

# Patients' with end stage renal disease



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The chronic disease identified for this report is about patients with End Stage Renal Disease. state that ESRD is a progressive, irreversible deterioration in renal function in which the body's ability fails to maintain metabolic, fluid and electrolyte balance. Clinical manifestations include oedema, uremia, anemia, gastrointestinal disorders, dermatologic symptoms and renal osteodystrophy. Stein A. & Wild J. (2002) state that physical symptoms may present as generalized discomfort, nausea, insomnia, fatigue, restless legs, leg cramps, sexual problems, low fertility, pallor, and pain. There are systemic disease that causes ESRD such as diabetes mellitus, hypertension, chronic glomerulonephritis, pyelonephritis, obstruction of the urinary tract, hereditary lesions as polycystic kidney disease, vascular disorders and infections medications.

The treatment of ESRD is dialysis, which is an artificial way of filtering the blood. Unless kidney transplantation is available, dialysis treatment is necessary for patients diagnosed with ESRD (Gokal & Noph, 1994).

Leatherland (2007) describes that even those patients who are lucky enough to undergo renal transplantaion still have frequent hospital appointments. Patients who already undergone kidney transplants, still have to adhere a strict regime of medications such as immune suppressants and their side effects. There are two dialysis modalities. In haemodialysis (HD) the blood is purified by an external artificial kidney. The American Association of Kidney Patients (2011) explains that HD patient's access is either a fistula or a graft that he/she is needled every dialysis session. Patients have to attend for HD treatment either three times weekly or alternate days for four hours; this depends on their level of creatinine. In peritoneal dialysis (PD) the peritoneal

membrane functions as an artificial kidney (Cameron, 1996). A peritoneal dialysis catheter (PD catheter) tube is inserted in the patient's abdomen which acts as a permanent pathway into the peritoneal cavity. The catheter is used to fill the abdomen with the dialysis solution which contains percentages of dextrose. There are two types of PD treatment, Continuous Ambulatory Peritoneal Dialysis (CAPD) which is a process of draining and filling that takes about 30 to 40 minutes. A typical schedule takes for four exchanges a day, each with a dwell time of four to six hours. During this dwell time that patient can continue with their normal daily activities. Another form of PD is the Ambulatory Peritoneal Dialysis (APD) where the patient requires a machine to fill and drain the abdomen, usually while the patient is sleeping. Besides the treatments that the patient with ESRD has to undergo, they have to follow a highly restrictive diet, limit their fluid intake and follow a specific medical regimen. Consequently, if the patients do not follow their treatments plans, serious complications often develop.

The impact of end stage renal failure does not stop with these physiological stressors, patients also suffer socially and financially. Auer J. (2002) explains that patients with ESRD are restricted in their choices of occupation, hobbies, and leisure activities and limitations in their diet intake. Besides ESRD patients have psychological stressors such as loss of self-concept and self-esteem, feelings of uncertainty about the future and feelings of guilt towards family members. Most of the patients feel depressed and avoid socializing with friends and colleagues due to their illness and the demands of their treatment.

When an individual is diagnosed with a chronic disease, in this case ESRD, Auer J. (2002) states that the patient go through the process of bereavement. This transitional process involves the experience of shock and trauma, denial, grief and anger before reaching the stage of acceptance. When people deal with life challenges they experience emotional upsets especially if encounter a difficulty for the first time. They include fear (“ What does the future hold with an implanted catheter?”), anger (“ Why me?”), grief and depression (owning to the threat of PD complications). These emotions cannot be avoided. Hooper J. & Cohen L., (2004) suggest that patients can experience these stages in random order for varying lengths of time and often revisit them. This latter situation poses difficulties for the nurses as one day a patient may appear to be accepting his/her situation, but the next day the same patient may be back to being tearful and angry.

Adherence to treatment is such a problem for dialysis patients. Therefore it is important to understand why patients do not adhere to medical regimen. The Common Sense Model (CSM) of self-regulation which was recognized by Leventhal et. al (1984) was developed to understand and explain health and illness behaviour (Cameron & Leventhal, 2003). The CSM is aligned on the individual and his/her idea of health and illness. Hence the patient is “ an active problem solver.” Horne (2003) states that the individual tries to identify reasons between their illness representations and the procedures to cope with the disease, which includes the perceptions of treatments necessity. The CSM have five illness representations – identity, timeline, personal control, treatment control and consequences.

Starting dialysis treatment the patient embarks a completely new way of life that challenges the patient's coping mechanisms and involves a re-evaluation of their identity. Therefore it is essential that information about ESRD is provided to the patients to have a complete picture about their illness. In the study of Hagger and Orbell (2003) describe an illness coherence of a patient is: " I have a clear picture or understanding of my condition." Patients view their illness as the focus of their identity. Hagger and Orbell (2003) suggest that a personal model is created by the patients about their illness. Patients' adaption to a chronic disease is determined by their personal model belief about illness and treatment. During this process the patients are influenced by different network of people and information as they develop an internal representation of their illness. Patients read books, magazines and search in the internet to understand, manage their condition and to find others like themselves (Davidson, K. & P., Pennebaker, J. W., 1997).

Patients interpret the timeline of their illness as acute, chronic or cyclical: " my illness is likely to be permanent rather than temporary," or " my symptoms come and go in cycles." Most of the time, the symptoms determine the illness representations about timeline. Illness representations evaluating the acute, chronic or cyclic nature of the disease are often based on communications with medical professional, family members and other patients. Kahn (1995) states that the patients use defence mechanism to protect themselves from overwhelming situations and give them time to adapt the impact of the illness. Sometimes patients associate previous illnesses experiences and tend to expect illnesses to disappear or some sort

of cure will be available to treat the disease. For instance patients may think there has been a mistake or that it is just not something they need to worry about. Otherwise patients accept that they have the illness, but they start to convince themselves that they are going to be cured. However, in case of a chronic illness, reality forces patients to abandon this 'acute' illness model to be replaced with a 'chronic' model (Leventhal et al., 1984).

The patient's knowledge, capabilities, life experiences and socio-cultural background influence the patient's reaction to the disease. Some patients may identify illness in complete negative terms. When illness is perceived with the sense of destiny or viewed uniquely in terms of decline and loss, a negative experience is likely to follow. A negative perception of illness seeds unhappiness and depression. Perception improves when illness is viewed as something that occurs within a setting. Viewing illness as a normal part of life allows patients to live more fully in the present (Holaday, 1989). For instance, a patient learned to insert dialysis access needles into her own fistula to gain some control over her treatment. On the other hand another woman had a dialysis line but refused to look at it and requested to be covered with a dressing at all times.

When confronted with an illness, people create their own models and representations of the illness in order to make of and respond to, the problems they faced with, which is their personal control. Some patients state " what can I do to determine whether my illness gets better or worse?" Many patients placed on dialysis believe they no longer have control over their lives. Some of these people may try to regain control in a negative way by deciding to shorten their treatment or not taking prescribed medications.

Kammerer (2007) notes that some might feel such a loss of control that they develop a “ sense of futility” and just give up, discontinuing all treatment.

Another CSM domain is treatment control, where the patient believes about the usefulness of the treatments they are receiving: “ my treatment can control my illness,” “ there is nothing which can help my condition.” Besides having haemodialysis or peritoneal dialysis treatment, the patients have to be aware of keeping their restricted diet, fluid intake and also to take their prescribed medications. Medication intake for ESRD is specific to each patient. Sometimes patients are disappointed about their blood results especially when their haemoglobin is low, having high potassium or high phosphate. They think that although they adhere to treatment and are very concern about their limitations, they are not receiving the desired outcome. The patients’ perceptions of the treatment effectiveness may reflect indirect. As Denhaerynck et al (2007) suggest that if the patients’ believe that their treatment or medication is ineffective could influence the extent to which patients feel motivated to regulate their illness and to adhere to treatment guidelines.

Consequences and emotional representations are the effects that the patients associate with the illness and negative aspects of life such as social, family, self-image and economic changes. The emotional representations are the internal emotional reactions to the mental image of possible dangers imposed by the illness threat such as depression, fear, anger or anxiety: “ when I think about my illness I get upset.” For instance, most patients are ashamed about their self-image. Body image is the mental picture that people have of their own bodies and bodily functions, including associated

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external and internal sensations. The patients have a personal perception of the way others see them. For example most ESRD patients having a fistula either they cover it with a bandage or wear long sleeves to avoid comments from other people. Also patients on peritoneal dialysis, having a permanent peritoneal catheter can contribute to stress. For example they cannot swim to avoid infections. The patients feel dependent on completing their future plans or disappointing to undergo a previously peaceful relationship with the family.

Renal disease may affect sexual performance in both men and women. The cause or causes may be organic (hormonal change attributable to uremia), psychosocial (changes in self-esteem from alteration in body image due to the presence of the PD catheter, leading to feelings of sexual unattractiveness), or physical (distention and discomfort due to intraperitoneal fluid, uremic symptoms that decondition the patient on PD treatment). The effects of drugs prescribed as part of the treatment regime can cause sexual dysfunction. Employment may be lost due to lack of social recognition of the person's work capacity. Disturbance in self-concept may lead to depression- sometimes associated with suicidal thoughts. Poor self-esteem may be manifested by poor self-hygiene, by excessive dependency and lack of adherence to treatment requirements.

Corbin & Strauss (1988) introduce the Trajectory Model which explains how individuals shape their illness within their everyday living situation. When chronic illness is diagnosed, the perceptions of one's self become discontinuous — who the person is now is different from whom he/she was in the past, and hoped to be in the future. McCorkle & Pasacreta (2001)

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explains eight phases of chronic illness trajectory: initial phase - occurs before any signs and symptoms are present, trajectory onset phase - when signs and symptoms are present and patient is diagnosed with a chronic disease, crisis phase - is when problems pop up that interfere with the patient life, acute phase - the patient is controlled by the treatment prescribed, stable phase - when symptoms are controlled, unstable phase - the patient's symptoms are uncontrolled, downward phase - mental and physical advanced deterioration and dying phase - the last days of patient's life.

Horne (2003) states that, individuals pursue to reason between their illness representations and the procedures to cope with their disease which includes their views of treatment requirement. These perceptions are influenced by the information individuals receive about types of treatment, past treatment experiences of one' self and others, as well as, social and cultural norms about treatment. The outcomes are usually better when patients have a sense that they are in control of what happens to them (White, 2004). Consequently, as Richard (2006) recommends making patients actively involved in their health management, they need to be motivated, informed, and educated about their rights.

Fowler C. & Baas, L. S. (2006) state that, psychiatric disorders may interfere with treatment compliance. Depression is the most common psychiatric problem in ESRD patients and is associated with both mortality and morbidity. Therefore as Leug K. C. (2003) suggests it is vital to build a therapeutic relationship between the patient and the health care team to identify and discuss significant stressful and how they adjust to these events.

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This is important because if the patient has a prior history of depression it suggests other reasons for the depression. Such as past history of low self-esteem, divorce in the last five years, loss of a job, death of a parent, financial problems, perhaps growing up in a culture of poverty or a chronic history of health problems. As Fowler C., & Baas L. (2006) suggest that the patient can be referred to a psychologist to discuss and clarify situations that makes the patient stressed. Sometimes we become so focused on providing treatments, and all that go with them that health professionals forget or do not take the time to explore significant past psychosocial data about our patients.

Hence that is why effective communication is important as it involves a reliable health care team guiding and supporting patients who want to contribute to their own care. When patients are informed they understand what could happen and prepare in advance for how to deal with possible difficulties using the appropriate coping skills. ESRD patients must be able to distinguish between symptoms they can manage themselves and those that must be reported immediately to their health care providers. Although medical intervention will be necessary at times, improved quality of life requires that individuals take more proactive roles in their own health care.

Hasler & Schofield (1990) state that every patient is unique and although patients have the same symptoms and conditions view the threat differently and hence cope differently. Sedgewick (1998) declares that either there are patients, who feel that no matter what they do, it is wrong and will not help, or others who believe they can control their life and events around them, or, those who adopt a fatalistic belief that they have no influence over events at

all. Kammerer (2007) suggests that patients will not adhere to treatment plan unless they feel it is “ personally worthwhile.” Nurses should be sensitive to the needs and feelings of their patients, and make them feel that their opinions are important. It is essential that the nurse uses the behavioural modification approach to ask the patients if they notice a difference in their appearance or in the way they feel on days when their blood pressure is high. By using this approach, nurses help patients become aware of the way their treatment works and how non-adherence can affect them personally.

Empowerment of patients occurs during the interaction between patients and staff and aims to supply patients with the skill, force, right and power to take part in the decision making of their health and decrease uncertainty (Arvidsson, et al, 2006). Therefore it is essential the nurse explains the availabilities of ESRD treatment to the patient so that he/she makes the appropriate decision according to his lifestyle. Anything that increase self-efficacy and empowers patients is likely to aid the management of the patients' condition. So the health professionals should involve the patients in healthcare decisions, inform them of all treatment options, and place an emphasis on self-care. Anderson (1990) suggests that initially patients are given small self-care tasks to boost the patients' confidence and to encourage them to achieve control over their life again. For example, how to prepare the ambulatory peritoneal dialysis machine, performing self-monitoring during dialysis, and choosing their own interventions based on signs and symptoms they have self-assessed. The patients view there access as their lifeline. Therefore it is imperative that the patient on HD takes care

of the fistula through strengthening exercise, cleanliness and checking daily for proper blood flow to make dialysis treatment more manageable and effective (The American Association Of Kidney Patients 2011). On the other hand even patients on PD treatment are taught how care their PD catheter such as to keep the exit site dry, check their drain bag if the fluid is clear and inform the healthcare professionals signs of infection are noticed.

In the setting where I work, renal unit, patients that chose CAPD or APD treatment are given time to practise the procedures until they are comfortable to perform it by themselves. Also home visit is performed so that the renal nurse assesses if the home environment is appropriate for home choice treatment. It will be easier for the patients to adapt the therapy to their own lifestyle. Clinical reviews are performed so that the nurse assesses the patient for any changes in his/her management of care. Hasler J., & Schofield T., (1990) suggest that leaflets and hand-outs should be given to patients to remind them when they are in doubt of their procedure or treatment. Patients are given the contact number of the unit in case they have any queries.

The CAPD/APD clinic give the patients a sense of safety and ease where the peaceful and helpful environment let the patient ask about anything. When it is possible the same group of nurses are present at the clinic to increase the feeling of support and reassurance. The patients feel secured as they have a point of reference, someone with whom to open up and discuss matters when needed. The nurse provides a holistic approach towards every patient, which helps to get information in relation to the disease plus the person as a whole (Arvidsson et al, 2006). Eventually the nurse refers the patient to

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other members of the health care team if needed. All this help the patients to become more critically aware of their situation and take wise decision with regards their wishes. Support groups are helpful as patients verbalize thoughts and emotions with others having the same chronic illness. Patients feel a sense of belonging which prevents isolation (Arvidsson et al, 2006).

Moreover family members are involved in supporting patients. Studies have shown that good family support is associated with successful adaptation to dialysis and compliance with dietary restrictions (Kimmel P. L., 2000; Dobrof J, Dolinko A.,& Lichtiger E., 2001). Conversely, most patients' perception is that they feel burden to close family members that they end up to discontinue dialysis. There is therefore a need for health professionals to be aware how proxy influences the care of the ESRD patient, to communicate effectively with them and to provide support for this group when appropriate (RobertWood Johnson Foundation, 2003).

It is significant that the patients have a sense of control over their treatment, educate them how the treatment affects them personally and including spirituality as part of care (White, 2004). For instance, the important part of patients' dietary restrictions is their fluid intake. It is essential that nurses explain to patients what the consequences are if not adhering to their diet. Fluids are considered anything that is liquid at room temperature, including foods such as jelly and ice cream, and patients are typically recommended to keep intake to one litre a day (Cvengros et al., 2004; Faris, 1994). Research suggests that thirty to sixty per cent of patients fail to adhere to recommended fluid restrictions (Christensen, Moran, Weibe, Ehlers, & Lawton, 2002; Christensen et al., 1996; Wolcott, Maida, Diamond, & <https://assignbuster.com/patients-with-end-stage-renal-disease/>

Nesenson, 1986). The nurse together with the patient discuss barriers to come up with solutions, for example to take ice cubes to drink less. Failure to adhere to fluid restrictions can lead to complications such as hypertension, congestive heart failure, pulmonary oedema, and increased risk of mortality (Wolcott et al., 1986).

Also many foods have phosphate, it is essential that patients take phosphate binders before they eat to avoid itching and bone problems. Even high or low potassium can be life threatening. Adherence to recommended diet and fluid restrictions increases life expectancy and can help to reduce medical complications, treatment side effects, and improve quality of life. However many admissions are a result of patient having difficulty managing their medications becoming fluid overloaded or hyperkalemic or developing access problems such as lines in those on peritoneal dialysis or fistula infections in those on hemodialysis or peritonitis. These are problems that could have been prevented were patients given more information, education and support. Therefore it is essential that patients are referred to a dietician in order to have a clear picture regarding what type of foods are appropriate for their diet (Department of Health, 2004).

To sum up, as the number of ESRD continues to increase, the impact on the physical, psychological, social, and emotional domains rises as well. As health professionals we are in a position to do something about it, to encourage these people to empower themselves and live as normal as life as possible by reducing the effects the disease has on the patient's individual life. The positive effects of the recommendations as described above are all means identified as empowering the patients of ESRD to manage their life

and improve their overall adjustment. These aspects should be worked upon and implemented in our local health care system too, as these would ultimately lead to empowered patients who live their lives around the disease and not the other way round.