshani 2003, 603). According to Polit and Beck, there are four categories to consider to have a good quality research study. Transferability or the applicability to other group or situations. Due to its method a qualitative study, it cannot be generalized since it has a small number of materials used (Polit & Beck 2010, p492). The study is transferable to an extent that the challenges and diversities stated in all the nine articles chosen can also be found in real life hospital settings.

Credibility or the truthfulness of the data and their interpretations. (Polit & Beck 2010, p492) The literature was completely examined and that not all were outdated. All nine articles passed the inclusion and exclusion criteria.

Dependability works together with credibility to be achieved. This refers how consistent is the result if it would repeatedly be done in the same target group (Polit & Beck,2010, 492). The result met the criteria of dependability in the sense that structures, themes correspond to the framework used.

Confirmability reassures the accuracy, relevance, and meaning of data making sure that the data that is shown will not be from the imagination of the author (Polit & Beck,2010, 492). The result confirms the idea, and the objective of this study to which all articles found and used in this study comes from reliable sources with their proper references.

### **7.3 Conclusion**

All the nine articles in this study showed different views on how individuals face dialysis in their lives, but all had a common message, and that is the message of self-preservation. It is because of self-preservation that adults can learn to adjust having dialysis in the centre of their life along with the burden of factors that go along with it. Living a life with dialysis

especially those adults with chronic renal disease becomes a long tedious and challenging experience. An adult will have to live by adjusting his lifestyle to maintaining not only the dialysis treatment itself but also learning how to balance his emotional, psychological, mental and social health. For a once normal adult once diagnosed with kidney disease from the beginning of a dialysis treatment, it is important to be able to learn many things as much as possible about all the options and the questions that need to be asked. Nobody wants to start dialysis, but if ever someone finds himself or herself in the position of needing to do it, a positive outlook is needed in life. This can be done by seeking help and support from the closest person an individual knows because by not being alone can this unfamiliar experience of dialysis become a new normal in life.

This study has shown many types of challenges that adults experience during dialysis treatment, but do most of these challenges lead to even more diversities? The diversities that adult dialysis patients face are difficult and challenging but can these diversities be seen as problems as well? As nurses, it will be our duty to assist adult patients whenever they are going through dialysis treatment, during this time we use our skills and knowledge we have learned through our education to assist and assess the patient during his treatment to help prevent complications. But the most important role we have for patients with dialysis is to serve as shining beacons of hope to them, to encourage them that complying with the therapy as well as showing them the value of self-preservation giving them hope and encouragement in the face of bleak uncertainty. Dialysis treatment is not an easy thing to go through with but we nurses make all the difference in the world for people going through dialysis.

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## Literature review

Name	Article	Year	Aim	Method	Result
Bourbonnais F.F., Tousignant K.F.	The Pain Experience of Patients On Maintenance Haemodialysis	2012	To provide an overview of pain experienced by patients undergoing maintenance dialysis.	Semi-structured interviews were used to elicit the participants' personal experiences about pain.	This article was a study on the description of pain among some haemodialysis patients. The most common type of pain is physical pain which is physiological in nature. The emotional and social pain which is more psychosocial.
Calvey D., Mee L.	The lived experience of the person dependent on haemodialysis	2011	The aim is to know the lives of 7 patients on dialysis.	Phenomenological study. Interviewed using an in-depth semi-structured approach, following the philosophy of Heidegger.	This article which was a study about seven chronic haemodialysis patients showed that among the several themes that have emerged the future self which deals with hope for a normal life and the mortal/fragile self which deals with worrying about death and how delicate life is.
Clarkson K., Robinson K.	Life on Dialysis: A Lived Experience	2010	Aims to know how educated adult haemodialysis patients on disease and treatment process.	Interviewing 10 participants from ages 26-85 who is undergoing dialysis minimum of 3 months times. Six haemodialysis participants and four from peritoneal dialysis.	The article is about the story of people who are in the end stages of their renal diseases. Some perspectives that were shown is that they have developed restrictions in the life of dialysis patients and some problems with coping. This article also states the importance of the need for Social support.

Frazão C. M.F., Bezerra C.M.B., De Paiva M.D.G.M.N., De Carvalho Lira A.L.B.	Changes in the Self-concept Mode  of Women Undergoing Haemodialysis :  A Descriptive Study	2014	Analyse the changes in women undergoing haemodialysi s using of Roy's theoretical model.  .	A descriptive with interview script given to  24 women undergoing dialysis treatment.	This study focuses on a study about a group of women going through dialysis treatment in Brazil. The common result was these women showed low self- esteem issues and sexually related problems and dysfunction.
Guerra-Guerrerro V., Salas A.V.S., Plazas M.D.P.C., Gonzalez C.G.C., Cameron B.	Understanding the Life Experience Of People on Haemodialysis : Adherence To Treatment and Quality of Life	2014	To describe how patient adheres to the treatment and they view the quality of their lives.	The study includes interviews patients 18 years of age and above and has been on dialysis treatment for more than 3months. Qualitative interview	This study shows experiences with dialysis patients in relation to how they follow their treatment regime to have a better life. To which embracing the disease and the dialysis requires a significant change and through preventing progression of the disease through treatment place.
Herlin C., Wann-Hansson C.	The experience of 30-45 years of age and depending on haemodialysis treatment: a phenomenolog ical study	2010	To know how dependence to the treatment affects the life of an adult dialysis patient.	A descriptive phenomenolo gical approach. An experienced based interview.	This article describes the experience of 30-45-year-old haemodialysis patients to which based on data analysis resulted in showing that these patients may have a sense of fear, feeling of loneliness and dependence on caregivers.
Jonasson K., Gustafsson L.K.	You Live as Much as You Have  Time To: The Experience of Patients  Living with Haemodialysis	2017	Narrate the changes that happened during the course of the disease process.	Qualitative descriptive using interview questions.	This article was mostly about change in which dialysis patients express their transition from being normal to the current which is shown in the idea wherein patient changes from liberty to captivity, adjusting to the new lifestyle during the treatment and finally to move on and have reconciliation.
Sauvé C., Vandyk A., Bourbonnais F.F.	The experience of individuals transitioning from in-center haemodialysis to home	2016	The purpose of this study was to explore the transition from hospital to home	The qualitative descriptive design was used. Interviews were	Gives an idea on how renal disease patients can understand the "learn to live with it" approach in facing dialysis, this means living with renal failure with dialysis treatment can mean

	dialysis after a suboptimal start		dialysis in a sample of individuals who began dialysis in a suboptimal way.	conducted, audio-recorded, and transcribed verbatim. Thematic analysis was undertaken.	learning to live with loss, to manage fear and to live with hope too as well.
Viegas A., Muniz R.A., Schwartz E., Feijó A. M., Barboza M.C.N., Monfrim X. M.	Young adults undergoing haemodialysis: from the discovery of the disease to difficulties faced in diagnosis and treatment	2017	To make voice on young adults experience on haemodialysis from diagnosis to the treatment process	Descriptive, exploratory, qualitative study on ages 20-41 years of age.	Talks about the speeches of young adults with chronic renal disease undergoing treatment of haemodialysis. Focuses on bodily disorder which is the first symptom of chronic renal failure.