



Living on theory for chronic illness survival

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Abstract

The study explored the survival journey of long term dialysis patients which is described by their circumstances and experiences. It uses a grounded theory approach as its methodology. The respondents of the study are dialysis patients who have been on dialysis for more than ten years. The theory that has emerged from the study is that in order to survive the dialysis journey the patients must possess four elements. Personal, Spiritual, Economic and socio cultural. All of these components are interdependent with one another which means that a dialysis patient can effectively endure his or her condition when all of these four components are existing.

The personal component would discuss particular attitudes and behaviors that are controlled by a dialysis patient that would help him survive his dilemma. Next is the economic component, this would refer to finances in forms of support from the immediate and external support. Thirdly is the socio-cultural component, this is the support provided by the family, relatives and friends and lastly is the spiritual component. This has something to do with the steadfast faith of the patient on divine intervention.

Keywords: dialysis, kidney failure, survival

1. Introduction

Breakthroughs in medicines and the improvements of healthcare approaches are some of the most compelling reasons why the mortality rates caused by chronic illnesses have been reduced in the recent years. To those who are afflicted with chronic diseases, this can be a ray of hope provided by the medical science. Hoping is the process of positive thinking among the patients and the significant others in their lives who are typically the family members. Hoping is the process of putting aside anxieties brought about by the disease.

For Christians hope is a belief that God is omnipotent, faithful and merciful and help those who love him. Hope is this confidence that we have in God's goodness, power and fidelity that sweetens and makes bearable the hardships of life including this renal disease situation.

In the face of a chronic disease like End Stage Renal Failure (ESRD), hoping brought about by the bioscience can be futile. ESRD is not only a malfunction of one of the smallest body organ of one individual afflicted with the disease, but also to the physiological, emotional, social, and even spiritual domains of both the patient and the significant others in his or her life.

According to Leung (2002), when a person is diagnosed with ESRD, it causes havoc into his or her life. That life can be comparable to a roller coaster ride since the person must expect sudden and extreme changes in life. There would be a hodgepodge of unpleasant emotions like fear, anger, and despair. The situation is perplexing yet there is no other way but to confront it.

Kimmel, Peterson, and Weihs (1998) ^[25] observed that ESRD patients have to adjust to a number of changes in their life's routines. This includes adapting a new diet especially in their fluid intake. These changes would directly affect their social functioning since there are significant limitations that they have to deal with. These

limitations are expected to bring imbalance in the patient's beliefs of surviving and sense of personal control that would lead to anxiety, depression, inhibition of coping and adjustment.

Kidney Failure is a state wherein an individual's kidney function becomes incompetent to sustain life. It is a disease which is advancing and irreparable in which the kidneys are not anymore capable of filtrating body waste. According to the Health Science Journal (2014), since the body is unable to heal or repair, this results to an imbalance in maintaining metabolic and electrolytic functions thus uremia, metabolic acidosis, anemia, and endocrine disorders would set in. Although there are treatment choices, such as dialysis and transplantation, ESRD is generally viewed as very dangerous. Worse, this illness downgrades the person's quality of life.

Individuals affected by kidney Failure are on the rise every day. The National Kidney and Transplant Institute (NNTI) noted that renal failure ranks as the ninth leading cause of death among the Filipino people. According to the country's Department of Health (DOH), in 2013 close to 23,000 Filipinos had dialysis treatment due to kidney failure.

The rising cases of diabetes, hypertension and other lifestyle associated diseases are contributors to the escalating number of cases of renal failure according to the Department of Health. Furthermore, the National Kidney Transplant Institute (NNTI) said that before 2010 over 5,000 Filipinos had been undergoing dialysis. This means that in an hour range, one Filipino suffered from renal failure.

Patients with chronic illnesses such as Chronic Renal Failure have bigger needs and priorities compared to other patients. Kidney failure patients and their families have many things to think of, topmost of which is the relief of symptoms, and the increasing price of dialysis treatment to sustain the quality of life.

There are many different aspects in the life of a dialysis

patient that are affected by the illness. One of which is the psychological aspect; the patient may have a hard time accepting the illness or even the emotion and stress involved which in turn affects the coping mechanism of the dialysis patient and his or her family. Moreover the psychological status of the patient may also be a factor in surviving the dialysis crisis. Another would be the social aspect, which is also very important in coping with illness; this would include social support from friends and families.

On the psychological part, according to Gerogianni and Babatsikou (2014), chronic renal failure is an uninterrupted process of adapting changes in the patient's life which includes his or her family. Personally the patient has to accept his/her new image as a dialysis patient translated into daily routines and lifestyle changes which also affects his/her family.. They added that the most typical sources of anxiety are money, social and marital relationships, frequent hospitalization, limitations of leisure time, relationship with health caregivers, physical fatigue, growing dependence on the artificial kidney machine, uncertainty of the future and fear of becoming disabled or worse death.

Dialysis patients must make many alterations in their lifestyle in order to maintain well-being. Following religiously treatment routines is a must, as are severe dietary and fluid restrictions. Patients with Chronic Renal Failure have much more needs and priorities compared to other patients.

True to the Philippines and other developing economies of the world, the price of treating a kidney disease through dialysis is a very costly routine. This is to say that it is beyond the grasp of ordinary patients- those who belong to the middle income and lower income earner groups. A worst case scenario is kidney transplantation, a difficult process because of the cost that the treatment entails and the unavailability of kidney donors. Thus, the most ideal thing to do is to emphasize on prevention of the progression of the disease.

Not many people have enough money to pay for dialysis treatment and it is straightforward to say that without dialysis or kidney transplantation, patients die. To remedy their financial problem, patients are forced to ask medical assistance from government agencies and non-government agencies and in many cases, the dialysis patients must find new and creative ways to financially sustain themselves and their families if they are no longer able to maintain employment. But even with the dialysis treatment, the patient is still not safe from different complications.

It is the goal of this research to examine holistically different real life experiences of patients undergoing dialysis for a decade or more, describing the underlying themes through observation, interview and with the result, create a model that would entail methods,, techniques and routines to survive end stage renal disease.

By studying and observing the life of a dialysis patient survivor holistically, the researcher will be able to discover different patterns in the behaviors and practices which may be utilized as database to formulate a lifestyle model in surviving the dialysis crisis.

The product of the study would be beneficial to dialysis patients and significant others since its goal is formulating a theory about surviving renal failure. It is hoped that these patients can utilize the result of the study as a guide for them to survive in their journey as dialysis patient. Furthermore, the outcome of the study would also be

beneficial to the teachers as well as the nursing students, since it can be used as a reference in the clinical area in order to develop the nursing care process when they deal with renal patients. It can also serve as an example during discussions in the nursing education courses. And lastly, for nurse practitioners, the result of the study will guide them when they deal with renal patients, they can effectively advise them to survive renal disease.

The researcher is also a dialysis patient himself for nearly five years and has first-hand experiences on the different difficulties and challenges of being a dialysis patient. Knowing the different difficulties, challenges and seeing fellow dialysis patients die without warning motivates the researcher to undergo and finish this study as a contribution to fellow dialysis patients and their families.

There are already developed theories suggesting the process and describe the disease stage of chronically ill patients but none so that centers on helping them survive their condition. This study would like to develop a model theory based on the findings in the investigation of the lived experiences and circumstances of dialysis patients who have been undergoing dialysis treatment for more than ten years and help them survive their condition.

2. Material and Methods

This study utilized the grounded theory method. Specifically, it used the grounded theory which is the Glasserian approach (1978), a qualitative research method used in investigating the phenomenon of interest to generate a theory. Grounded theory is a method of gathering and analyzing data analysis that uses a systematic set of approaches that either start with details or generalizations (Glaser, 1992). The emphasis is the step by step procedure in collecting, handling, and analyzing data. Grounded theory's process gives importance on the participants' own interpretations, significance and meanings with only very little influence from the researcher. Interview and observation data are compared, coded, and analyzed. A theory grounded in these data is expected to emerge. (Glaser and Strauss, 1967).

The primary source of data in this study are the dialysis patients undergoing treatment for not less than ten years; this would include patients from Cebu City and other provinces. Snowball and purposive sampling was used as sampling design in this study. Secondary sources of data were the significant others of the patients- their families and or relatives, the physicians and the nurses. Interviews and observations were used as research tool to collect the necessary data.

A manageable sample size of participants was selected in studying the phenomenon intensively. According to Polit & Hungler (1995), small samples are adequate to capture a maximum class of themes that surface in relation to the topic, especially if the hypothetical sampling has been applied judiciously. The selection of participants from a variety of demographic backgrounds to capture a wide range of experiences was facilitated. When point of data saturation is reached the researcher would stop gathering data.

Since the study used a qualitative design it utilized the researcher as the research instrument. Using data saturation to determine the number of participant needed in the study. Each of the interview of the participants lasted from 45 minutes to an hour each.

Ethical Consideration

This research study is strengthened by the ethical considerations supported by the Belmont Report in 1974 which reviews three basic ethical principles significant to researches involving people as subjects which are respect, beneficence, and justice.

The participants of the study are treated as independent agents; the belief that people should be respected consists of two distinct moral conditions: the requirement to grant autonomy, and the need to protect those with diminished autonomy. The researcher guarantees that participants of the study participated willingly and are provided with adequate information in languages that are easy for them to comprehend and that they are not under threat. Moreover respect for individuals means honouring their privacy and preserving their confidentiality.

In the study, the participants may or may not answer the queries according to their preference that is why there are no guidelines on how much they should answer; they are given the freedom to deal with the questions asked. Furthermore, there are no students or children involved since the main participants are the dialysis patients and their significant others. The second principle which is Beneficence postulates that the researcher must exploit possible benefits and lessen possible harms. This means guarding the human welfare. The investigator should contemplate beforehand that the benefits should be to the full benefit of the participants and that the previewed risks should be stopped or reduced. The current study has ruled out any harm that might inflict the participants especially during the interview sessions. They are guaranteed that it should take place during their suitable time and place. They will not be obligated to answer inquiries which they think subtle or those that do not want to answer for any other reason at all.

The third principle is Justice which means impartial delivery of benefits and burdens of the research to the participants. This can be disrupted when certain benefit of a person which he or she is privileged is not provided without any justification or some burden is unjustly given. This refers to the process of selecting participants without biases, with all sections of the population having the chance to be part of the study.

In this research, there are no identified major risks since the context is of positive value related to the improvement of the lives of dialysis patients. There are also no possible harms associated with the study like psychological, physical, legal, social, and economic in nature. This is because, the method is an interview wherein participants are free to answer and give their opinions and insights and also share their health practices in surviving renal disease and that these responses would be held with utmost confidentiality in the part of the researcher. Moreover the expected outcomes of this research are expected to contribute to survival of dialysis patients

Content, Comprehension, and Documentation of Informed Consent

The participants of the study should be regarded as competent people; this is respect for the person's need. They are given the chance to select what they want and do not want during their participation of the study. This chance is given when accepted standards of informed consent are fulfilled.

According to Polit and Beck (2004) informed consent is a

significant process for the protection of the participants, specifically that of self-determination. This implies that the participants of the study be given enough information with regards to the research study, understand these information, and have the autonomy by allowing them to agree, disagree, or even cease participating in the study.

The method and context in which the evidences are conveyed is given much importance and is considered to be equally significant to the information itself in this research study. The presentation of the information is based on the participant's ability to comprehend which is consistent to their intelligence, rationality, and language. This is essential in order to discover that the informants have comprehended the information. The content of informed consent form will be conversed to them in detail and they are allowed to ask questions if they are not clear about a particular item. The researcher will explain and elaborate to them both in the participants' native language and in English.

Moreover, a contract to participate in the study comprises a valid consent since it is voluntarily given. The informed consent would contain conditions which are free of pressure and unjustifiable influence. In this research, the participants are free to answer or refuse to answer the questions, in that they are assured that that will not affect their job. Also the researcher is not a person of influence because she is of the same level with the participants, being a dialysis patient like them. Clearly, there will be no identifiable pressures that would occur since the researcher has no position of authority or commanding influence over the participants.

Authorization to Access Private Information

The participant of this research study has the right to accept that any data they make available will be preserved in the strictest confidentiality. In this research, there is no precise condition in retrieving private information since these data are embedded during the interview of their opinions and insights on the topic at hand. They would also be asked about their individual circumstances which they may or may not respond. Likewise they will be asked if they want their responses to be included in the script to be used as vignettes to support the discussion in the presentation of data. Also they will be asked about personal data like their medical history, however this is only for profiling purposes since the research believes, these information do not have bearing in the study because the focus is their opinions, insights and practices in using the mother tongue. Similarly, the parent informants are not asked personal circumstance questions; hence no authority to access private information is emphasized or utilized.

Confidentiality Procedures

This study highlights the assumption that any data the informants will give should be preserved in utmost confidence. It is the responsibility of the researcher in guaranteeing that the data they provided would be considered very private, thus it should not be divulged to anybody but only utilized for the purpose of the study. Intrusion to their private lives should not be violated by divulging personal information to other people. Anonymity is upheld during the gathering, interpreting, analysing and reporting of data. It would be insured that any information should not link to any participant of the study. Moreover, the information must not be made available to the public without their permission.

In this study confidentiality is upheld by assigning an identification number to each participant. According to Polit and Beck (2004), this is a good technique so that names of the participants are not reflected in a computer system or other database systems that are very easy to access. Every participant is numbered participant 1, 2, 3 and so on.

Debriefing, Communications, and Referrals

According to Polit and Beck, respect for the research participants can reduce emotional setbacks by giving much attention in applying the basic tenets of communicating with them. This can be done by being amiable and polite, simplifying questions tactfully, and being keen to cultural beliefs.

In the study, the researcher will communicate his respect and concern for the participants by offering them time to restate their responses throughout the interview if they want it, and constantly asking them if they want to answer a particular query or not. They also choose the time and place where they wish to be interviewed. Also the participants of the study will be told that if they wish, the researcher can bid to share the findings of the study to them once the data have been analysed. They are also certain that they can withdraw from the study as they wish or can complain on some indiscretions that may happen during the interview.

3. Results

Theme 1. Money matters

Theme 1 of the study is money matters in the survival of dialysis patient. The cost of the dialysis sessions and the medication is very expensive that it would take a lot of adjustments on the part of the patient.

“kwarta, kay kaning usahay naa man gyud tay obligasyon, naa man tay pamilya, naa man koy mga anak, usahay makuhaan ang atung budget para dialysis, kay adtu man ibayad sa eskwelahan” (participant 1)

“buwan kapin ko ngadtu kay mahal kayo dialysis ngadtu, four thousand two hundred nya wa pay labot injection. Ang injection ngadtu one three, nya five thousand three akoa, aw five four, pirti gud nga lisura, nya akong sweldo katorse mil ra” (participant 1)

“katung bag o pako dili kayo pa ko ka maintain tungud sa kamahal sa pagpa dialysis. mao ni nadaut akong mga mata. Kay once a week paman ko atu” (Participant 2)

The participants of the study had articulated that the cost and maintenance of the different medications and the dialysis treatment is very high and costly and sometimes they would miss their treatment; this would be very risky to their health and wellbeing.

Theme 2. Making use of the assistance given by different organizations

The second theme of the study is utilizing the help of government organization to be able to sustain the financial needs of the treatment. The participants verbalized that they ask help from the Philippines Charity Sweepstakes office or PCSO, Phil health and other organization to help pay for their dialysis treatment.

“makuha naman sa phil health ang payment sa dialysis, nya wa man sad koy injection kay taas taas man akong hemoglobin, nya naa man sad health insurance akong wife” (participant 2)

“pasalamat lang ko sa ginoo nga karun dako kaayog tabang ang phil health plus naa pa gyu’y PCSO ug DSWD. Mau nang maka sustain naku karun sa akong pag pa dialysis” (participant 3)

The participant of the study shared that the Philippine Health insurance and other organizations have been very supportive with regards to their condition and they are able to sustain their treatment by employing the help of these organizations.

Theme 3. It’s ok

The third theme of the study is acceptance. As expressed by the participants of the study, acceptance of the condition of having kidney failure and undergoing lifetime dialysis are both crucial in surviving the dialysis journey. The participants of the study noted that learning about their condition was both detrimental and hard to accept because of the financial cost of undergoing dialysis treatment.

“Ang ako ika share gyud nila kay ang pagdawat lang gyud sa sakit, kay ako sa una, wa pa gyud naku nadawat akung sakit, naglisud gyud ko, una pinansyal, nya akung huna huna, nawagtangan ko sa paglaum.” (Participant 1)

“kahinumdom ko sa una nga naglisod kug dawat aning sakita kay kinahanglan mag gyud ug kwarta kay katung sa una wa pa man to’y phil health nya tag 5,000 ka da session, naa gani to’y time sa una nga maka miss ko kay wa na may ika bayad.” (Participant 3)

Furthermore, the participants also shared that having learned of their condition had led to depression which caused missing several dialysis sessions which almost killed them in the process.

“Kung ingun ana dawat gyud ang sakit. Kay katu gud nanamilit gud ko kung asa ko mamatay, iuli gyud kog Leyte, adtu gyud ko, mao na dawaton gyud ang sakit, usa man gyud na, ayaw lang gyud ka wa sa paglaum. Kay ako sa una nawagtangan sa paglaum. Medyo ni lapse ko ug pila ka semana, mga duha ka semana, wa’ na nisaka akong creatinine, din a gyud ko katu’g.” (Participant 1)

Moreover, based on experience the participant shared that by not accepting the health condition would only lead to despair and weakness further lowering the levels of health.

“niabot man gyud tong mga una nga wa pa gyud koy tuig, gisuwayan na ko nga wa gyud ko nidawat, unya maluya na sad ko, naa sad koy kauban didto sa gawas mao say niistorya nako, ayaw gyud pagluya luya, ang huna huna nato nga maluya gani ta, bata pa kaayo ta, kaya ni natong sakita, sige kog pangutana sa uban, ang uban kuno nga pila ka buwan wa naman” (participant 1)

Acceptance is vital in the survival of a dialysis patient because by accepting the disease condition allows a dialysis patient to go on with life and learn to live with it achieving happiness and satisfaction in life.

“Dugay naman ni nako nadawat kaning akong sakit, nya kontento nako ug malipayon ko sa akong kahintang karun.” (Participant 2)

Theme 4. Optimism and positive mindset

The fourth theme of the study is optimism which means never losing hope in times of hardship and desperation as expressed by the participants in the study. Furthermore they noted that a dialysis patient should never lose hope since being one does not mean that he or she is useless.

“Dili gyud ta magwagtangan ug paglaum ning atung sakit kay kaya paman natu molakaw basta pirmanente lang na atung dialysis, ang atung vitamins naa man, naa tay maintainance, makalihok pa man ta” (participant 1)

One participant of the study said that dialysis is not a death sentence therefore one should go on with life. Another expressed that he will survive his dialysis journey because of his family, saying that he would want to see his children finish school.

“Dili buot ipasabut nga abi nag dialysis ta, mamatay nata, padayun gihapun ang kinabuhi, ako gahuna huna gihapun ko sa akong kaugmaun.” (Participant 2).

“mo survive jud ko aning sakita para sa akong pamilya, para sa akong mga anak.kayahon gyud na ko para sa akong pamilya gusto pa ko makakita nga mo graduate akong mga anak. Di ko magpa luya - luya tungud aning sakita, mo survive pa gyud ko” (participant 3)

Theme 5. Striving for normalcy.

The fifth theme of the study is going on with life like a regular person would. The participants of the study verbalized that renal disease should not be a hindrance in achieving our goals in life. One of the participants even describes that he never stop working because he wants to see his children finish school.

“kay ngano man uy nga nakaya man to nako katong mga panahona, akong mga bata, highschool ang usa, dagan ko diri, magluto ko diri, nakaya pa to nako Ma'am, dagan dagan dagan, niya nahimo ra jud to until nakahaman ang mga bata, nakatabang na sila diri nako, ang usa nako ka bata mao nay, ako nang gitudluan sa furniture, kato akong nurse, registered nurse na gyud unta to siya, niya kini laging di ko gustong magbuwag ta dong uy, kay life is too short, nya naka kuan kog luto luto, nag cater cater ko, gipaskwela lang nakog kanang naa lang gud sa TESDA commercial cooking, mao nay naka survive namo “ (participant 4)

Theme 6. Heed the advice of the physician

The sixth theme of the study focuses on the value of the advice of the physician being crucial in the survival of dialysis patient. It cannot be denied that the physician plays a very important role in the lives of the patients. To a dialysis patient following or not following the advice of the physician determines the health outcomes.

“karon gud mam 73 na man na si doktora., pero grasya jud sa Ginoo kay abtik pa, ang iya karong life mam wan

a gyud sa pangwarta mam more on atiman, mapobre ka or madatu, iya jud kag monitoron, niya naay daghan nagpaabot na kwarta, pasyente pero di jud kinahanglan magpaabot mo or di, iya jud to atimanon, niya kana siya diha sa philhealth naa man nay doctor's fee sa uban hospital “(participant 4)

Theme 7. Proper nutrition is essential in surviving renal disease

The seventh theme of the study is the role of nutrition in the health of a dialysis patient and its contribution to their survival. A renal patient should always follow the prescribed dietary regimen because if not then this could prove detrimental to the overall health of the patient.

“E maintain gyud nga maka kaun gyud ta kay wa man tay vitamins, wa tay madugay nga vitamins sa atung lawas ba, kay makuha man sa makina nig dialysis, labi na nga katulo na ko ron” (participant 1)

Theme 8. Never miss a dialysis session as much as possible

The eighth theme of the study centers on the importance of never missing a dialysis treatment as much as possible. All of the participants agreed that missing a dialysis treatment is very dangerous and could be fatal to a dialysis patient.

“basta di ko ka dialysis mang hupong ko, unya maglisod nako ug ginha wa. Maglisod nako ug katug, kay sa karon nga nahitabu nga nag 3-2 3-2 sukad nga nag 3-2 dialysis katulo kaduha, nindut nakaayu ang akung katug, na maintain nasad nako ang katug, sa una sir magsige ko ug hangad ani diri, kapyut kapyut lagi ko. (Participant 1)

Theme 9. Family and friends

The tenth theme of the study is family support and social support. As agreed by all the participants of the study, support is very crucial in their lives as dialysis patients. Their families and other significant people in their lives is one of the reasons why they have survived for many years as dialysis patients. One of the participants revealed that his children are very understanding because as a father he is unable to provide them with some of their needs since most of the family finances would go to the dialysis treatment.

“sa tinuod lang kung way suporta gikan sa akong pamilya dugay na siguro kung namatay.kay kung way suporta sa pamilya di na man ta ganahan mabuhi. Mau nang usa na sa pinaka importante nga ang usa ka nag dialysis ma ka sugakod pa gyud”. (participant 3)

“grabe gyud ning suporta sa akong asawa ug anak, akong asawa napugus lang tawn ug trabaho, ako nag negosyo negosyo nalang ko. Ang mga anak nako mosabut nalang kay usahay din a ko kapalit sa ilang gusto paliton kay mao lagi nahurut ang among budget sa pagpa dialysis ug ang mga maintenance nga tambal. (Participant 3)”

Furthermore, the participants verbalized the value of having good friends and co-workers; they stated that some of their close friends have helped them financially with their problems regarding their dialysis treatment.

“Mosuporta pa gyud sila, labi na katung naa sa abroad. Ma ka feel jud ka ba nga gamit gyud ning ma mundo ta ug daghang amigo.mao bitaw nga bisag unsa ang isugu nila nako musugut ra ko. (Participant 2)

Theme 10. Entrustment of oneself to god matters

The last theme of the study is trust and faith in God. All the participants in the study agreed that their faith in God plays an important role in their survival journey. According to the participants God has helped them with the different trials like their financial needs. Moreover the participants expressed profound gratitude to the immeasurable help God has given to them over the years.

“God is good gyud, gi tawagan ko sa akong insurance, niya ang ako diay sakit covered disease, dapat lang tagaan ko sa akong insurance, gitagaan gyud ko kaluoy sa Ginoo, so nakapaskwela gyud ko sa mga bata, basta kay, unsa to uy, maghilak lagi ko, naka learn gyud ko nga you have to live one day at a time, kuan man ka helpless man ka pero ma -feel gyud nimo nga God is alive.” (participant 4)

“Más ni kusog ang akong pagsalig sa Ginoo, mas maampuon ug mas mapasalamaton ko niya. Magpasalamat ko nga hangtud karun buhi gihapon ko, pasalamat ko nga hangtud karun grabe gihapun ang suporta sa akong pamilya nako.” (Participant 2)

4. Discussion

Dialysis patients face many challenges on a daily basis; Rittman (1993) ^[41] stated that living on dialysis is comparable to an overhaul of lifestyles and routines. One of the challenges is addressing financial problems since the cost of dialysis treatment and the maintenance medication prescribed is very expensive that sometimes a dialysis patient could not comply. The result of the study yielded that the participants are unanimous in saying that money is very essential in surviving renal disease because there are many other financial obligations that should be satisfied like the school fees as verbalized by one participant.

“kwarta, kay kaning usahay naa man gyud tay obligasyon, naa man tay pamilya, naa man koy mga anak, usahay makuhaan ang atung budget para dialysis, kay adtu man ibayad sa eskwelahan” (participant 1)

Theofilou (2013) ^[54] described that all patients with renal failure have to adjust with many challenges which would include work and economic status. These limitations are directly manifested in the physiological and psychological states of the patients. This will lead them to set priorities in their personal lives.

To cope with these financial constraints of being dialysis patients, the participants expressed that they utilized the assistance of the Philippine Health Insurance, Philippine Charity Sweepstakes Office, Department of Social Welfare and Services, and other organizations to help finance the treatments and medication.

“Dako kaayog tabang ang Phil health plus naa pa gyu’y PCSO ug DSWD. Mau nang maka sustain naku karun sa akong pag pa dialysis” (participant 3)

The Philippine Health Insurance or Phil – Health covers ninety (90) dialysis sessions per year while the Philippine Charity Sweepstakes Office (PCSO) supports dialysis patients by giving financial assistance of sixty thousand (60,000) pesos on a yearly basis. Both organizations give dialysis patients a fighting chance in surviving.

Furthermore, the result also showed that acceptance and optimism are integral parts of a successful management and in surviving renal failure. The participants of the study noted that knowledge about their condition was both detrimental and hard to accept because of the financial cost of undergoing dialysis treatment. A study by Bapat, Nayak and Kedleya (2008) which focuses on the different factors that affect acceptance of chronic Kidney Failure found out that finance greatly affects the acceptance of illness in renal patients.

Dialysis treatment is an expensive treatment procedure, along with the medications and dietary needs; effective management is no ordinary feat.

“Ang ako ika share gyud nila kay ang pagdawat lang gyud sa sakit, kay ako sauna, wapa jud naku nadawat akung sakit, naglisud gyud ko, una pinansyal, nya akung huna huna, nawagtangan ko sa paglaum.” (Participant 1)

“kahinumdom ko sa una nga naglisod kug dawat aning sakita kay kinahanglan mag gyud ug kwarta kay katung sa una wa pa man to’y phil health nya tag 5,000 ka da session, naa gani to’y time sa una nga maka miss ko kay wa na may ika bayad.” (Participant 3)

Moreover, the outcome of the study disclosed that the Acceptance of the condition of being lifetime renal patient can lead to compliance to treatment and management leading to improving health condition. According to Zalewska, Miniszewska, Chodkiewicz, and Narbutt (2007) ^[60], the challenge of patients with chronic disease is how they accept the condition because this can lead to non-compliance, thus causing disadvantages to the patient. Nagle (1998) described coming to terms with the loss and limitations help dialysis patients in moving on with life.

Acceptance of the illness means better adherence to treatment hence promoting optimum health and better quality of life. Poppe, Crombez, Hanouille, Vogelaers, and Petrovic (2013) ^[39] in their study that describes the improvement of quality of life of renal patients, found out that acceptance is an important positive variable in determining quality of life.

In contrast, by not accepting the illness would only lead to negative outcomes like depression and poor compliance with the medical treatments, medications and dietary requirements. A study by Chiang, Livneh, Guo, Yen, and Tsai (2015) ^[6] that describes the effect of acceptance on a dialysis patient found out that non-acceptance to the illness is associated with poor clinical outcomes.

Acceptance will no longer make chronic kidney disease an obstacle for living life to the fullest. In fact, it can make them do better in many areas in their lives. They can have this renewed hope and optimism, thinking that since they have been the bottommost point of their lives and have survived such point, there is no reason for fear and uncertainty to dominate their lives. They can even find their

purpose and drive, something that they did not see prior to their illness. They live each day to do better and enjoy whatever life may bring. Being diagnosed with CKD can turn a person's life around. It is how the person looks at it that will determine which direction his life will go on. Since the treatment of Chronic kidney disease is very limited, with only dialysis and kidney transplantation as the options, acceptance on the part of the patients is crucial to allow them to continue to survive and even thrive in their lives. By acknowledging that the disease is a part of them, they will learn to live with it. Undergoing hemodialysis twice or thrice a week will be like going to the mall for them, something that is not extraordinary. Selecting food appropriate for them will no longer be an excruciating task. Experiencing fatigue, breathlessness, and generalized pain in the body will not make them panic, but would make them reevaluate what they had done throughout the day, something an average person would not be able to do.

In addition, optimism or being positive about surviving renal failure brings positive health outcome to the condition of a renal patient. Fournier, de Ridder, and Bensing, (2002) in their study which investigates the effect of optimism to the health condition of a renal patient found out that optimism contributes to effective coping, implying that optimistic belief are specifically beneficial when patient suffer from chronic illness to the extent of it being controllable.

“tagaan jud ka sir ayaw jud pagwagtangan og paglaum, aku jud sya giingnan, katu silang Areston sa ubos sige na tug wheel chair, daot na kaayu tu” (participant 1)

Gurklis and Menke (1995) [19] found out that striving for a positive attitude as one of their most commonly used and most effective coping mechanism. Dialysis patients should keep a positive attitude by having realistic hopes, keeping life as normal as possible, and perceived themselves as being healthier than before starting dialysis treatments. Moreover, a study by Mulkana and Hailey (2001) [35] which explains the role of optimism in health-enhancing behavior found out that optimism greatly influences the health enhancing behaviors of patients.

Also, optimism in dialysis patients is very essential on their lives because thinking positively about the health condition contributes to progressive health outcome. Thinking negative thoughts brings only negative health outcomes like depression and sometimes non-compliance to the treatment because the patient would no longer believe in the recovery of the condition and this causes delay in the improvement of health.

Another result of the study is that dialysis patients tend to strive for normality in their lives. Resuming all the activities like a normal person would like going back to work.

“murag ang ginoo nangitag gyud “way” ba so dili gyud ni natu ikabahala atung sakit. Total maka lihoc man ta, makatan aw maka paminaw man ta. Maka diskarte man ta. Maka trabaho man ta; ato lang nga continuous lang ang atong dialysis” (participant1)

Lindqvist (2000) [27], in his study distinguished a general topic as an overall of “wishes for independence and normality,” which have subthemes of “wish for normality,” “wish to manage one's own life,” “being deprived of a

“normal life” and “concerns”. Rittman (1993) [41] depicted dialysis treatment as taking on a new understanding of being. The topic of being in dialysis simply means a feeling of being at home which eventually a normal way of living becomes.

Acceptance of the disease, optimism about survival and striving for normalcy are all essential in the survival of a dialysis patient. It helps in the adjustment of the patient in his transition to the different changes in the lifestyle of the renal patient.

Likewise, the result of the study generated that patient behavior is integral in the survival of a dialysis patient. Behaviors like compliance to the advice of the physician and following recommended dietary intake are the central themes of the study. One of the participants of the study confided that she is very grateful with her physician saying that she is one of the reasons for her survival.

“karon gud mam seventy three na man na si Doktora., pero grasya gyud sa Ginoo kay abtik pa, ang iya karong life mam wan a gyud sa pangwarta mam more on atiman, mapobre ka or madatu, iya jud kag monitoron, niya naay daghan nagpaabot na kwarta, pasyente pero di jud kinahanglan magpaabot mo or di, iya jud to atimanon” (participant 4)

A major obstacle to successful health management is the patient's failure to follow the recommendations of his or her physician and other healthcare providers. Adherence is described as “the extent to which a person's behavior coincides with medical advice.” Thus, if a person does not follow his/her medication schedule, this is plain disobedience. (Delamater, 2006) [15].

Compliance has long been accepted as an important issue in health-care. According to Miller (1997) [29], deference to the order of the medical professional managing the disease and the degree to which their suggestions are followed provide a difficult, however an engaging challenge. In a medical condition like ESRD, developing habits in food intake and undergoing treatment are at present the only feasible way to treat the disease

In addition, following the recommended dietary intake is very essential in promoting health. Manley and Sweeney (1986) [30] noted that the reduction of kidney function demand an intensive dietary adaptations in order to decrease the danger of morbidity and mortality. These changes consist of the intake of energy foods, selection of macronutrients, minerals, and fluids.

“E maintain gyud nga maka kaun gyud ta kay wa man tay vitamins, wa tay madugay nga vitamins sa atung lawas ba, kay makuha man sa makina inig dialysis” (participant 1)

According to Theofilou (2011) [52], hemodialysis has changed the medical forecasts of ESRD patients, but its advantages are unfortunately often threatened by non-adherence to the medical routines. This observation is also confirmed by Moran, Christensen, & Lawton (1997) [34], who said that the choice of food and the volume of fluid is essentially a factor for maintaining quality life among hemodialysis patients (Moran, Christensen, & Lawton, 1997) [34].

Good health management outcomes basically depend on the

patients' obedience to suggested treatment regimens. The patient's non-adherence can be an enveloping threat to his/her health and overall wellbeing.

Likewise, the results indicated that Family support and social support are very essential in the health management of a renal patient because all the aspect of the patient's life is affected. A diagnosis of end stage renal disease creates chaos that infiltrate into the person's life. The diagnosis triggers a mixture of different emotions such as fear, anger, despair, and hope. Life is a rollercoaster of ups and downs. With all the challenges and problems that are triggered by the onset of renal disease, support of the patient's significant others plays an important role in their survival.

“mutabang sila uy, mga kauban naku sa gawas sa trabaho, mga ka batch naku sa high school, dako kaayu kog pa salamat, sa pag ampo nila, pag hatag nila ug financial, hatag gyud sila maayo gud sila nako, wa jud ko ka kuan, mao na hangtud ka run, mag sigi gyapun ko nilag kuan, pa salamat, mga pagampo, mga iyaan naku, saakung pamilya, ig agaw, tanan, mga pag umangkun, daghan gyud nga mga pag umangkun naku nga nanabang gyud, kabaw gyud sila unsa ning sakita, mao gyud na di gyud ni siya basta basta akong sakit, gasto man gyud, labi na nga nay kay maintenance, laboratory nimo, so ang ato lang, mag ampo ug taban” (participant 1)

McClellan, Stanwyck and Anson (1993) ^[32], in their study involving social support and mortality among renal patient found out that dialysis patients who report a diminished capacity to provide supportive relationships for friends and family are at increased risk of dying. The study suggested that the perceived inability to provide social support may be an independent risk factor for mortality.

In the same manner, Cohen's (1995) in his study on how the onset of the illness affects families of the patients discovered that that not only spouses are directly affected but also children. Despite these affects, families also survive in the process of supporting their members who are on dialysis.

“sa tinuod lang kung way suporta gikan sa akong pamilya dugay na siguro kung namatay.kay kung way supporta sa pamilya di na man ta ganahan mabuhi. Mau nang usa na sa pinaka importante nga ang usa ka nag dialysis ma ka sugakod pa gyud”. (Participant 3)
“grabe gyud ning suporta sa akong asawa ug anak, akong asawa napugus lang tawn ug trabaho, ako nag negosyo negosyo nalang ko. Ang mga anak nako mosabut nalang kay usahay din a ko kapalit sa ilang gusto paliton kay mao lagi nahurut ang among budget sa pagpa dialysis ug ang mga maintenance nga tambal. (Participant 3)”

According to Frank, (1988) ^[16], when one member of the family is undergoing dialysis or a kidney transplant, it can be said that everyone experience it vicariously. This is due to the chronicity of the illness and the physiological and psychological stressors that everybody in the family is experiencing. Thus, the support of the family members can contribute to a positive adaptation to a new routine in life.

(O'Brien, 1983; Rodrigue, Greene, & Boggs, 1994) ^[42]. Because of all these, it is suggested, according to Pender (1996) that families, peers, and health care providers should be significant interpersonal influences to the patient so that their health promoting behaviour would heighten.

Finally, trust and faith in God is an integral part in surviving renal ailment, all the participants in the study agreed that their faith in God plays an important role in their survival journey. According to the participants God has helped them with the different trials like their financial needs. Moreover the participants expressed profound gratitude to the immeasurable help God has given to them over the years.

God is good gyud, gi tawagan ko sa akong insurance, niya ang ako diay sakit covered disease, dapat lang tagaan ko sa akong insurance, gitagaan gyud sko kaluoy sa Ginoo, so nakapaskwela gyud ko sa mga bata, basta kay, unsa to uy, maghilak lagi ko, naka learn gyud ko nga you have to live one day at a time, kuan man ka helpless man ka pero ma -feel gyud nimo nga God is alive. (Participant 4)

Mas ni kusog ang akong pagsalig sa Ginoo, mas maampuon ug mas mapasalamaton ko niya. Magpasalamat ko nga hangtud karun buhi gihapon ko, pasalamat ko nga hangtud karun grabe gihapun ang suporta sa akong pamilya nako. (Participant 2)

Albaugh (2003) ^[1] in his study about religion and coping found out that spirituality has a significant influence on the life of people who have life-threatening diseases. This faith has provided them the essence of surviving. The participants of the study elaborated some situations how their spirituality sustain them by providing them strength in facing the life, many blessings despite the hardship of the illness, and trust in a divine being to see them through the journey. All participants of the study shared that they were able to ascertain the essence of their lives.

Many studies have proven the effect of spirituality or the belief in higher power can contribute to the health of a sick person. Gurklis & Menke (1988) ^[19] found out that the essential factors in dealing with the illness are their belief in God, prayer life, and purpose to live. Interestingly, Landis (1996) in his study discovered a negative correlation between psychosocial adaptation and spiritual well. This is supported by the study of Kaczorowski (1989) who found out that among cancer patients who are highly spiritual, anxiety is lower than their counterparts.

In addition, according to Tanye and Werner (2008) whose study focuses on the experiences of women on dialysis, religious sensitivity or attachment help the dialysis patients in overcoming the different symptoms of ESRD. As observed, these women had become better persons in terms of their attitude towards life, their significant others, and their social support. This results to avoidance of self-destructive character like drug abuse. Ruo, Rumsfeld, Hlatky, (2003) ^[43] also stressed that strong spiritual faith in a Divine being decreased instances of stress which eventually improve social life. They added that the improvement will also lead to physiological wellness.

5. Propositions Derived from the Themes of the Study

Based on the themes generated in the study, the researcher

was able to generate five propositions:

Proposition 1: Financial competence is vital for surviving renal disease

The first proposition was created using themes number one and two which emphasize the role of money in surviving renal disease and the importance of asking help from different government organization. Basing on these themes, it can be said that a dialysis patient must be financially competent to be able to effectively resolve the different monetary difficulties that is the result of being on dialysis treatment.

ESRD is a dangerous life threatening state and is mostly treated by dialysis. If renal patients do not receive dialysis treatment they will inevitably die in a matter of weeks or a few months. Long term dialysis is almost non-existent in most third world countries. Once they have learned about their illness, most patients would not comply with their treatment modalities. Even in patients who comply with dialysis treatment, the dialysis management is insufficient by acceptable standards. Dialysis is given once or twice a week which last four to eight hours and the treatment is directed by the patient's health condition and economic status. Patients eventually lessen the number of dialysis sessions and finally terminate it which would lead to death (Rao, Shirly and Jacob, 1998) ^[40].

Dialysis treatment is a very costly medical treatment especially in a third world country like the Philippines. To handle up with these economic constraints of being dialysis patients, one must be wise in spending his/her money.

Proposition 2: Chronic illness survival depends on the right attitude: Optimism

The second proposition was fashioned using the third, fourth and fifth themes of the study. These three themes focus on acceptance and optimism along with striving for normality in the daily living of dialysis patients. It can be inferred that these three themes center on the attitude of the dialysis patient in surviving renal disease, therefore proposition two was created.

Optimism is a mental state that has been connected with good health and good adjustment. The opposite is true with depression, hopelessness, and even death that have been associated with ESRD (Taylor, 1991) ^[50]. There is a notion that people's actions are greatly affected by their beliefs about health (Scheier and Carver, 1987) ^[45]. Being positive is an overall confidence expecting good outcomes. It is associated with ego strength and internal control. This is true among positive thinkers who believe that things are under their control.

Optimism or being positive about surviving renal failure takes positive health outcome to the illness of a renal patient. Hopefulness among dialysis patients is very vital. Thinking positively about the health situation adds to progressive health outcomes. Thinking negative thoughts brings only negative health outcomes like depression and sometimes non-compliance to the health management because the patient would no longer believe in the recovery of the illness, thus health improvement is delayed.

Proposition 3: Renal disease survival is influenced by one's health related attitude: compliance

The third proposition was formed using the sixth, seventh, and the eighth themes of the study. These themes

concentrate on the following; the recommendation of the physician, following the diet plan, and never missing a dialysis session. From these three themes it can be implied that there should be emphasis on the behavior or the actions of the dialysis patient to survive the condition, hence proposition three was born.

The objective of chronic disease treatment modalities is to achieve the optimum wellbeing and lessen the symptom and severity of the illness (Clark, 2003) ^[7]. In dialysis patients, the goal is difficult without the patient's compliance on self-management. (Curtin, Johnson, Schattel, 2004) ^[13].

For renal patients, compliance to the treatments and medicine schedules is not only significant but also complicated. Renal patients must comply with a routine dialysis schedule which is inconvenient. Not following the prescribed medication and schedule is related to an escalating danger of complications and even death (Bernardini, Nagy, & Piraino, 2000) ^[3]. Moreover, all dialysis patients are required to follow a diet and fluid consumption and medications - in addition to adherence to an overall healthy routine. Unhealthy practices such as smoking and drinking alcohol should likewise be avoided.

Gruman and Von Korff (1996) explained that the patients' self-management is associated with routines that safeguard and encourage healthy state; management of sign and symptoms of their disease; compliance to the modalities of treatments; and their management of the effects of renal disease on their activity, emotional state, and interpersonal relationships. On the same manner, Curtin and Mapes (2001) described management as the individual's actions to supervise and be highly involved in their own health care in order to maximize wellness.

Proposition 4: Family and social support helps in the survival of a dialysis patient

The fourth proposition was shaped using the ninth theme of the study. This theme tells about the importance of the support from the family and the friends of the dialysis patients in their survival, thus the fourth theme.

In the current times, longer life expectancy is evident among people with chronic illness. According to Coyne & Smith (1991) ^[12], the long term treatment and management of chronic illness pose some lifestyle restrictions not only on the patients but also their families. ESRD has a great affect on both the patient and their significant others (Stokes 1991) ^[49].

Chronic disease takes its toll on the wellness of the patient's family (Sexton & Munro 1988) ^[44]. The significant others should be flexible on the routines of the patient and must adjust to the changes in roles and lifestyle. Patients often feel helpless in facing their illness (Tsay 2004) ^[56]. This feeling of helplessness causes negative emotional responses such as being lonely and depressed. Tsay (2004) ^[56] explained that a dialysis patient goes on a complex management which entails both treatment and also a variety of several shifts and turns that are linked to both patients' interpersonal and emotional aspects.

Proposition 5: Trust and faith in god is a determinant in the survival of dialysis patient

The last proposition of the study is rooted from the tenth theme which implies that the trust and faith of the dialysis patients in God or the belief in a higher power helps them survive in their life journey.

Religion is always associated with increase fulfilment in life, happiness, positive affect, morale, and other factors of well-being. There are now researches that connect religion and spirituality to the health outcome (George, Ellison, & Larson, 2002)^[17].

Matton (1989) in his study explained that individuals who verbalized an association to God experience a number of positive health benefits: less loneliness and more self-esteem, furthermore Hall and Edwards (2002)^[22] describe that closeness to God brings lesser depression, and more mental maturity and increase emotional competence. The perception of being close to God appears to help individuals in stressful situations.

Studies have compared God to an attachment figure (Kirkpatrick, 1995)^[26]. As children look up to their parents for guidance and protection, individuals can look to God as a safe haven, a being who provides care and security in periods of needs and problems. Attachment theories have suggested that individuals who have experience a deep faith with God should also experience greater comfort in situations that are stressful and greater strength and confidence in living every day. Lower levels of physical stress and lower levels of depression are other rational products of deep faith and trust in God.

6. Conclusion

The theory generated in the study is the L.M. Derasin’s living on Theory for Chronically illness survival which is composed of four components namely: Personal, Spiritual, Economic and Socio cultural. All of these components are interdependent with one another, which mean that a dialysis patient can effectively endure his or her condition when all of these four components are present.

The first element of the theory is the personal component. This would refer to specific attitudes and behaviors that are possessed by a dialysis patient that would help him survive his predicament. This would start with the acceptance of his condition, and then being optimistic about what life could still offer even with the circumstance. There is also a motivation to live a normal amidst the crisis. Furthermore, another part of the personal component is the behavior modification which implies a complete change in the routine like following the regular dialysis treatment schedule, strict diet, following the advised of the physician such as taking the prescribed maintenance medication and finally learning from personal and other dialysis patient’s experiences.

A dialysis patient may be able to afford all the expenses needed in his or her medical treatments but if he lacks the personal component, this can be a drawback. The inability to accept his condition, lack of motivation and optimism, along with non-compliance to the advice of the healthcare providers; the condition would still be futile on the part of the chronically ill patient.

The second element is the economic component. This would refer to finances in forms of immediate and external support like government and non-government organizations’ financial assistance. In relation to this, prudent management of the resources is significantly emphasized.

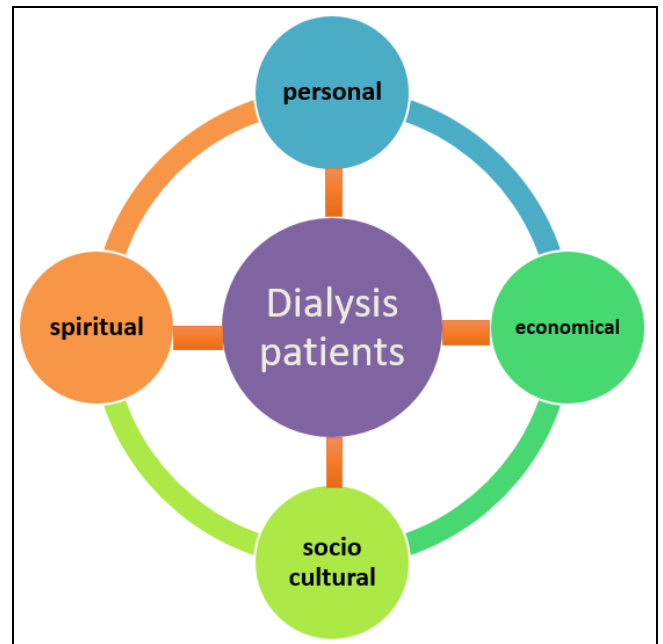
A chronically- ill patient may be very compliant with the doctor’s advice, he or she may have accepted his condition and may be optimistic about his health but if he lacks the economic component like the capacity to finance himself, it would still be useless on the part of the patient.

The third element is the socio-cultural component. This is

the support provided by the family, relatives and friends in the form of financial, emotional and spiritual aspects.

Even with an able finances or a compliant behavior, a dialysis patient still requires the support of their friends and families otherwise the health condition of a would be in danger.

Finally the last element is the spiritual component. This has something to do with the steadfast faith of the patient on divine intervention. God plays an important role on the lives of a chronically ill patient. He or she may be well endowed financially, or health compliant and may have the support of his family and friends but without god’s graces everything will be futile.



Conceptual framework of the theory generated

Fig 1: L.M. Derasin’s living on Theory for Chronic Illness Survival

Impact to Education

The theory generated in this study has a valuable and priceless impact that goes beyond the four-wall classroom which is the traditional way of educating people. This study specifically educates people within the parameters of health. The study has a great contribution to the Filipino people’s mental health frame because there has been a misconception about being chronically ill. These patients had been labeled as “the doomed” or the “end thing” and in fact there is a direct and indirect discrimination in their circumstances especially in the availability and accessibility to health care. This theory will serve as evidence-based tool in educating people with such mental frame.

The study will serve as a guide for healthcare practitioners in managing the chronically ill patients. The four components identified in the theory should be nurtured and given emphasis by the healthcare provider during interaction with the patient. It is the advocacy of this research study to disseminate and educate dialysis patients and their families on how to survive chronic illness.

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