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The Experience of Living with ESRD and Hemodialysis

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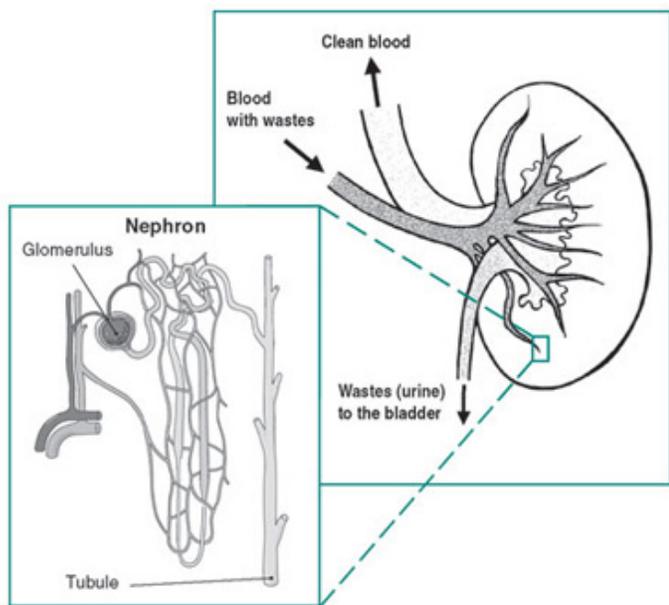
Abstract

End stage renal disease (ESRD) is a progressive, chronic, terminal illness whose incidence is growing annually. The altered life process of ESRD is explored as is the experience of living with ESRD and hemodialysis. Mishel's Uncertainty in Illness Theory is discussed and is applied to one individual's experience of living with ESRD and dialysis. An aesthetic experience is presented depicting one client's experience of uncertainty in relation to ESRD. The client's response to working with the student nurse is discussed in the realms of regulation, cognition, and perception. The student's learning in response to the interaction with the client is discussed as well. Throughout the paper, nursing research and literature is cited to provide credibility.

The Altered Life Process of End-Stage Renal Disease

Approximately 375,000 people in the United States have ESRD (Compton, Johnson, & Provenzano, 2002). The incidence of this illness increases annually by 7% (Phipps, Monahan, Sands, Marek, & Neighbors, 2003). The leading causes of ESRD are diabetes mellitus (44%), hypertension (16%), glomerulonephritis (17%), and other causes (23%) which include but are not limited to urinary tract obstructions, chronic pyelonephritis, polycystic kidney disease, cyclosporin nephrotoxicity, multiple myeloma, and sickle cell anemia, to name a few (Phipps et al., 2003). ESRD is the final stage of chronic kidney failure in which 90% of the nephrons in the kidney are not functioning. It is progressive, permanent, and, without dialysis, fatal (Banasik & Copstead, 2001).

Figure 1. Model of Kidney & Nephron



Source: National Kidney & Urologic Diseases Information Clearinghouse

A nephron is the smallest filtering unit of the kidney. It has two structures, the glomerulus and the renal tubules (see Figure 1). The glomerulus is composed of podocytes, octopus-like cells that wrap around the glomerular capillaries, forming slits that allow certain substances to pass from the plasma into Bowmans capsule and the renal tubules, forming filtrate. Glomerular filtration can be seen as essentially a mechanical filter in which water, glucose, amino acids, and nitrogenous wastes are filtered from the blood into the renal tubules. The renal tubules are responsible for reabsorbing water, ions, glucose, and amino acids. This reabsorption of water and ions is regulated hormonally in response to current blood levels in order to maintain fluid and electrolyte balance. Urea, creatinine, and uric acid are substances that are reabsorbed to a small extent or not at all. Other wastes that are not reabsorbed are secreted by the tubules into the filtrate; these substances include hydrogen and potassium ions, some creatinine, ammonium ion, and certain organic acids (Marieb, 2001).

The kidneys play an enormous and vital role in maintaining acid-base balance, hormone metabolism, and fluid and electrolyte balance (Charney & Charney, 2002). In ESRD, the nephrons essentially quit working. Glomerular filtration slows and stops altogether. If the glomerular filtration rate slows, more of the wastes that are normally disposed of are reabsorbed into the blood. This alters the concentration gradient present in the renal tubules that influences the reabsorption of certain materials. The renal tubules also atrophy, which further impedes their ability to reabsorb and secrete substances and keep blood constituents within homeostatic levels. This process of slowed glomerular filtration rate (GFR) and tubule atrophy leads to

electrolyte and fluid imbalances such as hyperkalemia, hyperphosphatemia, and hypervolemia; rising levels of blood urea nitrogen and creatinine; and metabolic acidosis (Banasik & Copstead, 2001). Creatinine is not reabsorbed at all by the renal tubules in the healthy kidney, and plasma creatinine levels remain constant as long as muscle mass remains constant. Therefore, plasma creatinine is an accurate indicator of kidney function. It is formed when creatinine phosphate in skeletal muscle combines with adenosine diphosphate (ADP) to form adenosine triphosphate (ATP). In ESRD, blood urea nitrogen (BUN) is also elevated. Urea is a waste product of protein catabolism. Elevated BUN and serum creatinine indicates a decrease in glomerular filtration rate, which does not occur until 75-80% of the nephrons in the kidney are damaged (Banasik & Copstead, 2001).

The signs and symptoms of ESRD are fairly predictable. The rising BUN level leads to uremia, the clinical syndrome in which elevated BUN levels secondary to ESRD begin to affect other systems of the body. Signs and symptoms of uremia are presented in Table 1.

Table 1. Manifestations of Uremia

MANIFESTATIONS OF UREMIA		
SYSTEM	ALTERATIONS WITH UREMIA	ETIOLOGY
Central nervous system	Uremic encephalopathy	Brain cells shrink because of osmotic gradient
Peripheral nervous system	Peripheral neuropathy Muscle weakness	Waste interferes with nerve transmission
Cardiovascular System	Decreased cardiac output Pericarditis	Increased waste has negative inotropic effect Uremic crystals deposited in pericardium
Hematologic System	Bleeding tendencies Anemia Infection	Decreased platelet aggregation; decreased coagulation factor Decreased RBC life Decreased immune cell function
Gastrointestinal System	Anorexia	Appetite suppression, vomiting
Skin	Pruritus; uremic dermatitis Uremic frost Delayed healing	Waste crystals Impaired collagen synthesis

Source: Banasik & Copstead, 2001, 679

Other signs and symptoms of ESRD include distension of the jugular veins, bounding pulses, rales, peripheral pitting edema, shortness of breath, and hypertension as a result of the kidney's inability to filter water and sodium. Renin, continually released from the kidneys in ESRD, activates the rennin-angiotensin mechanism. This inevitably leads to the release of aldosterone by the adrenal cortex, which causes an increase in sodium and water retention and only adds to the problems associated with fluid overload. In addition, the end product of the renin-angiotensin mechanism, angiotensin II, is a powerful vasoconstrictor which increases systemic blood pressure (Banasik & Copstead, 2001).

In ESRD, the kidneys decrease their production of erythropoietin, which is the hormone required by the bone marrow to produce red blood cells. This leads to anemia and feelings of lethargy and fatigue in the client (Charney & Charney, 2002). Calcitriol has also been noted to be abnormal in clients with ESRD. Calcitriol, secreted by healthy kidneys, is the active form of vitamin D and plays

a very important role in the absorption of calcium from the small intestine. Abnormalities lead to abnormal calcium and phosphorus levels and eventually to osteodystrophy (Charney & Charney, 2002), a unique condition that is characterized by abnormal bone growth and damage, including spontaneous fractures and osteoporosis. This results from continuous stimulation of the osteoclasts by parathyroid hormone and leads to decreased bone growth, demineralization and avascular necrosis (Banasik & Copstead, 2001).

The main goals in treatment of ESRD are to correct fluid imbalance, prevent hyperkalemia and other electrolyte imbalances, treat acidosis, improve nutritional status, prevent further nephron damage, avoid infection, and prevent anemia (Banasik & Copstead, 2001).

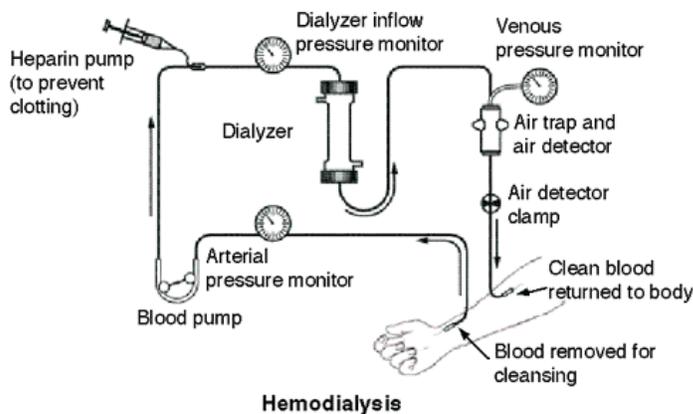
Systemic effects of fluid and electrolyte imbalances in ESRD are regulated mainly by dialysis and nutrition. Pharmacological therapy may be used to control hypertension and attempt to prevent further loss of nephron function. ACE inhibitors and calcium channel blockers have been shown effective for this function. Hypocalcemia and hyperphosphatemia can be treated with calcium and vitamin D supplements as well as phosphate binders such as aluminum hydroxide. The anemia that results from decreased production of erythropoietin can be treated with injections of Epogen, synthetic erythropoietin (Banasik & Copstead, 2001).

Nutrition therapy involves providing enough calories and protein to prevent muscle breakdown without causing fluid and electrolyte imbalances or an increased need for dialysis. ESRD is associated with an increase in energy output, a profound catabolic state, a negative nitrogen balance, and impaired metabolism of carbohydrates, lipids, and fatty acids. Typically, an ESRD client's diet is restricted in fluid, potassium, sodium, and protein. In addition, phosphorus may be restricted, whereas calcium may be supplemented. Also, folic acid and other water-soluble vitamins need to be supplemented (Banasik & Copstead, 2001).

The Process of Hemodialysis

Hemodialysis (see Figure 2) permanently replaces the function of the kidneys and sustains life in individuals with ESRD by filtering toxins out of the blood, correcting electrolyte and acid-base imbalances, and removing excess water. This process involves pulling a person's blood from his/her body, channeling it through a dialyzer where diffusion and filtration take place, and then returning the filtered blood to the client's body. The dialysate is adjusted depending on the client's electrolyte levels and fluid status so as to allow for diffusion of excesses out of the blood. Creatinine, urea, uric acid, excess electrolytes, and water are all filtered out of the blood. Protein molecules and red blood cells (RBCs) are too large to be filtered out of the blood (Phipps et al., 2003).

Figure 2: The Process of Hemodialysis



Source: National Institute of Diabetes and Digestive Kidney Diseases

Hemodialysis is a very time-consuming and restrictive treatment that must be maintained for the remainder of an individual's life. It usually must be undertaken three times a week and takes up to 3 to 5 hours each time. As a result, an individual's life is sustained but the quality of life may be altered due to restrictions caused by the treatment (time consumed by treatment, traveling to dialysis center, feeling fatigued, inflexible dialysis schedule).

A qualitative study looking at the experience of suffering from ESRD found that most participants viewed the hemodialysis machine as an actual and symbolic lifeline which allowed them to avoid death but caused them a loss of freedom (Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001). They may in the beginning of treatment view dialysis positively; however, as time passes, they begin to see the "ongoingness in their lives" that is "periodically, arbitrarily interrupted by complications reminding them of its inherent uncertainty" (Polachek, 2003, p. 48). Over time, one cannot help but begin to see the limitations of dialysis and, as a result, uncertainty about the future develops (Polachek, 2003). Clients with ESRD have to make numerous adjustments in their lives to facilitate treatment regimens at a time when they are increasingly feeling ill. They have completely lost control of their bodies and as a result may feel powerless to control their health. As they become more dependent on dialysis and other people, they may experience disturbed role identity and decreased self-esteem, and become socially isolated. They also may develop an altered body image as a result of the presence of a sub-clavian or femoral catheter, changes in skin color and texture, reduced urine output and control of excretion, dependence on dialysis and medication, and fatigue, in addition to numerous other factors. This altered body image may lead to depression, anger, and sexual and relationship dysfunction (Harries, 1996). A general lack of energy, variability in well-being, feelings of dependence and powerlessness, and uncertainty are major symptoms identified in many nursing studies related to clients' experiences of living with ESRD and hemodialysis (Polachek,

2003; Hagren et al., 2001; Barret et al., 1998; Thomas-Hawkins, 2000; Pelletier-Hibbert & Sohi, 2001; & Bultman et al., 2002).

Lack of energy, dry mouth, and itchy skin were the most frequently identified symptoms of hemodialysis patients in a study presented in *Nephrology Nursing Journal* (Bultman, Curtin, and Thomas-Hawkins, 2002). Other important findings of this study were that ESRD patients experienced a wide range of symptoms, many of which may not appear to health care providers to be acutely important from a medical perspective. These symptoms cluster around the issues of fatigue/sleep, sexuality, and mobility, and negatively affect the clients' physical and mental functioning. However, these symptoms are significant to the clients as they deal with them on a daily basis.

In another study that appeared in the *Journal of Advanced Nursing* (Polaschek, 2003), several distressful symptoms of ESRD and dialysis were identified by participants: a general lack of energy, insomnia, pruritis, and nocturnal restless legs. The majority of the participants also identified variability in well-being in relation to their dialysis treatment as a distressing experience. In examining symptom distress and day-to-day changes in functional status in chronic hemodialysis patients, Thomas-Hawkins (2000) found that relatively small changes in functional status occurred throughout the week in relation to hemodialysis treatment. These small, incremental changes may appear minor to others but are very significant to someone with a chronic illness. The study also found that most of the dialysis patients were able to perform the essential activities of daily living necessary to maintain life (i.e., eating, bathing, eliminating, etc.); however, their performance of household and social activities was very low.

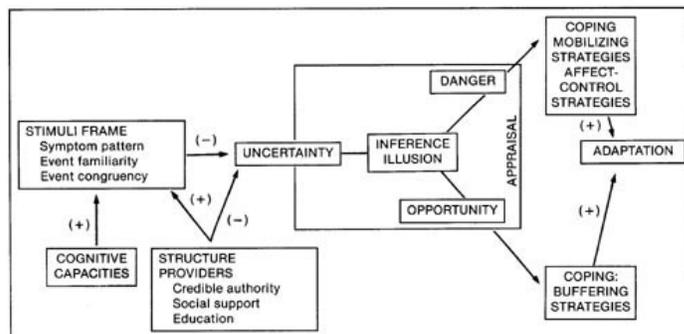
Mishel's Uncertainty in Illness Theory

Mishel's Theory of Uncertainty in Illness explains how individuals cognitively process illness-related events and information and as a result develop meaning. Uncertainty is defined as "the inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225). This develops when an individual is unable to develop a subjective interpretation of illness-related stimuli known as a cognitive schema. In referring to illness, there are four types of uncertainty: "(a) ambiguity concerning the state of the illness, (b) complexity regarding treatment and systems of care, (c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability of the course of the disease and prognosis" (Mishel, 1988, p. 225).

In this theory, the stimuli frame, cognitive capacities, and structure providers are all antecedents of uncertainty. The three components of the stimuli frame (symptom pattern, event familiarity, and event congruency) are inversely related to uncertainty and provide the stimuli the patient

utilizes to structure a cognitive schema. If this task is accomplished successfully, less uncertainty results. The three components of the stimuli frame are in turn influenced by the individual's cognitive capacities and structure providers. Cognitive capacity, the patient's ability to process information, therefore indirectly affects uncertainty. Anything that diminishes a client's ability to process information would lead to increased uncertainty. Structure providers are the resources available to assist the client in processing information from the stimuli frame: credible authority, social support, and education. The presence of these variables decreases uncertainty both directly and indirectly.

Figure 3: Model of Uncertainty in Illness



Source: Mishel, 1988, p. 226

Uncertainty in and of itself is not positive or negative until it is appraised by the individual. Using the processes of inference and illusion, the patient appraises the uncertainty. Inference, an evaluation of uncertainty utilizing other recalled examples, is based upon one's personality, experience, knowledge, and contextual cues. Illusion, the construction of beliefs formed from the uncertainty, is generally positive. This appraisal of uncertainty is viewed either as a danger or an opportunity. When the appraisal is danger, coping strategies are used to reduce the uncertainty and the emotions resulting from this dangerous appraisal. The coping strategies used are mobilizing, affect management, and information seeking. When the appraisal is one of opportunity, the coping strategies used are aimed at blocking the communication of new stimuli that would decrease the uncertainty or alter the positive view of uncertainty, referred to as buffering. If these coping strategies are effective, adaptation will occur. Adaptation is referred to as an individual's normal biopsychosocial behavior. It is determined on an individual basis and can be "operationalized" as "psychosocial adjustment, recovery, stress, life quality, or health" (Mishel, 1988, p. 231).

Mishel's original Uncertainty in Illness theory is particularly useful in describing patients' responses to acute illness. In the Reconceptualization of the Uncertainty in Illness Theory (Mishel, 1990), the application to chronic, terminal illness is explored. The theory proposes that in

this situation, the patient develops a new life view in which uncertainty is accepted as a natural part of life and therefore an opportunity. The individual then functions to maintain this new view through interactions with support resources and health care providers.

Application to Client

Client Summary

Edward (fictitious name), an 88-year-old man whom I worked with on a medical floor in an acute health care setting, has End Stage Renal Failure. He has been receiving hemodialysis for the past seven months as an outpatient; he goes to dialysis three times a week and each treatment lasts approximately three hours. When I met him, he was being treated as an inpatient for pneumonia. He had been on his way to dialysis four days earlier when he passed out and was taken to the emergency department, where it was discovered he had pneumonia and was hypoxic. He is married and lives at home with his wife; they have no children. Edward had a bleeding ulcer one year ago and also has a pacemaker, though he could not articulate the date it was placed.

Regulation

The day Edward was admitted to the emergency department, he was scheduled to receive dialysis; however, he did not make this appointment and therefore did not receive dialysis that day. As a result, his labs drawn the day he was admitted give an accurate illustration of his decreasing kidney function. His creatinine was 5.4 mg/dl, with the normal range being 0.8-1.5 mg/dl. His BUN was 45 mg/dl, with the normal range being 9-21 mg/dl. His albumin was 2.6, with the normal range being 3.5-5.0 g/dl. His total protein was 5.3 g/dl; the normal range is 6.4-8.3 g/dl. His MCV was 78.4mm³, with the normal range being 80-95 mm³. His MCH was 27.3 pg, with the normal range being 27-31 pg.

The MCV, the mean corpuscular volume of the blood, indicates the average size (volume) of a single red blood cell (RBC). The MCH, the mean corpuscular hemoglobin, indicates the average amount of hemoglobin within an RBC. These two measures are used together to classify anemias. In renal failure, anemia can result from lack of production of erythropoietin by the kidneys. This would be evident by a decrease in MCV (size of RBC) and a normal MCH (hemoglobin content). Edward's MCV was decreased and his MCH was within normal limits, indicating he was anemic as a result of his renal failure. The severe inability of his kidneys to adequately filter the blood and maintain homeostasis is evident by the increased creatinine and BUN values. In addition, his decreased albumin and total protein indicate poor nutritional status. Serum albumin levels lower than 4.0 g/dl have been associated with poor outcomes in dialysis patients. In looking at this

specific client, there are other signs that point toward inadequate nutritional status. His muscles were atrophied and he was very weak. He had dyspnea as a result of his pneumonia (mild when inactive and severe with mild activity) and had difficulty swallowing. This made eating a very difficult and slow process. His diet usually consisted of soft foods such as mashed potatoes, jello, and soup.

He needed complete assistance dressing, bathing, and repositioning in bed. He had moderate peripheral edema of both lower extremities, brownish-toned skin, and pruritis. In addition, he was not urinating and needed to be straight catheterized every 12 hours. His voice was soft, quiet, slightly jumbled and hard to understand. He had difficulty hearing and I needed to speak very loudly. He had stated that he was not in any pain but was very tired.

It is also important to briefly examine what is going on related to regulation and his pneumonia, as these two illnesses are not occurring independent of one another. When Edward arrived at the ER, he was hypoxic with an oxygen saturation of 88%. Four days later when I cared for him, his oxygen saturation was 93% on 4 L oxygen through a nasal cannula. He was dyspneic and coughing up moderate amounts of yellow-green mucous. He was on Rocephin and Zithromax, both antibiotics used to treat respiratory infections. He also was using Albuterol, an inhaled medication utilized for its bronchodilating effects. His white blood cell (WBC) count the day he was admitted was very high, and the day I cared for him (four days later) was just within normal limits for the first time since admission.

Cognition

The day I cared for him he was easily confused when discussing any new or current information. For example, I had placed him on the bedpan, given him the call light, and instructed him on how to use it. When I returned five minutes later to check on him, he was attempting to use the telephone to call me (he thought it was the call light) to come take him off the bedpan. Later on in the day he was attempting to use the call light to call his wife. I again explained the use of the call light to him and gave him the telephone to use instead. He could not get the phone to work, so I attempted to show him how to use it. He told me I did not need to explain it to him because he knew how to use a phone.

I also explained to him the importance of coughing and deep breathing. He told me he would start doing this and when I asked him an hour later if he had been trying to do this, he said he had. When discussing the past, both recent (one to six months) and distant (a year or more), he was very clear in his information. He was able to clearly articulate his understanding of his disease and dialysis. He explained to me that the dialysis machine replaced the function of his kidneys and cleaned his blood for him because his kidneys could no longer do this. He also dis-

cussed with me how he grew up on a farm. When I asked him to tell me why he was in the hospital, he said because he had fallen and they found out he had an infection. He did not know how his treatment was going or how long he was going to be in the hospital.

Perception

Perception refers to the way in which an individual perceives his/her illness. Describing how he feels on a day-to-day basis, Edward stated that it changes. Upon further questioning, I was able to get an answer that some days he feels good and others he does not. By “feeling good” he is referring to his fatigue level and the amount of activity he can tolerate. He also explained to me that this is fairly unpredictable and he is not sure in the morning how the day will go. In addition, he stated that since being in the hospital, he has felt much more tired and attributes this to a greater decline in his kidneys. He understands the ultimate end of all this for him will be death. However, he does not know when, how, or how long from now that will be. He told me that for him it could occur anytime, that he was ready; however, he does not want to leave his wife alone. He sees his dialysis as his way to continue living and to avoid death. His view of dialysis is positive in this regard. However, he also stated that because of the dialysis, he does not know how much longer he will actually live; it is prolonging his life, but for how long? In this way, he views dialysis as negative. He also stated that he believes God will ultimately decide when it is his time to go and will take care of him and his wife.

Incorporation of Nursing Theory into Regulation, Perception, and Cognition

Edward’s continually fluctuating regulation processes (ESRD, pneumonia) and the contexts (home vs. hospital) he is in, produce the stimuli that need to be organized into a cognitive schema. His decreasing cognitive status indirectly influences the development of uncertainty by affecting how he interprets (perceives) these illness-related stimuli. His cognitive status is also affected by his regulation processes (i.e., nutrition status, anemia).

Mishel’s theory of uncertainty in illness is effective in describing the processes of regulation, cognition, and perception and how they are all related in this client. Edward’s kidneys have essentially lost their regulatory function. As a result, he must rely on dialysis to function as his kidneys. The effects of relying on dialysis are that he feels very fatigued and this fatigue fluctuates daily in an unpredictable manner. His fatigue is familiar yet unpredictable; therefore, his symptom pattern is inconsistent, which generates uncertainty. Generally, event familiarity is present in his weekly trips to dialysis; however, he was in the hospital for pneumonia, which was not familiar to him and caused an increase in uncertainty. In addition, he was feel-

ing more fatigued than usual in the hospital, which was probably due to his body fighting off the respiratory infection; however, he attributed this to a decrease in kidney function. He had expected to feel progressively better in the hospital as his infection improved; however, he stated he did not notice a change in how tired he felt as the days went on. Therefore, he did not experience event congruence and this also increased his uncertainty.

His cognition was somewhat impaired. He had a hard time retaining and understanding any teaching I attempted with him. He did know a great deal about his kidney failure but was slightly confused as to the progression of his pneumonia or why he was in the hospital. His decreased cognitive capacity negatively influenced his ability to perceive a symptom pattern, event familiarity, and even congruence, which resulted in increased uncertainty. His uncertainty was also increased by a lack of structure providers. He had a great deal of education regarding his ESRD and its trajectory. However, he was having a difficult time categorizing his symptoms, such as his increased fatigue as related to the pneumonia and not a severe decrease in kidney function. He also was having difficulty learning new material, which made it difficult to attempt to teach him any new information to decrease his uncertainty. He does have social support from his wife; however, at this point in his life he is lacking a strong social network to provide him with information, feedback, and support. This also leads to uncertainty. He does have trust and confidence in the healthcare team and looks to them for information and support. This somewhat decreases his uncertainty.

Living with ESRD is characterized by periods of stability, instability, and returned stability. Uncertainty can result from the inability to predict if and when the client’s health will take a turn for the worse, when it will be stable, how long dialysis will manage symptoms, how long it will sustain life, and how the client will feel after dialysis or on any given day (Pelletier-Hibbert & Sohi, 2001). The Theory of Uncertainty in Illness explains how all this can lead to the uncertainty. In a chronic illness such as ESRD, uncertainty is the norm. Edward seems to have accepted that uncertainty is now the norm and has seemed to incorporate it into his worldview. He acknowledges that he does not know how long he can live on dialysis and he never knows how each day is going to go or how he’s going to feel. However, he does not appear distressed by this. If he was, he did not verbalize this or show any sign of it to me. Therefore, he views this uncertainty as an opportunity. It allows him to just accept that he will have good and bad days and will be fatigued more one day than the next. He did seem to be distressed by the fact that he was ill and in the hospital in that he attributed this to an exacerbation of his kidney problems. His perception was that his kidneys were getting worse, which to him meant he might not live

much longer even on dialysis, which goes against his fluctuating worldview. It brought to his attention that there would be an end to his disease, that being death, and that it is possibly nearer than he had imagined. That distressed him in that he would be abandoning his wife. So, in this way, he shifted his view of the illness-related stimuli to being a danger since being in the hospital. He relied on his faith in God to take care of him and his wife. Since this is an effective coping method, it would appear that adaptation had occurred. Drawing support from faith in God was identified as a coping strategy used by family members to deal with the uncertainty of living with a spouse or family member with ESRD (Pelletier-Hibbert & Sohi, 2001).

Aesthetic Experience

This quote from a family member of an individual with ESRD describes the experience of living with uncertainty; “Being like a loose buoy I am floating, bouncing back and forth just like a ship without a sail, I guess. I never know if I’m coming or going with this illness” (Pelletier-Hibbert & Sohi, 2001, p. 414). This painting below and metaphor describe my client.

Figure 4. Experience of Uncertainty in ESRD



Source: Samuelson, n.d.

The buoy represents Edward. The water represents his illness. One day the water may be calm. This would represent a good day when he does not feel as fatigued. The next day it may be rough and choppy. This would be a bad day when he is too tired to do much of anything. Just like the sea, this illness is very unpredictable. Edward never knows for sure how he will feel the next day just as the sailor cannot predict with certainty what the seas will bring tomorrow. He also feels he has no control over the course of this illness. It decides how he is going to feel and he is helpless to change this, just as the buoy can only float and allow the water to bounce it as it wishes. It is helpless to do anything but just ride out the weather. In addition, Edward feels his life course is controlled by a greater power, that being God. Anyone who has ever been flopped around out on a boat during a storm would likely agree there was a greater power at work in that situation as well. The boat can try to power through, but usually to no avail. All that can be done is to ride out the storm with faith that the controlling force will see one safely through to live another day. That is the same with Edward. He knows he cannot control the outcome of his illness. So, he has decided to just ride out the waves and put his faith in God to steer his course.

Our Interactions and Their Influence on Regulation, Cognition, and Perception

Regulation

Edward had numerous processes going on in relation to regulation. During the time I spent with him, I continually assessed Edward for any deteriorations in regulatory functioning. His pneumonia made gas exchange difficult. Therefore, I monitored his respiratory and cardiovascular function to watch for signs that he was becoming hypoxic. I assessed his pulse, heart sounds, blood pressure, capillary refill, respiratory rate, rhythm, and depth as well as lung sounds, pulse oximetry, and skin color and temperature. All of these activities fall under the NIC intervention of Respiratory Monitoring (Bulechek & McCloskey, 2000). He also had numerous regulation processes going on in relation to his renal failure. Therefore, I assessed his input and output, edema, and skin. These activities would be classified under the NIC interventions of Fluid/Electrolyte Management and Skin Surveillance (Bulechek & McCloskey, 2000). I utilized the Nursing Interventions Classification (NIC) intervention of Positioning (Bulechek & McCloskey, 2000) to elevate Edward’s legs to promote venous return and his head so as to allow for ventilation of the lung bases.

I also taught him coughing and deep breathing to help expel mucous and promote gas exchange in his lungs. I am unsure how long he actually retained this information, though he did for the duration of the time I was with him

(4 hours). I also helped him eat his breakfast by feeding him. Since he has difficulty swallowing and breathing, eating is very difficult for him. However, his nutritional status is very important to help him fight off this infection (pneumonia) and to have the energy to be able to do the things he is used to doing. Therefore, helping him to eat promoted nutritional intake, which hopefully would positively impact his regulation processes by increasing the energy available to fight off the pneumonia and perform Activities of Daily Living (ADLs). I also performed a straight catheterization because he does not urinate on his own. By utilizing these nursing interventions, I promoted optimal regulatory functioning in this client.

Cognition

I provided Edward with health information by teaching coughing and deep breathing and explaining why I was doing the assessments that I performed. I also encouraged his autonomy by empowering him to take some control over this situation to improve his health by coughing and deep breathing. In addition, I provided health information regarding pneumonia and why it was important to change positions and cough and deep breathe. Encouraging autonomy in any way is positive in clients with ESRD on hemodialysis therapy, who have to cope with being dependent on dialysis to sustain life. Dependence is supported by in-center hemodialysis (Boyette, 1998). Several qualitative studies have shown that patients with ESRD who are able to self-manage aspects of their care and treatment show increased well-being and functioning (Bultman et al., 2002). It appeared that he did benefit from this teaching and appreciated the time I spent with him explaining coughing and deep breathing and providing information regarding pneumonia.

Perception

Working with Edward that one morning greatly improved his perception of his situation, at least for the time I was actually with him. He had been very tired recently and had no energy or desire to eat or bathe when I first met him. I told him we could plan out his day so that he could do an activity, such as eat breakfast, and then rest awhile before doing something else such as bathe. He said that worked for him. By making an individualized schedule of alternating activity and rest, I was helping to maintain or enhance his activity performance during a time when he felt it had decreased. The meaning of this decrease in activity performance to someone with a chronic illness can be very significant (Thomas-Hawkins, 2000), as it was to him. Scheduling his activities for the day enabled him to do more than he had previously been able to (during the last four days). This increased his feelings of well-being.

I also questioned him about his disease and feelings

regarding the disease, about his family, and about his past. He seemed to really enjoy talking to me about all of this. He made the statement that he really enjoyed spending the morning with me. He said he really liked that I had the time to sit down and just talk to him. A study of male hemodialysis patients found (Cormier-Daigle & Stewart, 1997) that the most preferred form of coping with ESRD was seeking support, preferably from peers or professionals. Also, perceived support was associated with positive psychological adjustment and life satisfaction. This feeling was mostly influenced by the amount of support the clients felt they could call upon, rather than the support they actually received. It was evident to me that by the end of my shift Edward had begun to perceive me as a supportive person he could talk to. He also told me he felt the doctors and nurses he worked with were great, and he had confidence in their abilities. By being an active listener, I was being supportive, and hopefully my interactions with him further strengthened his confidence in the health care system and the amount of support he could call on in this system.

During his dialysis treatment, I stayed with him the majority of the time. I used the NIC intervention of reminiscence therapy (Bulechek & McCloskey, 2000) during this time. He seemed to really respond to this. When I asked him about his family, he provided many details about his life growing up on a farm. He appeared to be at ease and happy when relating all this to me.

My Learning from this Experience

I have had very limited experience interacting with individuals who have chronic, terminal illnesses. Every time I do talk with individuals with such an illness, I am always amazed at their strength and resiliency, and Edward was no different. He had such an incredible view. He was ready to go and end his suffering but did not want to leave his wife all alone. I walked away from this interaction feeling that I had taken just as much or more away from the conversation as the client. First of all, I felt honored that he let me into his world and feelings for a period of time. Second, I have a renewed realization that I really do not have anything to be worried or stressed out about. Here is this man who is dying and he is not worried about it. I should not be worrying about getting my paper done or doing the laundry. In the grand scheme of things, my incidental worries are of minimal importance and not worth getting upset about. I also came away with a renewed view of life's fragility. I realized that I really don't know what tomorrow will bring, just as Edward does not know either. However, that is something I take for granted and he does not.

In addition, I learned how wonderful reminiscence therapy can be if someone is receptive to it. It is so easy to use and really can help reduce anxiety. I also witnessed how it is possible to build a trusting relationship with a client in a

few hours through the use of open, warm, honest, and genuine communication.

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