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The Development of a Family Support Program for Caregivers of Hemodialysis Patients

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Abstract

Family caregivers of hemodialysis patients have a heavy burden based on negative experiences, long-term care hours, total physical dependence of patients, comorbid health conditions, and financial stress treatment procedures. This study design is a mixed method followed by 114 participants in the quantitative phase and eight participants in the qualitative phase. The research instrument used Zarit Burden, a demographic profile form, semi-structured interview questions, and a recorder. Data analysis used ANOVA, t-test, and thematic analysis. The results showed that most participants were 51 to 60 years old, patients' wives, college graduates, had a monthly income below ph10,000.00 and had cared for patients for 20 to 24 hours. Participants have experienced high physical and financial burdens and loss of control over life, as well as very high emotional and social burdens. Significant differences were found in the levels of emotional, social, and financial burdens when grouped by education level. Monthly income affects the level of social and financial burdens. Physical exhaustion, emotional suffering, limited social life, role conflict, financial poverty, and fear of the future are the themes of challenges in caregiving. Participants coped with their challenges by seeking help and sleep, emotional adjustment, acceptance, maintaining friendships, resisting the urge to participate in social activities, utilizing family resources, seeking financial support from politicians and government agencies, and borrowing money. The proposed stress relief support program has the potential to be an intervention to enable family care with various forms and levels of caregiving burden.

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INTRODUCTION

It is a well-recognized phenomenon that caring for patients with chronic illness by family members has an impact on the physical, emotional, and mental health of caregivers and financial strains that overwhelm the caregivers. The occurrence of end-stage renal disease (ESRD) is universal and is becoming a silent epidemic. Hemodialysis is the commonly used renal replacement therapy that imposes various challenges and difficulties to the patients and to the family caregivers as well. Nurses' involvement is critical in preventing the adverse outcomes of caregiving among family caregivers. To date, there is no specific support program being implemented for family caregivers of hemodialysis patients in the Philippines. Thus, the purpose of the study is to determine and explain the experiences and burdens of caregivers of patients undergoing hemodialysis and design a support program that would address caregiver burden.

Research Paradigm of this study utilized the Input-Process-Output (IPO) system that rests on the assumption that there is a relationship between caregiving stress, difficulties, and challenges that contribute to the burden of caregiving.

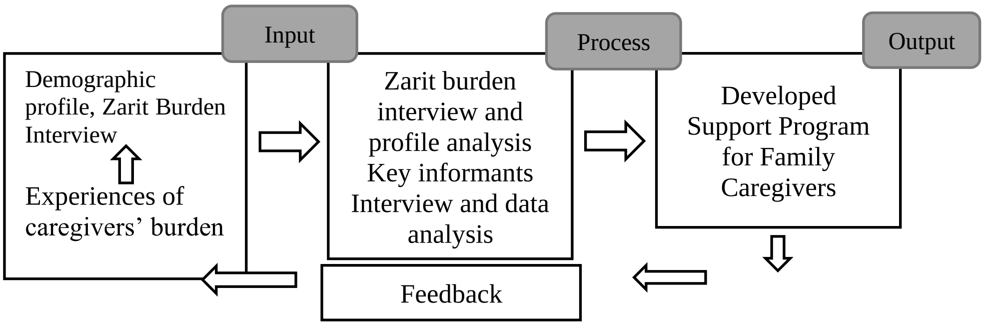

Figure 1. Research Paradigm

Figure 1 shows the input that reflects the demographic profile, the tool on Zarit Burden Interview, and the experiences of family caregivers. The process involved the mediating mechanisms that converted inputs to outputs. The output resulted in developing a support program that would address the burdens of caregiving.

This endeavor intended to develop a support program for family caregivers of hemodialysis patients in Bukidnon, Philippines to address the burdens of caregiving. The general objective of this study is to develop a support program for family caregivers of hemodialysis patients in Bukidnon, Philippines to overcome the burden of caregiving. The specific objectives of the study are to identify the profile of the subjects (age, gender, marital status, education level, monthly income, relationship with the patient, and number of hours of care), identify the level of caregiver burden of the subjects, analyze the differences in the level of caregiver burden based on the profile, identify the challenges faced by the subjects when caring for patients undergoing hemodialysis (physical, emotional, social, financial aspects, loss of control over one's life), identify what strategies are used by the participants to overcome the challenges (physical burden, emotional burden, social burden, financial burden, and loss of control over one's life), and identify what caregiver support programs can be proposed.

METHODS

This study utilized the explanatory sequential mixed method design wherein phase 1 involved a descriptive survey under quantitative design and phase 2 or qualitative part described and explained the result of the quantitative research through themes. The participants of the Study are 114 family caregivers of hemodialysis patients who participated in phase 1 (quantitative) and eight participants in phase 2 (qualitative). Participants were chosen by way of purposive sampling with the following inclusion criteria immediate family members of the patient, 18 years old and above, have cared for the patient for at least six months, living in the same residence with the patient; and able to read and comprehend the Zarit Burden interview tool in English language or Bisayan dialect translation. The research approval of this study was obtained from the Institutional Ethics

Review Board (IERB) of St. Paul University Philippines as well as from the presidents of the hospitals with hemodialysis units in Bukidnon. A courtesy visit to the chief nurses and hemodialysis department supervisors took place to explain the purpose of the study. Data collection procedures, starting with a demographic profile form were distributed to all family caregivers to identify those that meet the inclusion criteria. In phase 1, those who willingly signified to participate and have signed the written consent were given the Zarit Burden Interview tool. The analysis of the collected data followed thereafter; in phase 2, the collection of the data was done through face-to-face interviews with eight participants who had participated in phase 1 of the study. The average time for of the interview was 34.69 minutes.

The results of this study in phase 1, descriptive statistics including mean, frequency, and percentage were utilized to answer the demographic profile of the participants. ANOVA and t-test were used to see the significant difference in the level of caregivers' burden. Generation of quartile was used to interpret the different levels of the physical, emotional, social, and financial burdens, and loss of control over one's life. In phase 2, the transcribed data was analyzed using Colaizzi's method.

RESULTS

The results of this study were 28.2% of participants were in the age range of 51-60 years with an average age of 46 years and 64.91% of participants were female. 45.61% of participants acted as wives. 45.61% had an income below Php 10,000.00 per month.

The results of this study revealed that 29.82% of participants had experienced high levels of physical burden, 27.19% had very high emotional burden, 32.46% had very high social burden, 62.28% had high financial burden and 30.70% had high levels of burden on loss of control over one's life when grouped according to each profile variable.

Based on the data analysis, it was shown that there was no significant difference in the level of physical burden (p-value = 0.272), emotional burden (p-value = 0.569) and loss of control over one's life (p-value = 0.198) of participants when grouped according to their income.

The results of the data analysis also showed that there was no significant difference in the level of physical burden (p-value = 0.198), emotional burden (p-value = 0.342), social burden (p-value = 0.739), financial burden (p-value = 948) and loss of control over one's life (p-value = 0.577) of participants when grouped according to their relationship with the patient.

Data analysis showed no significant difference in the level of physical burden (p-value = 0.170), emotional burden (p-value = 0.094), social burden (p-value = 0.401), financial burden (p-value = 0.440) and loss of control over one's life (p-value = 0.175) of participants when grouped according to the number of hours of care spent.

DISCUSSION

Demographic Profile of the Family Caregiver Participants

This study revealed that (32 or 28.2%) of participants belong to the age range of 51-60 years old with a mean age of 46 years and the majority (74 or 64.91%) of the participants are female. Several researchers supported this study and found that women take the predominant role of caregivers all over the world, even in the care of psychiatric patients and the elderly (Nagasawa et al. 2018),(Sharma, Chakrabarti, and Grover 2016). The majority (82.46% or 94) of the participants are married and several researchers support that the majority of the caregivers of hemodialysis patients are married (Bawazier et al. 2018), (Mohebi et al. 2018), (Jafari et al. 2018). Most (38 or 33.33%) of the participants were college graduates, while other research results stated that 51% of caregivers were illiterate (Mashayekhi, Pilevarzadeh, and Rafati 2015).

Furthermore, almost 50% (52 or 45.61%) of the participants were wives. A total of 22 research subjects, using various methods of measuring the burden of caregiving, found that most women had a higher burden. pointing out that more female spouses are caregivers (Xiong et al. 2020). Among the participants, 45.61% had an income below Php 10,000.00 per month. The findings imply that most of the caregivers are on the poverty threshold according to the Philippine Statistics Authority of which on average, a family of five needs no less than Php 10,481 to meet essential and non-basic food requirements. This study is similar to the study conducted in Indonesia which most (28%) of the caregivers have income less than the provincial minimum wage (Bawazier et al. 2018). Almost 50% (42.11% or 48) participated in the care of the patients for 20 to 24 hours. It reported that the majority (71%) of the caregivers have spent more than 9 caregiving hours in the home and in the hemodialysis centers (Bawazier et al. 2018).

Participants' Level of Caregivers' Burden when Grouped According to Profile Variables

The findings of this study revealed that 29.82% of the participants have experienced a high level of physical burden, 27.19% have a very high emotional burden, 32.46% have a very high social burden, 62.28% experienced a high financial burden and 30.70% experienced a high-level burden on the loss of control over one's life when grouped according to each profile variables. This means that caregivers who belong to the age range of 51 to 60 years old, female, married, a college graduate with a monthly income below Ph10,000.00 per month, being the wife of the patient, and spend 20 to 24 caring hours experienced a high level of physical and financial burdens and loss of control over one's life and a very high level of emotional and social burdens. The data implies that the older the participant, the higher the level of physical burden. Research results supported the findings of this study that when the caregiver is older, there is an overall increase in caregiving stress as well as a psychological or emotional burden. When the care provider is aged, female, and without a job and the caregiving cost and time are higher, the caregiving stress (Thakur, Mande, and Mitra 2017).

In addition, the high level of financial burden among 51 to 60 years old. Research results show, 87% of the family caregivers reported a high level of financial stress as a result of caregiving for their elderly relative (Nortey et al. 2017). The majority (64.91%) of the participants are female. This indicates that the majority of the participants who experienced high levels of physical burdens were female which is supported by the findings that 68% of the female caregivers have a higher physical burden especially when the patient has more functional limitations (Oshio and Kan 2016). The findings that being a female is a factor associated with a very high emotional burden specifically high depression (Souza et al. 2017). index among caregivers of patients with spinal cord injury (Thakur et al. 2017). The findings that female caregivers have a higher level of financial stress and greater role strain (Sharma et al. 2016). The majority (64.91%) of the participants in this study were married. This is contrary to the study that 75.86% of married caregivers experienced less physical burden due to marital debt (Paschou et al. 2018). Further, supported the findings that married caregivers are more emotionally burdened and depressed (Souza et al. 2017). Also, most of the participants experienced a very high level of social burden which is contrary to the findings of among caregivers of stroke patients (Kashyap et al. 2019).

As to educational attainment, most of the caregivers who are college graduates experienced a high level of physical burden which runs contrary to research results of that better-educated caregivers have lower levels of physical burden (Schnitzer et al. 2018). Regarding the number of caring hours spent, those who spent 20 to 24 hours have experienced a high level of loss of control over their life which is supported that caregivers who provide care for a longer period of time have experienced loss of control over their lives (Oyegbile and Brysiewicz 2016).

Test for Significant Difference in the Participants' Level of Caregiver Burden when Grouped According to Monthly Income

The data indicates that there is no significant difference in the participants' level of physical burden (p-value= 0.272), emotional burden (p-value=0.569), and loss of control over one's life (p-value=0.198) when grouped according to their income. This suggests that the level of the physical and emotional burdens and the loss of control over one's life is not affected by income. However, this study shows that the level of social burden (p-value=0.011) and financial burden (p-value=0.003) are affected by income, among caregivers of a dementia patient supports the findings that a higher degree of caregiving burden was experienced by those with low income.

Test for Significant Difference in the Participants' Level of Caregiver Burden when Grouped According to the Relationship to the Patient

The data indicates that there is no significant difference in the participants' level of physical burden (p-value= 0.198), emotional burden (p-value=0.342), social burden (p-value=0.739), financial burden (p-value=948), and loss of control over one's life (p-value=.577) when grouped according to their relationship to the patient. This suggests that participants' relationship with the patient does not significantly affect the level of caregiving burdens. On the contrary with reported that wives surfaced to be the most vulnerable caregivers of the role-specific burden (Chappell, Dujela, and Smith 2015). Do not usually face conflicts in discharging family, work, and caregiver roles. The caregiving role of women is an extension of their usual role and engaging self in caregiving comes after family and societal expectation.

Test for Significant Difference in the Participants' Level of Caregiver Burden when Grouped According to Number of Caring Hours Spent

The data indicates that there is no significant difference in the participants' level of physical burden (p-value= 0.170), emotional burden (p-value=0.094), social burden (p-value=0.401), financial burden (p-value=0.440) and loss of control over one's life (p-value=0.175) when grouped according to the number of caring hours spent. This implies that the level of the physical burden, emotional burden, social burden, financial burden, and the loss of control over one's life is not affected by the number of caring hours spent by the caregivers. The result of this study contradicts the findings among caregivers of older adults that increased hours of care lead to the increased burden (Longacre et al. 2017). Reported that time spent in caregiving every 24 hours is highly predictive of anxiety and depression among caregivers (Bawazier et al. 2018).

Challenges Encountered by the Participants while Caring for Patients Undergoing Hemodialysis

The challenges were categorized according to physical challenges, emotional challenges, social challenges, financial challenges, and loss of control over one's life challenges.

Physical Challenges

Providing care is stressful and requires energy to juggle a lot of caregiving tasks which may result in physical challenges. The main theme is physical exhaustion.

Physical Exhaustion

Exhaustion is a state of physical fatigue or tiredness brought about by the total dependence of patients to their caregivers along with competing demands of care with other domestic responsibilities and sleep deprivation. Providing care is stressful especially when the patients are totally and physically unable to perform self-care activities. The total dependence of the patients has contributed to the physical exhaustion of the caregivers through the following accounts:

P1: "To assist him was really hard. We have been assisting him until this time because he has difficulty balancing his body…It's really tiresome…my whole body has been aching because I am alone lifting my father and he's very heavy."

P4: "It's really hard for me especially when I gave him bath, I will assist him to sit on the toilet and bathe him in the bathroom... even in changing his clothes it's really hard for me because he's like a child that I need to change his diaper, he cannot wear his underwear on his own."

Factors contributing to total dependence are the patient-related factors such as paralysis secondary to motor accident, stroke, amputated leg, and blindness secondary to diabetes mellitus. These comorbidities made the caregivers as the eyes, hands and the feet of the patient. The results of these narratives that stair climbing and bathing were the common care needs of patients on maintenance dialysis (Hung et al. 2014). Likewise, patient's higher degree of disabilities, physical dependency and more caregiving hours contribute to a greater burden (Metzelthin et al. 2017).

Caring for a patient with a functional disability is physically taxing. Family caregivers did not only assist their patients in their physical limitations but also reported doing almost all the house chores and farm works resulting in competing for care demands and doing domestic responsibilities. This is exemplified by the following accounts:

P4 "It's hard because I do all the work in the house.. even if it's a man's job it's mine..when the cages of the pigs break I will fix it."

P6 "My experience has been very tiresome because I am the one who is doing the house chores, then I have to go to the farm because this is the only means of our finances for his dialysis."

Participants in this study reported that they have to do almost everything for their patient. Aside from caregiving activities and domestic responsibilities, participants also managed to work on the farm and run their own business. Research supported the findings of this study that female caregivers do multiple gender-related responsibilities for their patients and families (Oyegbile and Brysiewicz 2016).

Another factor contributing to physical exhaustion is sleep deprivation. Since all caregivers in this study is living in the same residence with the patient, it is not surprising that at any time they are needed by the patient. Common reported physical symptoms due to sleep disturbances and lack of sleep are headache, drowsiness, dizziness, feeling of passing out, fatigue, and exhaustion. For the caregivers, there exists a consensus that:

P3: "Sometimes I couldn't sleep because he wakes me up if he's uneasy... you're already sound asleep but he wakes you up because the tube was removed. I'll have headache the next day and I feel very drowsy. My back hurts, my head is aching, I have nape pain as if I'm becoming hypertensive. I feel like I'd pass out.. I'd feel dizzy."

P7: "It's really exhausting .. it's really exhausting... like really exhausting. I could not sleep well because he always calls me. I have headache.. I have backache."

Majority of the caregivers reported disturbed sleep patterns resulting in sleep deprivation due to the frequent care demands of patients. Participants also reported that they cannot earn rest and don't have peace of mind because financial problems beset all over their being. Provision of care to patients who are totally dependent result to physical exhaustion. However, a wife participant expressed that despite how exhaustive was her experience never did it comes to her mind that she was tired because responsibility cannot be given to anyone else because of commitment and marital vows "till death do us part". Qualitative findings explain and support the quantitative result that family caregivers are experiencing a high level of physical burden.

Emotional Challenges

The stress of caregiving may overwhelm the emotional capacity of caregivers. In this study, the emotional challenges are composed of 2 main themes that include emotional anguish and strained relationship.

Emotional Anguish

Emotional anguish or emotional distress is a term used to describe some type of emotional suffering that translates into anger, fear, feeling unappreciated, depression and anxiety among others. Participants of this study shared the following accounts:

P1: "I just get irritated when he would abruptly and impatiently demands when he needed something..Sometimes I also feel irritable. Sometimes I would feel some kind of self-pity… you know sick people are irritable."

P4: "Sometimes I do get mad at him…when he ask me to do something regarding the farm.. I can't see that he was happy with my work.. my effort is not appreciated."

All the participants in this study have expressed numerous challenges that have affected their emotions. They have experienced anger whenever patients become hard-headed and defiant with dietary restrictions. Participants were also irritated when the patient would suddenly and abruptly demand something they needed even when the caregiver is asleep. Caregivers also experienced some kind of hurt feelings because despite shreds of evidence that caregivers were overwhelmed by the household chores, managing the farm and caring for their own children, they do not see that patients are happy with their work. For the caregivers, it is hurting to know that their efforts were not appreciated.

Social Challenges

Family caregivers are facing a number of social challenges. The overwhelming care demands and financial strain have prevented family caregivers in socializing. Social challenges in this study occur when caregivers cannot participate in the various social activities that they have enjoyed before. Demanding care-related activities, financial difficulty, physical disability of the patient, fear of leaving the patient behind and prioritizing the patients over the social needs and parental responsibilities of the caregivers are factors contributing to social challenges. The social challenges can be summarized into two main themes that include restricted social life.

Restricted Social Life

The theme restricted social life is directly related to the inability to engage in social activities due to deprivation of personal time brought about by the demanding caregiving tasks and physical dependence of the patients. Restricted social life encompasses the inability of the caregivers to participate in the normal processes of social life such as attending parties, reunions, prayer meetings, family outings, picnics, swimming in the beaches, going to church together, fiesta, going to other places and vacations. This is exemplified by the participants narrative accounts:

P1: “I couldn’t just go anywhere I want to..We can no longer do family outings, going to Davao,going to picnics, swimming in the beaches. Going to Oroquita and Cotabato, I can no longer attend reunions.. batch reunion.”

P6: “What I have missed doing before was going to the beach together..we went to church to pray together but now to go around or somewhere is just a wish.”

The participants have expressed that their caregiving responsibilities have really affected their social lives. Participants’ reached a consensus that care-related activities have prohibited them from participating in various social activities. Participants claimed it difficult to bring along their patients and also unfair to leave their patients behind during vacations. It was expressed too that they don’t have the pleasure of time for family outings and vacations due to the present condition of their patients.

One participant expressed that going out with friends and attending activities set for the Couples for Christ and prayer meetings was really a challenge and a hard blow on her when her husband got paralyzed due to a motor accident. For some, going around is just a wish because the money to be spent on pleasure is just a waste and better spend it on dialysis. Restrictions in doing social activities is really a burden for family caregivers which is congruent with the quantitative result of this study that caregivers are having a very high level of social burden.

Financial Challenges

Family caregivers have been experiencing financial challenges which refers to the financial difficulties experienced by the caregivers due to the long-term and costly hemodialysis treatment, maintenance medications, high cost of hospitalization and other medical related expenses of the patient. The never-ending financial strain can be described in one main theme as “financially impoverished”.

Financially Impoverished

Financial impoverishment usually results when nothing has been left to the financial resources due to the high financial cost of physical illness. In this study, financially impoverished refers to the long term and high-cost medical treatment where family resources such as lands, videoke machines, and jewelry were either pawned and sold leaving the family with huge debts and even left to nothing. All participants in this study narrated how distressing are their experiences when it comes to the financial burden which made them financially impoverished. This is exemplified by participant 1:

P1“It’s really a burden.. We spent so much. We have been to anywhere to borrow money just to support his needs. My mother’s jewelry is all gone…we already sold some pieces of land. It’s really hard if one is hospitalized. It’s really difficult when physical health claims its share. You are left to nothing.. so hard. It lead us to debt because this is a lifetime treatment”.

The impact of the financial burden among the participants has affected the individual and family levels. The cost of hospitalization is very high especially when patients get admitted to the Intensive Care Unit (ICU) and when the fistula of the patients gets clog, infected, and needs to be changed. Financially, it was too hard that they needed to pawn some pieces of land properties, jewelry, motorcycle, and videoki machines to support the dialysis treatment.

One participant reported that it was extremely challenging because there were times that they don’t even have any single centavo to buy for their rice. Participants reported that they have been to anywhere to borrow money because nothing has been left due to a lifetime treatment.

Challenges Related to Loss of Control over One’s Life

Loss of control over one’s life refers to the caregiving experiences of caregivers that made them think that nothing can be done to reverse the situation resulting to feeling of losing control over their lives. This also involves feeling that caregivers are in a miserable and hopeless situation due to the never-ending financial problems. The challenges experienced by family caregivers in relation to loss of control over one’s life is fear of the future.

Fear of the Future

In this study, the theme fear of the future described how participants are fearful about the inevitable death of the patient since hemodialysis does not cure the disease. The following accounts express how the participants were afraid of the outcome of the disease.

P5: "Even if I am at work my thoughts are with my son because I am scared something bad might happen to him."

P7: "I'm really scared .. the time when he'll pass away... I'm not yet ready..it's already the end-stage.. so it can be anytime."

In this study, participants are aware that the patients are not getting any better. For this reason, they are afraid that at any time their patients may die. One participant expressed that he had mixed emotions during the time when his father almost died. Two participants also reported that even when they are at work their thoughts are always with the patient. This simply means that they put superior priority to their patients over their personal activities.

The qualitative result has explained that participants do not have any hold of the future of which the quantitative result has proven that family caregivers experienced a high level of a burden when it comes to the loss of control over one's life. This is supported research resulth that caregivers struggle to cope with the trajectory of the disease and fearful about the worst that may come to their patients (Wingham, Frost, and Britten 2017).

Strategies Employed by Participants to Address the Challenges in Terms of Physical Burden, Emotional Burden, Social Burden, Financial Burden and Loss of Control over One's Life

Strategies employed by the participants were categorized into 5 aspects: the physical burden strategies, emotional burden strategies, social burden strategies, financial burden strategies, and loss of control over one's self strategies.

Strategies Employed to Manage Physical Challenges

In this study, seeking help and sleep emerged as themes to manage the physical challenges.

Seeking Help

Help-seeking behavior is a behavior or actions being done to elicit help from others. In this study, seeking help refers to actions that help ease the physical burden by hiring somebody to do hard work and requesting children and the participant's mother to take care of the patient whenever participant's need to go somewhere. The following narratives have been shared:

P2: "There are instances that I left her in the care of my child..I demand my children to take care of their mother…sometimes, I call my mother to look after my patient."

P6: "When there was something very hard to do in the farm, I would ask and hire somebody to do it."

Many of the participants have sought help to relieve them of the physical strain by urging their children to take care of their mother and at times patient is left to the care of the participant's mother. Another participant explained that when she is at the farm and there is some heavy work to do, she just hires somebody to do it for her. Seeking help from mother, children and neighbors have given a bit of relief to the participants. This is supported that seeking help is a strategy that had help most of the friends who are caregivers of the patient (Umubyeyi et al. 2016).

Sleep

Sleep is a basic human need according to Maslow's hierarchy of needs. Sleep is important in health maintenance and disease prevention. In this study, sleep as a strategy was the only solution used to address fatigue and physical exhaustion and to avoid getting sick. This is exemplified in the following accounts:

P3: "I would lock the room and sleep the whole afternoon..I really need to sleep..My only solution is sleep."

P7: "Sometimes when my father is asleep, I strive to sleep too even for a short time."

A considerable amount of stress has been experienced by caregivers in relation to the physical burden. Nevertheless, many of the participants reported that they are also doing activities to regain their strength and address physical exhaustion. The most reported strategy used to address sleep deprivation, maintain health and prevent disease is sleeping. Participants expressed that when their patients are sleeping, they find time to sleep too to avoid getting sick. This means that despite the overwhelming challenges of the physical burden they are brushing elbows with every day they did not forget to take care of themselves.

Strategies Employed by the Participants to Address Emotional Challenges

In the process of caregiving, caregivers have experienced various challenging emotions. Managing emotional challenges will benefit both the caregiver and the patient because it is a way of caring for self. In this study, emotional adjustment was used as strategies to address emotional challenges.

Emotional Adjustment

Emotional adjustment is helpful in maintaining emotional equilibrium when a person is bombarded with external and internal stressors. Emotional adjustment in this study refers to the use of emotional behavior that would avoid arguments by keeping silent, ignoring the patient, leaving the patient, not listening to the patient, not talking back to the patient, tolerating the patient, and being patient. It also means acceptance, patience, and adjustment which are exemplified in the following narratives:

P1: "at times I won't listen to him.. just ignore his nagging because if you give attention to him, you will also get irritated... you will get affected just leave him alone…"

P6: "I just keep quiet… I kept being patient with him... I forgive him. ..I just pray for patience."

Most of the participants in this study showed emotions and behavioral responses to avoid further arguments. Some participant also expressed that they do not talk back to their patients with the fear that something bad might happen to them.

Strategies Employed to Address Social Challenges

This involves a theme on maintaining the friendship and withholding desire in social activities.

Maintaining Friendship

Maintaining relations of friendship is a form of self-care. Caregivers are so often wrapped up with the intensity of stressful caregiving jobs. However, stepping out a moment to maintain the connection with friends will ensure a healthy life balance. In this study, maintaining the friendship refers to maintaining the connection with friends where a caregiver can share problems and ventilate feelings, and also by hanging out with friends. This is exemplified by:

P2: ".I hang out with friends but I don't stay overnight..I have curfew..I don't lose friends. I confide my worries to them…If they ask me out I go with them."

Despite the different degrees of caregiving burdens participants managed to respond positively to the negative impact of caregiving that is befalling them through maintaining friendship. One participant said despite the present condition of his wife he sees to it that he lives a normal life by maintaining the friendship because it was really helpful when he confides his problems and worries. This implies that being with the circle of friends has really contributed a positive outlook in their social life.

Withhold Desire for Social Activity

Participation in social activities brings happiness and a positive outlook in life. However, to some participant withholding desire and participation in social activities would be beneficial. Withholding desire in participating in social activities is defined as the coping strategy used to save money for dialysis treatment instead of pleasure. This is exemplified by saying:

P6: "… now, to go around or somewhere is just a wish...because if we have to go somewhere, the money will be of waste, instead spending it for pleasure, we better spend it for dialysis."

While some participants have actively participated in some social activities, one participant bravely narrated to withhold participation in previously enjoyed activities such as a having vacation and going to the beach together due to financial hardship. Further, it was explained that going around for a vacation is just a wish. This means that the financial strain of the long-term treatment made the participants withhold vacation and other social activities due to the dire need of money for the dialysis.

Strategies Employed to Address Financial Burden

Financial strategies are actions taken by the participants in order to secure money for the dialysis treatment. Financial impoverishment in this study was addressed through family resource utilization, soliciting financial support from politicians and government agency, and borrowing money or loan.

Family Resource Utilization

Family resource utilization is the use of family resources to secure money for hemodialysis treatment, medications and for medical related needs of the patient. In this study, it refers to using family resources by selling pieces of land and videoke machines, pawning some lands and jewelry and have some of their buildings rented in order to provide money for the dialysis treatment. The following accounts were shared by the participants:

P1: "we have also sold pieces of lands…the jewelry of my mother is all gone."

P6: "Before we have 3 hectares but it was leased and other portions were sold."

P7: "we have a building for rent .. but we have sold one of our lands for his dialysis."

All the participants have utilized resource utilization to solve their financial challenges. Most of them sold some land properties and others have their lands pawned. One of the participants expressed that he needed to pawn the jewelry of his mother to support the dialysis expenses because even if he has lands planted with corn and sugarcane, it takes months or a year for it to yield some produce and earn an income. Some participants had their buildings rented for additional income and one participant narrated that all their videoke machines were sold for the dialysis expenses. Due to the increasing health care cost and long-term dialysis treatment, participants used their acquired resources as a means of providing financial support.

Soliciting Financial Support from Politicians and Government Agency

Soliciting financial support from politicians was another strategy employed by family caregivers. These are actions made by the caregivers in order to secure money for dialysis by approaching and asking financial help from the mayor, governor, kagawad and from DSWD. This is exemplified by participant 8:

"this time, I would go and ask help from any politician who I think I can get help.. I went to ask help from the mayor, DSWD, from the governor and the councilor."

Many of the participants have come to the point of soliciting financial support from the mayor, the governor, the councilors and from the Department of Social Work and Development (DSWD). Participants have expressed that asking for help from the politicians is really embarrassing but this time they have to bear the consequence of losing their face as they try to solicit money for their patient's dialysis treatment. Financially, dialysis has a devastating effect on the family's economic status forcing the participants to ask and solicit help. Undeniably suffering from financial strain, that lack of financial resources led them to ask for help since the government scheme does not provide all dialysis treatment and medicines (Surendran et al. 2018).

Borrowing Money and Loan

Another strategy used by the participants is the borrowing of money and loans to solve their financial strain. Participants have approached members of the family, friends or anyone whom they can borrow money for the dialysis expenses of the patient. This is exemplified by this narrative account:

P5: "When sometimes money is so difficult to find I would go to anybody to borrow money..you need to approach any of your friends, even if you don't know each other that much just to ask help from them."

Many of the participants reported that they have been to almost anywhere just to borrow money.

Strategies Employed to Address Loss of Control Over One's Life

To address the fear of the future and sense of hopelessness, family caregivers have employed two main themes that includes acceptance and prayer.

Acceptance

Acceptance in this study means that whatever is the will of God for their patient and whatever happens to the patient they will accept it. Caregiving is not only physically, emotionally, socially, and financially taxing. It also made caregivers think that they loss control of their personal lives. Thoughts of concern and caring for their patients made their lives revolve in the care of their patients. It is saddening to know that patients are at the end of the line. So despite the burdensome caregiving responsibility, they continued to care for their patients to the best of their capability and accept whatever may happen to their patients. This is exemplified by participant 1:

" whatever be the will of God for my father.. we will accept it.. "

Using acceptance is striving to continue living and accept whatever may come despite of the pain and psychological distress that anytime their patient will die.

Prayer

To address the sense of hopelessness, participants have used prayer which is a spiritual communication with God. Spiritual faith exercised through prayer was used to relieve the sense of hopelessness due to the miserable situation and never-ending problems. This is exemplified through the narrative accounts:

P1: "We really prayed hard to the Lord for whatever his will for my father."

P5: "I continue to pray so I won't stress myself."

One of the challenges befalling the caregivers is a sense of hopelessness and prayer was used as a way to relieve them of their hopelessness and an expression of dependence to the Almighty God. One participant reported that he really prayed hard to the Lord and expressed that if the Lord will make his father well again, he would be happier because his father would still be with his family for a longer time. Prayer is basically talking to God but it must be offered in faith.

The Proposed Support Program for Family Caregivers

The stress-busting program with spiritual activities is a 6-week program designed to have two hours meeting per week to support family caregivers. During the weekly sessions, caregivers will learn educative information on stress and its management. It also includes sessions with activities where caregivers can have the opportunity to work as a group in selected activities and share their experiences so caregivers can learn from each other and spiritual activities such as singing band and prayer.

Majority of the caregivers were female, married and wives of the hemodialysis patients which suggests that more women caregivers are susceptible to the burdens of caregiving. In addition, it shows that more female spouses look after the care of their husbands on hemodialysis and are more vulnerable to caregiving burdens due to spousal obligation and commitment. They also have spent a lot of time caring for the patients which means that most of the caregivers are in constant contact with the patient in the provision of necessary care. With their low income, they also experience a high level of financial burden. Along with financial difficulty, they have experience high level of emotional and social burdens. However, despite of the many challenges and high levels of burdens, family caregivers have come out strong by employing different coping mechanism.

CONCLUSION

Family caregivers normally experience high to very high levels of caregiver burden and distress due to the financial repercussions of long-term treatment. Despite the many challenges they have experienced, they are able to employ different strategies to manage their physical, emotional, social, financial burdens and loss of control over one's life. Based on the expressed needs of the participants, the Stress Busting and Spirituality Program for Family Caregivers has a great intervention potential to address the needs of the caregivers of hemodialysis patients with respect to being able to effectively manage and cope with their varied forms of.

SUGGESTION

Hemodialysis nurses should be vigilant in assessing the symptoms of stress among family caregivers while they are at the hospital and hemodialysis centers so that comprehensive attention and referral to health educators and chaplains can be done to address their burdens. Other nurse researchers may embark on studies related to caregiving experiences to validate the current level of burdens among family caregivers of hemodialysis patients. Nurse Administrators may consider providing the caregivers with the opportunity to receive a caring support by implementing the proposed program for caregivers of hemodialysis patients. Hospital Administrators consider providing a waiting area for caregivers designed to provide privacy and comfort conducive for rest and sleep while waiting for their patient's undergoing hemodialysis. Hospital Chaplain may consider creating spiritual programs for caregivers that would address the sense of hopelessness of the caregivers.

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CONFLICTS OF INTEREST

The author has no conflict of interest to disclose.

AUTHOR CONTRIBUTIONS

The author confirms sole responsibility for the conception of the study and design, as well as data collection, analysis and interpretation of results, and manuscript preparation.

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