

Lived Experiences of Individuals with Chronic Renal Failure Undergoing Hemodialysis in Selected Hospitals

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Abstract- Different themes emerged from the lived experiences of the 36 co – researchers, here referred to individually with their fictitious names. The following are the themes and their respective meaning: A) Desensitizing information - Initial reactions of the condition: counting the days left, full of disbelief, unbearable, unacceptable, Why me!, What have I done?, and difficult to explain; (B) Holistic disease experience – individual symptomatic experience: Fluid restrictions, Easy fatigability, Vomiting, fever and abdominal pain, Edema /heaviness, Gasping for breath, Increased / decreased blood pressure, fragile, easily fatigued and weak, lost my appetite, think more often, afraid to die and difficulty urinating, weak and body pains; (C) racing against the waves - coping with the illness and support systems: hemodialysis treatments, medications, self – discipline, compliance to restrictions, available financial support, familial bonds, prayers and strong faith and internet learning; (D) Self in relation to family and society - perception of relationship to others: closer family ties, religious freedom, psychological resilience, friendship rekindled, reunion with friends, words of encouragement, informal support group and lost companionship; (E) Rocky roads to wellness - aggravating circumstance/s: financial incapacitation, acquired debts, presence of other medical conditions, worsening symptoms, distant dialysis centers and skipping of dialysis treatments and (F) Quality of life – sense of productivity: typical routine was severely changed, a lot of dramatic changes, restrictions are abound and ability to go to the market and cook foods and do most of the household chores. Based on the preceding findings, the following recommendations were made:

1. Continued research focused on the lives of chronically ill patients, as well as exploration of the caregivers' perspective, to determine how they continue with their lives is needed.
2. Moreover, the establishment of evidenced – based practice for the promotion of the enhancement of the quality of life of other chronically ill individuals should also be taken into account.
3. A follow - up study can be conducted to further view the co-researchers' lives after this study.
4. Finally, the proposed Health Teaching Guide be adopted by nurse managers for them to discover its usefulness and effectiveness as a health teaching guide to individuals with chronic renal failure undergoing hemodialysis to reinforce any knowledge that these individuals have on their conditions.

Index Terms- Hemodialysis, Health Teaching Guide, Hemodialysis Patient, Lived Experiences

I. INTRODUCTION

The world today is overwhelmed with advances in technology with the prime goal of promoting the general well – being of people. A wide array of devices and machines were ultimately developed to serve one common goal, to help people recover from seemingly hopeless scenarios exemplified in many terminal illnesses. In the field of medicine, numerous countless advances have been proven to be effective in prolonging life of terminally ill people. Dialysis in its various forms has been taken as one of the most common measures to help people cope with kidney disease, primarily the end – stage renal disease (ESRD).

According to the Department of Health, kidney diseases, especially end stage renal disease (ESRD), are already the 7th leading cause of death among the Filipinos. One Filipino develops chronic renal failure every hour or about 120 Filipinos per million population per year. More than 5,000 Filipino patients are presently undergoing dialysis and approximately 1.1 million people worldwide are on renal replacement therapy. Reliable estimates reveal that the number of these patients will double in 2010. In the past, chronic glomerulonephritis was the most common cause of chronic renal failure. Today, diabetes mellitus and hypertension have taken center stage in the causation of ESRD which together account for almost 60% of dialysis patients. The cost of medical treatment for kidney disease is really exorbitant, beyond the reach of ordinary patients. Renal transplantation is limited due to the expense and the shortage of donors. The best that can be done at present is to focus efforts on the prevention of progression of renal diseases. Strict blood pressure and glycemic control and adoption of “healthy lifestyle” play a major role in reducing if not totally controlling the epidemic of renal failure and this could be achieved through proper education. (<http://www.nkti.gov.ph>)

Since the 1960s, when hemodialysis first became a practical treatment for kidney failure, much have been learned about how to make hemodialysis treatments more effective and minimize side effects. In recent years, more compact and simpler dialysis machines have made home dialysis increasingly attractive. But even with better procedures and equipment, hemodialysis is still a complicated and inconvenient therapy that requires a coordinated effort from the whole health care team, including the nephrologist, dialysis nurse, dialysis technician, dietitian, and social worker. The most important members of the health care team are nurses and the patient's family. By learning about the

treatment, a patient can work with the health care team to give the best possible results, and can lead a full, active life (NIH, 2006).

Unfortunately, treating kidney failure is a burden borne not only by the patient, but by the entire family. A family member or caregiver is needed to care for the patient, attend to medications and meals, and assist in providing treatment, whether by performing dialysis itself with peritoneal disease (PD) or accompanying the patient to hemodialysis (HD) facility. Commonly, a family member has to stop working to care for the dialysis patient. The patient is too weak to provide self-care and loses independence. Patients who cannot afford treatment rely on other family members to look for the needed funds. Children stop schooling, savings are used up, objects of value are sold, and all the earnings of those who work are used to pay for dialysis. This results to families that are impoverished because of a single patient with kidney failure who needs treatment. The cost of treatment therefore is not limited to the cost of dialysis. Rather, the cost is multiplied a hundredfold, and becomes the burden of an entire family (Dañguilan, 2008).

Different aspects in the life of a hemodialysis patient are also affected. Psychologically, hemodialysis patients may have a tough time accepting their condition. This involves their emotions that may greatly affect on how they will cope to the stressful events in their life brought by the situation caused their disease. Hemodialysis patients' psychological status can be a great factor for them to overcome the stress that they are going through. Social aspect involves the interaction of hemodialysis patients to people that surrounds them. Support is very important for people going through stressful circumstances. This support can give courage to hemodialysis patients for them to never lose hope in life and be able to surpass their present situation. Spiritual aspect involves the beliefs of patients to supreme beings. This belief gives them upliftment to their inner being. Physiologically, a hemodialysis patient undergoes a series of changes. These changes affect their physical state and may have a long – term effect in their life (Paraiso, Manigsaca, Romero and Turla, 2009).

Chronic renal failure / end – stage renal disease (ESRD) was dubbed as a “worldwide public health crisis” noting that the rate of new cases (Mason, 2005). The thought of having a chronic disease such renal failure can trigger an enormous grief response in an individual. As defined, grief is a dynamic process that changes in nature. It does not represent a rigid linear progression in emotions and thoughts as behavior but a continual move across different phases or stages. Being diagnosed with chronic renal failure does not only place a person to worry on financial demands but more than not, that person experiences psychological distress (Caronan, 2001).

Chronic renal failure can be treated by renal replacement therapies, such as hemodialysis, transplantation, and peritoneal dialysis (ERA-EDTA Registry, 2006). Transplantation has become the answer to many patients with kidney failure. Kidney

transplantation affords patients with kidney failure good health sufficient to resume their normal lives. With this second chance at life, a better lifestyle commonly emerges. Patients become smarter eaters, refrain from smoking and alcohol, and take better care of themselves. Dialysis remains an excellent option, but for those who have been transplanted, life just got better (Dañguilan, 2008).

Renal Replacement Therapy is the major form of treatment for patients with ESRD. It is either artificial and intermittent (hemodialysis and peritoneal dialysis) or biologic and continuous (kidney transplantation), both of which aim to replace some of the functions of the diseased kidneys such as removing excess wastes and fluids, and keeping the balance of electrolytes appropriate. While not a cure, it is a life-sustaining process to keep you live as best as you can (<http://www.stluke.com.ph>).

II. IDENTIFY, RESEARCH AND COLLECT IDEA

Initial contact was initiated to meet with key hospital administrators, nurse managers and respondents, taking into account some of the problems associated with data collection like the possibility of reluctance of patients to take part in the interview process and of the hospital administrators to allow their patients to take part in the study. Of the three (3) foreseen hospitals, one declined to allow their patients to participate in the research study. To counteract these negative aspects, ethical and legal considerations were given utmost importance.

Using a Road Map as a guide as it embodies a collective representation of lived experiences, data collection was performed using semistructured interviews and story – telling in the dialysis units of selected hospitals in La Union. Interviews with patients receiving hemodialysis treatments in a free standing dialysis center was recorded with permission from the informants, transcribed verbatim, and analyzed using phenomenological methods. The overall theme of (1) personal meaning of chronic renal failure while undergoing dialysis treatment, (2) managing and monitoring health, (3) lifestyle consequences, (4) family impact, and (5) informal support structures were derived into account during the interview process.

Participants were asked about their experiences of chronic renal failure by using the following five questions: (1) I have no experience of chronic renal failure; how would you explain to somebody like me what it's like to live with chronic renal failure? (2) What helps you to live with chronic renal failure? (3) What changes chronic renal failure had brought in to your life? (4) What makes it harder to live with chronic renal failure? (5) What support systems / solutions have you found to deal with these problems, and is there anything else you can think of that would make life better for people with chronic renal failure?

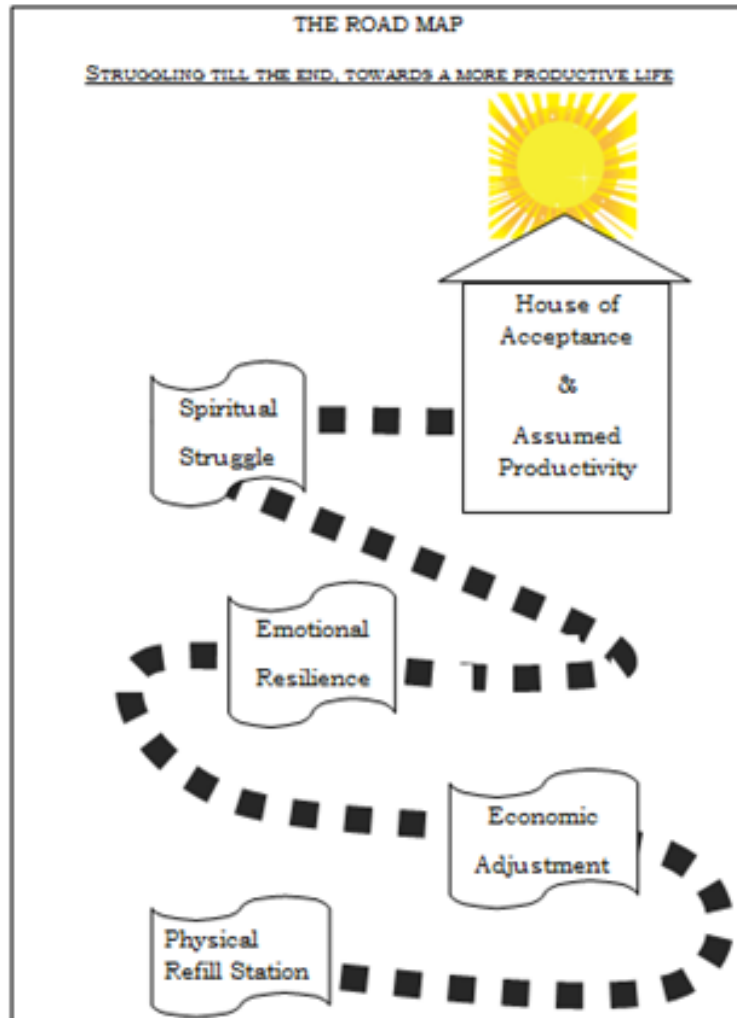


Figure 1 Road Map

III. WRITE DOWN YOUR STUDIES AND FINDINGS

Results and Discussion

Primary Reflections: Primary Experiences and Thematic Reflection

First level of discussion/interpretation

The researcher's interest in this study has been nurtured by acquaintance to friends and colleagues working in the dialysis units of several hospitals in La Union and Pangasinan as well as his exposure as a nurse caring for patients suffering from kidney problems. Notably, the researcher's grandfather (from the mother side) died from kidney disease. What are the circumstances that could lead to kidney failure? What do patients with chronic renal failure undergoing hemodialysis think and feel regarding their illness and the economic preparations and consequences of such treatments? How do they and their families adjust to their conditions and to the economic outcome of hemodialysis

treatment? How it affects their way of living? These were the concerns this study looked into.

In the analysis of the lived experiences of individuals with chronic renal failure undergoing hemodialysis, the researcher used the modified van Kaam method as described by Donna Hathorn (2009) for data analysis. The researcher found this eight step approach effective in organizing, analyzing, and synthesizing the data. Specific themes were drawn from the data collected.

Step One: Listing and Preliminary Grouping

The researcher listed and conducted a preliminary grouping of the data by transcribing each audio file verbatim. The researcher did not skip over any statement or word from the transcription, and considered each phrase equally relevant. This is known as horizontalization, viewing each statement as having equal value.

Step Two: Reduction and Elimination

The researcher did data reduction by constantly reading every transcript and eliminating statements that did not answer the guiding question. Overlapping, cyclic, and vague expressions

were also eliminated. The remaining statements became the invariant constituents (the meaning units or horizons) of the experience, and described the phenomenon in exact descriptive terms. As participants were added, the invariant constituents increased. The researcher have provided an example of how the data was reduced to the composite invariant constituents that answered the guiding question: “How would you explain to somebody like me what it’s like to live with chronic renal failure?”

Step Three: Clustering and Thematizing the Invariant Constituents

The researcher clustered the invariant constituents and defined the “core themes of the experience”.

Table 1: Themes and Definitions of the Lived Experience of Patients with Chronic Renal Failure Undergoing Hemodialysis

themes	definition
Desensitizing information	Initial reaction of the condition
Holistic disease experience	individual symptomatic experience
racing against the waves	Coping with the illness Support systems
Self in relation to family and society	Perception of relationship to others
Rocky roads to wellness	Aggravating circumstance/s
Quality of life	Sense of productivity

Step Four: Final Identification of the Invariant Constituents and Themes by Application: Validation

The researcher checked the invariant constituents and the themes against each individual transcript to make sure the theme was expressed either overtly or was well-matched with the constituents. This process helped determine the congruency of the experience.

Step Five: Construction of Individual Textural Description

For each participant the researcher described what the patient experienced using excerpts from the transcript. This was done essentially by explaining the themes in a narrative format. This process helped the researcher to understand “what” the patient experienced.

Step Six: Construction of Individual Structural Description

For each participant the researcher incorporated into the textural description a structure explaining how the experience occurred. As the researcher wrote the textural description, the

researcher reflected on the conditions that precipitated what the client experienced. This process helped the researcher to understand “how” the experience occurred. The researcher used “acts of thinking, judging, imagining, and recollecting, in order arriving at core structural meanings”.

By using imaginative variation, imagining the experience occurring in a variety of structures, the researcher perceived the experience occurring in different circumstances and identified the conditions that accompanied the experience. This helped the researcher understand how the clients’ experience came to be what they were and the conditions that were met to develop actions.

Step Seven: Construction of a Textural – Structural Description

For each participant the researcher merged the two narratives (textural and structural) that were created from steps five and six. The finished narrative description included the researcher’s understanding of “what” (texture) occurred, and “how” (structure) the experience occurred for each participant. After an exhaustive imaginative and reflective study, the researcher explained the experience according to how the researcher understood it, from his vantage point, and described the essence of the experience.

Step Eight: Composite Description Textural-Structural

The researcher used synthesis to create a composite textural and structural description. This process helped him to determine the essence of the overall experience. For example, the co-researchers’ feelings and attitudes toward their condition varied and changed according to the circumstances or structure of the situation within their family or society. The co-researchers’ various attitudes toward their condition when they perceived that quality patient care was threatened or when hemodialysis session is impossible.

Thematic Presentation

Data analysis revealed the co-researchers’ varied lived experiences. The researcher gained an understanding of what outlook the clients experienced and how various emotions and experiences arise. On the process, six (6) themes emerged with holistic disease experience on the central focus. These themes are as follows and are described thereafter: a) *desensitizing truth*, b) *holistic disease experience*, c) *racing against the waves*, d) *rocky roads to wellness*, e) *esprit de corp: self in relation to family and* f) *society and quality of life*.

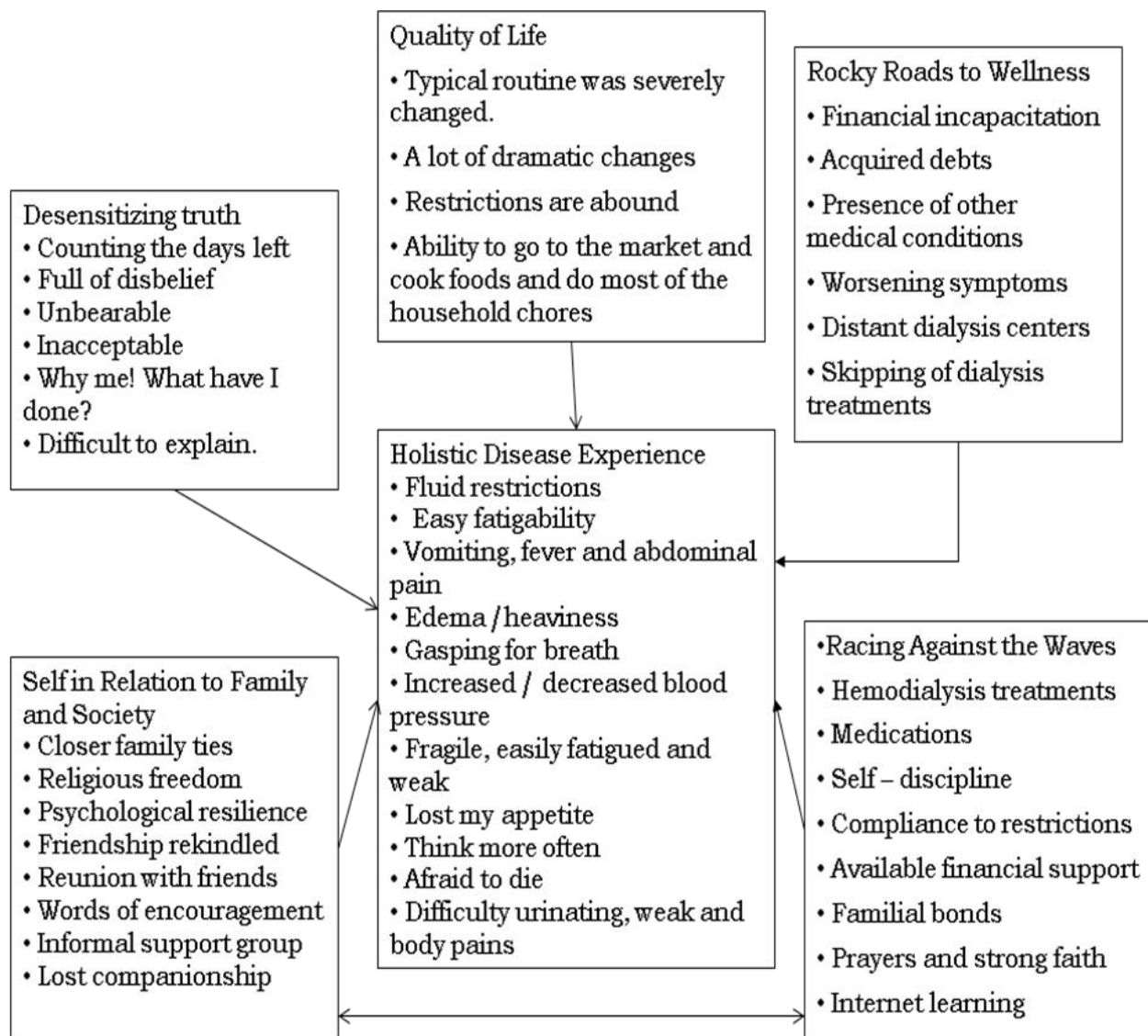


Figure 2: Thematic Representation of Lived Experiences of Individuals with Chronic Renal Failure Undergoing Hemodialysis

Desensitizing Truth

The participants expressed in unison an extreme initial disbelief that their kidneys started to fail and that they have to undergo a series of hemodialysis treatment in order to sustain and prolong life. For example, Mandy stated, “It’s abrupt! I just can’t believe it happened. It’s present now and there’s nothing that can be done.” The clients’ reaction was influenced by the belief that once on hemodialysis treatment, a lot of restrictions have to be imposed and that death is imminent.

Holistic Disease Experience

Indications of kidney failure can vary from person to person. Someone in early stage kidney disease may not feel sick or notice symptoms as they occur. When kidneys fail to filter properly, waste accumulates in the blood and the body. If the disease progresses, symptoms become noticeable (if the failure is of sufficient degree to cause symptoms). Kidney failure is often accompanied by noticeable symptoms. The respondents

verbalized invariant experiences with chronic renal failure or end – stage renal disease (ESRD).

Racing Against the Waves

Man has an inert nature to make adjustments whenever he is surrounded by stressors, much more so if chronic illness struck him. In the fight against chronic renal failure, patients often face a seemingly insurmountable problem that can range from psycho – physical to economic difficulties. Technologically wise, more often than not, patients will always find ways to remain standing battling the disease. Hemodialysis treatments provided in some hospitals in La Union offer an unwavering hope that life can be sustained or prolonged.

Rocky Roads to Wellness

The reality that the respondents have to follow a strict regimen of a combined medical, dietary and hemodialysis treatments frequently complicate their situation. Continuous dialysis treatment sessions mean more financial demands that

must be met in order to obtain such regimen and this commonly makes matters worse as more families continue to acquire debts. Consequently, many of the respondents acquire their condition from a pre-existing medical condition and that respondents feel recurrence of disturbing symptoms.

Esprit de Corp: Self in Relation to Family and Society

The disease experience, no matter how much drastic changes it caused to the respondents, had brought in several good aspects in their lives. Some of the respondents even become closer to their friends, who offer unsolicited support.

Quality of Life

Admissibly, chronic kidney failure has brought drastic changes in the lives of the respondents. Majority of the respondents are at their productive years.

IV. CONCLUSION

Secondary Reflections: Eidetic Reduction

Exploring the previously discussed themes by relating the researcher's own personal insights with the experiences of his co-researchers, the secondary reflection or eidetic reduction has been reached.

The first eidetic insight is that patients suffering from chronic renal failure develop resilience through supportive family structures. This can be viewed from the indomitability of the human spirit. True enough, even relatives abroad would lend a helping hand and offer assistance to affected family members.

Co – researchers are pretty much aware that they acquire their disease from various reasons: genetic outcome, hereditary factors, unhealthy lifestyle practices, pre-existing medical condition and improper fetal programming. Thus, they claim that their condition runs in the family. Some would consider their case as an outcome of lifestyle they lived as a possible reason. One co-researcher even believed his condition arises from the fact that he was a post-menopausal baby where at later stage of life, some body parts will eventually fail. Most of the time, notwithstanding the deteriorating state and lack of financial resources, families of chronic renal failure patients have dealt with their infirmity with an optimistic attitude that is, an attitude of acceptance as an alternative to denial or the feeling that one has to stressfully fight against an event. Family relationships serve as a strong foundation to patients' lives. Caring for each other is indeed so much a part of the values of the Filipino family. Filipino values are, for the most part, centered at maintaining social harmony, motivated primarily by the desire to be accepted within a group. While there is strength of the family, though government support is commonly seen as rather weak or negligible, majority of the co-researchers are benefiting from social support and services provided by the government. Only a fraction of the co-researchers wish that they may also avail such aids from the state.

Another insight is that chronic renal failure patients are transformed from a state of illness to a state of health through stronger family ties, prayers, healing and spirituality. During the disease process, the chronic renal failure patient goes through an experience of fear, denial, regret, self – pity, desperation, hopelessness and a desire to die. But with advancements in

medical science and technology, devices such as the dialysis machine offers hope. Emerging low from bouts of illnesses, patients discover the path to wellness through the power of stronger family ties, prayer, healing by faith and spirituality matched with technological advancements.

Third Reflections: Transcendental Reductions

Based on the content of the experiences of co-researchers, the insights validated by co-researchers themselves, and through review of literature, the researcher studied the concealed meaning of these experiences and arrived at the third level of reflection, the transcendental reduction.

Beyond the sensible and evident individual outlook, there is a need for a holistic approach to compassionately care for clients with chronic renal failure and that a humanitarian society equipped with a unique struggle to maintain health and wellness of the society through educational and informative sessions. This is the fruit of the third reflection – a fully established mechanism bound with shared goal of a well – informed society and productive community. Thus the struggle for health is the struggle to decrease incidence of chronic renal failure and increase health awareness.

Symbolic Reflection

Symbolically, the lived experiences of individuals with chronic renal failure undergoing hemodialysis can be compared first to a situation where a man is contentiously watching the waves as it endlessly kissed and punish the shore. It reflects the reactions of clients when faced with such insurmountable condition. It connotes the resilience, serenity and strong faith that co-researchers show as if everything will be alright (at the right time).

Recommendations

Although conclusions from this research study cannot be generalized beyond the sample, the consumer of qualitative research findings should determine the degree to which they can relate to the findings from a practical point of view. Based on the findings of this study, the researcher strongly recommended the following for action:

5. Continued research focused on the lives of chronically ill patients, as well as exploration of the caregivers' perspective, to determine how they continue with their lives is needed.
6. Moreover, the establishment of evidenced – based practice for the promotion of the enhancement of the quality of life of other chronically ill individuals should also be taken into account.
7. A follow - up study can be conducted to further view the co-researchers' lives after this study.
8. Finally, the proposed Health Teaching Guide be adopted by nurse managers for them to discover its usefulness and effectiveness as a health teaching guide to individuals with chronic renal failure undergoing hemodialysis to reinforce any knowledge that these individuals have on their conditions.

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