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Silvia Amaya

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KIDNEY DISEASE AND ITS IMPACT ON CAREGIVER BURDEN AND MARITAL SATISFACTION

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

Silvia Amaya

May 2025

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Approved by:

Carolyn McAllister, MSW. Ph.D., Faculty Supervisor, Social Work

Armando Barragan, Ph.D., M.S.W. Research Coordinator

ABSTRACT

The purpose of this study is to review and analyze the relevant literature focusing on research studies that examine the impact of kidney disease and chronic illness on caregiver burden and marital satisfaction. Studies show that, as the older population increases and, with it, the rise of chronic illness and caregiver need, the quality of marital and relationship satisfaction between patients and caregiver spouses/partners will have a significant impact on the care that patients receive and on the social and community costs that such care will incur.

A scoping review is proposed to search, analyze, and synthesize the existing body of literature based on evidence-based therapeutic interventions available for marital dyads where one spouse is diagnosed with a chronic illness. This proposed study will benefit social work practice and education by identifying effective interventions that target those marital dyads where the chronic illness of one spouse places the partner/care provider at higher risk of caregiver burnout. It will also benefit social work macro practice by helping to identify communities where high rates of caregiver burnout negatively impacts the social and financial cost of care for those with chronic illness.

ACKNOWLEDGEMENTS

“The greatest disease in the West today is not TB or leprosy; it is being unwanted, unloved and uncared for. We can cure physical diseases with medicine, but the only cure for loneliness, despair and hopelessness is love.” – Mother Teresa

My acknowledgements to all those caregivers that have shown compassion and love with integrity while taking care of their loved ones facing a devastating chronic illness. They have inspired me to pursue this topic as the focus of my research.

I would like to thank my Thesis Advisor, Dr. Carolyn McAllister, for providing me with the support, encouragement, and guidance for my thesis. You have made this a positive and worthwhile learning experience.

DEDICATION

A special dedication to my parents, Abg. Luis A. Jaramillo Andrade and Dra. Ivonne Chan de Jaramillo, for always encouraging me to continue with my studies. Los amo y esta es la mejor forma de demostrárselos.

To Nicholas, my dearest son, there is no lost time when the books take over - It is always a winning moment. I want to always be your inspiration, and see you pursue your dreams.

Someone has told me that the most important person is always the last one to be mentioned, and that person was and is my husband, Felipe Luis Amaya. You have been the main reason and motivation for this career and seeing how compassionate you have been has driven me to this. More than a dedication, it is a gratefulness for all the support you have provided me, the patience and love that comes with it is invaluable. Thanks for being with me on this journey. This thesis is dedicated to our 30th wedding anniversary this month and year.

My greatest dedication is to God our Lord. I am so grateful for all Your blessings, for holding my hand in those moments when I felt hurt, and You have shown me the way to smile and overcome any obstacles with every single blessing.

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CHAPTER ONE

PROBLEM FORMULATION

Description of the Problem

Chronic kidney disease (CKD) in which the function of the kidneys starts to deteriorate, is the seventh leading chronic illness among adults in the United States (National Council on Aging, 2023). More than 1 in 7 adults, about 35.5 million people, or 14% are estimated to have CKD (Centers for Disease Control and Prevention, 2023). In addition, as many as 9 in 10 adults have CKD and do not know it, and as many as 1 in 3 adults have severe CKD and do not know it (Centers for Disease Control and Prevention, 2023). It is clear that CKD and its related conditions are a growing public health concern and it is predicted that this population will significantly expand in the coming decades. Projections indicate that approximately 16.7% of adults over age 30 will be diagnosed with CKD by 2030 (Hoerger, et al, 2015).

About 808,000 U.S. adults are currently diagnosed with end-stage renal disease (ESRD), which is the last stage of CKD in which there is little to no kidney function (National Institutes of Health, 2023). This number is expected to increase to approximately 1,259,000 by 2030 (McCullough, et al, 2019). When a patient with CKD is diagnosed with ESRD, there are three different treatment options available: in-center treatment, in-home treatment, or kidney transplantation (National Institutes of Health, n.d.). In-center treatment, also called hemodialysis, takes place in a medical clinic. A patient can also do hemodialysis at home where, with the assistance and support of a caregiver, the patient performs more frequent treatments for shorter treatment times. Another home modality is peritoneal dialysis, where patients access the abdominal fluid in the peritoneal cavity through a catheter.   This, too, requires support and assistance from a caregiver.

Chronic illness and kidney disease have a significant impact on spouses who are primary caregivers. According to one study, approximately 22% of caregivers, or about 9 million adults, are caring for a spouse or partner, and this number is expected to grow as the population ages (Centers for Disease Control and Prevention, 2023). Caregiving for a spouse can impact the marriage by:

1. Creating marital strain, which includes financial strain, family strain, frustration, fatigue, and resentment among spouse and family.
2. Emotionally impacting the caregiver as well as the one needing care. Studies show that spousal caregivers may be at a higher risk of depression than those they care for.
3. Creating feelings of loss. The change in the marital dynamic can create sadness and grief over the change in roles. A spousal caregiver can also feel alone and isolated.
4. Impacting the couple emotionally and physically. Both members of a marriage can start to feel angry, anxious sad, isolated, exhausted, and guilty, and often both members of a couple have no other option but to take their feelings out on each other. (Firstlight Home Care, 2023).

Practice Consequences

Policy Implications

Dialysis is a costly medical condition to treat, both on an individual and national level. Currently, the national policy allows patients under 65 years old, diagnosed with ESRD, and receiving dialysis treatments to qualify for Medicare benefits, as long as they also meet the work history requirements (Healthline, 2021). Dialysis treatments can cost up to $90,000 per patient annually, accounting for 7% or $28 billion of the Medicare budget. In comparison, dialysis patients make up about 1% of the Medicare population (University of California San Francisco, 2023). Access to Medicare means, not only access to dialysis treatments and transplants, but also access to other important healthcare benefits such as transportation, medications, and other medical care issues.

Many Medicare patients with ESRD in California will also be enrolled in the state's Medi-Cal program due to their impacted financial status. Medi-Cal is California's version of Medicaid, where people who are no longer able to work because of their kidney failure and have very limited financial means must rely on the state for a significant portion of their health care. However, there are no reliable statistics available regarding the number of Californians who have both Medicare and Medi-Cal and are on kidney dialysis.

Micro Implications

It is understandable that, when the burden of care for a dialysis patient is placed on the caregiving spouse or partner, the partner can easily feel overwhelmed by this enormous responsibility (National Kidney Foundation, 2023). Several studies, such as Wilson-Genderson et al. (2009), Khaira et al. (2011), Daneker et al. (2001), and Pruchno et al. (2009) explore the relationship between patient depression, caregiver burden, and marital satisfaction. These studies found, to differing degrees, that depression and marital stress directly correlate with caregiver burden and caregiver satisfaction. Additionally, among dialysis patients and their partners, marital satisfaction was found to be inversely proportional to depression. Finally, access to family, community, and social support had a significant positive impact on marital satisfaction and a negative impact on patient depression.

Macro Implications

The ramifications of caregiver burnout can mean a significant increase in medical costs to society related to increased hospitalizations, skilled nursing care, or hiring privately paid caregivers to help at home when the caregiver is no longer able to assume this function. This would translate into greater costs for the Medicare system and it would also impact costs on the state level through the Medi-Cal program. Medi-Cal usually fills the financial gaps by covering up to 20% of dialysis and related medical treatments, in addition to paying for adjunct health care services such as transportation and in-home help through the In-Home Supportive Services program (IHSS) (Medi-Cal Eligibility Procedures Manual, 1997). Finally, those who don’t have adequate insurance coverage would have to pay for much of their care out of pocket, which could financially bankrupt couples and families and force them into public assistance. In other words, caregiver burden and marital stress can have a significant, direct financial impact on the medical cost of dialysis patients on both the micro and macro levels.

Relevant Theories

Although kidney disease can affect anyone at any age, most dialysis patients fall into Erikson's Psychosocial Stage of Generativity vs. Stagnation (middle-aged, about 40-65 years old) (Bailey, 2023). By this time, most patients are already married and have established a long-term marital relationship. Kidney failure and dialysis can present a unique challenge to people in this stage, as it affects a person's ability to maintain work, develop a career, and ultimately reach the life goals they have set for themselves as young, healthy adults. Additionally, this could also affect the development of the spouse/caregiver, who now must alter their life goals and objectives to care for a sick partner with complicated medical needs. It is easy to see why social support is important for caregivers in this position – it would help a caregiver's acceptance to understand that they are not alone.

Maslow's Hierarchy of Needs can also play a role in a caregiver's ability to provide care to their loved ones as well as care for themselves in the process (Bayoumi, 2012). The patient in the dyad would feel the need for safety and security, and a caregiver providing not only support but assistance with their dialysis treatments would be able to help fulfill this need. At the same time, a patient would also need love and belongingness, and it would be up to the spouse/caregiver to be able to provide comfort to the patient and not abandon them at their most vulnerable. On the other hand, the spouse would be focused on issues of Self-Esteem, in that they would want to be seen as a unique individual rather than just the “caregiver” for their sick partner. If the spouse does not receive this support, either through their partner or through their social contacts, it could increase the sense of burden for the caregiver and create feelings of burnout and resentment.

Contribution to Social Work Practice

This study proposes the following exploratory research question: In a marital dyad where one spouse is diagnosed with kidney disease, what are effective interventions that couples can utilize to decrease burden, decrease depression, and increase marital satisfaction?

This study will survey the literature to review and analyze previous studies whose focus is dialysis patients, their caregivers, depression, caregiver burden, and marital satisfaction. Thus far, studies seem to show that decreased burden among caregivers is correlated to lower depression and higher marital satisfaction. Studies also seem to show that increased social support and networks play an important role in lowering the sense of burden and depression among caregivers. This study will address the interventions that have been shown to reduce burden and depression among caregivers, as well as increase marital satisfaction. The study will also explore and focus on those interventions that result in lower burden and depression and discuss practical ways to implement these interventions in the dialysis setting.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This study proposes the following exploratory research question: In a marital dyad where one spouse is diagnosed with a chronic illness, what are effective interventions that couples can utilize to decrease burden, decrease depression, and increase marital satisfaction?

In the United States, approximately 47.9 million caregivers care for a physically needy older or dependent adult (Well Spouse Association, 2024). Spouses account for about 12% or 5.7 million caregivers for older adults and this is expected to rise to about 17.2% by 2030 (Centers for Disease Control and Prevention, 2024). Spousal caregivers tend to dedicate more hours per week to caregiving than other relative caregivers. They also tend to provide more intensive daily care including bathing, toileting, dressing, and medications, and they tend to be female caring for their male partners (Family Caregiver Alliance, 2024). The value of services provided by informal caregivers is estimated to be approximately $470 billion (Family Caregiver Alliance, 2024). This means, on average, a caregiver provides approximately $10,000 worth of service each year to a loved one with a chronic illness.

The intensity of caregiving inevitably takes its toll on the caregiver’s health. 14.5% of caregivers report experiencing 14 or more mentally unhealthy days in a given month, and 17.6% of caregivers report experiencing 14 or more physically unhealthy days in a given month (Centers for Disease Control, 2024). In addition, 40.7% of caregivers report having two or more chronic diseases, 33% of caregivers report having a disability and 14.1% of caregivers report coronary heart disease and/or stroke (Centers for Disease Control and Prevention, 2024). The incidents of chronic illness and disability increase as the age of the caregiver increases.

The need for family caregivers will increase as the population increases and gets older. Currently, there are 7 potential family caregivers per older adult. By 2030, it is estimated that there will be only 4 potential family caregivers per older adult (Centers for Disease Control, 2024). The policy implications for this are clear. As the population ages, there will be an increase in caregiver burden on family members, especially spouses and partners, and there will be fewer available family caregivers to meet the needs of the aging population. Ultimately, there will be a serious strain on medical, community, and financial resources to care for our aging population.

Since the burden of care for our older population will fall on families, especially spouses and partners, it is important to examine the factors that can cause increased caregiver burden and decreased marital satisfaction. It is logical to assume that, if a caregiver is experiencing increased stress and burden related to care, and decreased marital satisfaction, they would be at higher risk of utilizing outside resources and/or considering institutionalization to provide adequate and appropriate care to their loved one. Since these resources tend to be very expensive and prohibitively out of reach for most middle-class couples and families, it would also be logical to assume that a higher caregiver burden and lower marital satisfaction would translate to a higher financial and social cost to the community to utilize these services.

Caregiving And Chronic Illnesses

Many chronic illnesses and diseases have an impact on a patient and his/her care partner. Studies that look at the impact of chronic illness on the marital relationship focus on those illnesses that are widespread, such as neurological diseases like Multiple Sclerosis, Parkinson’s Disease, Alzheimer’s Disease, and other dementias. Other studies look at how the marital dyad is affected by diseases such as breast cancer, stroke, and kidney failure. Still, other studies look at the mental health impact of chronic disease in general, especially as it affects the caregiver.

Caregiving and Dementia

Many studies focus on the effects of caregiving for patients with dementia. In a study conducted by Wang et al. (2014), the link between caregivers with chronic illness and the burden of care for persons with dementia was examined. There was a strong correlation between caregivers of persons with dementia and chronic illnesses among caregivers. Higher rates of chronic illness were found among older caregivers (65+ years) and spousal caregivers. Most significantly, older female spousal caregivers were found to be at the highest risk for chronic illness, even higher than older male spousal caregivers. This correlated to the higher care burden that older female spousal caregivers reported. Also of note, older caregivers reported hypertension (for female caregivers), cancer, and heart disease (for male caregivers) at rates that were higher than in the general population.

In a research overview by Reese et al. (2001), most of the research seems to indicate that caregivers' quality of life worsens throughout a patient's illness. In many cases, caregiver partners reported greater psychological distress than did patients. Most reported higher rates of depression, anxiety, and somatic complaints. Spouses of patients with Alzheimer's Disease describe "a feeling of limbo – not widowed but not married either – which can persist for many years" (Reese et al., 2001). Reese's research findings also confirm that older female caregiver partners take on a greater proportion of the caregiving burden. Other factors for increased burden and impact include caregivers who live alone with their partners and those who are of lower socioeconomic status.

Patient characteristics seem to be less impactful on caregiver burden. According to Reese et al. (2001), the link between a patient's disease severity and a partner's quality of life is not very strong. However, a patient's mental health status has more of a direct negative impact on a partner's quality of life than a patient's physical health. Reese also points out that caregivers of patients with Alzheimer's disease experienced increased burden when patients exhibited behavior disturbance, rather than cognitive impairment. Finally, the patient-partner relationship is impacted over the long term when the partner continues to care for the patient over the years.

On the other hand, according to Reese et al. (2001), many caregivers report that their role in caring for their partners has also resulted in positive effects, including increased self-esteem, pride, gratification, and feeling closer to their spouse. Partners who have positive experiences of their role as caregivers report developing a sense of "meaning" and "purpose" to their lives and they report that their roles as caregivers have resulted in increased care and affection towards others, not just their spouses. Finally, Reese et al. (2001) discovered in the literature that there is an inverse correlation between the educational level of the caregiver and the positive impact of providing care. In other words, caregivers with lower levels of education report increased satisfaction and self-esteem from their roles as caregivers to their partners.

Caregiving and Other Neurological Diseases

Several studies, such as DeRosier et al. (1992) and Lee et al. (2015), explore the experience of caregivers caring for partners with Multiple Sclerosis. Because of the gradual progressive nature of the disease, these caregivers had to rely on their spouses for emotional support, resulting in social isolation which increased their anger and frustration. According to DeRosier et al. (1992), "…never having time away from their husbands strained the marital relationship and threatened the supportive nature of the relationship." Many of these caregivers had to create personal spaces for themselves in the home so that they could give themselves a "time out" and manage their stress. The caregivers reported that the intensity of the caregiving role profoundly negatively impacted the marital relationship.

Lee et al. (2015) explored the gender differences between female spouses/caregivers and male spouses/caregivers in a group of 106 caregivers in France. Female spouses/caregivers reported higher levels of caregiver strain, higher need for emotional support, and higher perceived emotional support. Female caregivers were also reported to take on more of the caregiver burden in terms of time as well as tasks, such as attending to personal care needs and medication management/ administration, as opposed to tending to a partner's finances or buying groceries.

In Carter et al. (2004), caregiver burden was measured in comparison to the stage of Parkinson's disease. According to the study, caregiver tasks tripled between early-stage Parkinson's (Stage 1) and late-stage Parkinson's (Stage 4/5). Negative changes in lifestyle and caregiver depression significantly increased by stages 4/5, and positive mutual regard between caregiver and spouse began to decline by stage 2.

Caregiving and Other Chronic Diseases

Lim and Zebrack (2004) review the pertinent literature detailing caregivers' perception of quality of life. The authors reviewed 19 articles in which the characteristics of patients are correlated to caregivers' perception of quality of life. The literature reveals that there is a strong correlation between the patient's physical and emotional characteristics and the caregiver's perception of their quality of life. Several studies also examined the relationship between caregiver characteristics and quality of life and it was reported that the caregiver's age and gender had the most direct correlation to a caregiver's quality of life. Specifically, the older the caregiver, the more likely the caregiver was to perceive a negative quality of life. Additionally, female caregivers were more likely to feel overwhelmed and depressed by their caregiving duties than male caregivers (Lim & Zebrack, 2004). This is in line with earlier studies that indicated that caregiver spouses of patients were more likely to be older females.

Another important conclusion of Lim and Zebrack (2004) is that caregivers who utilize effective coping methods are more likely to report a positive quality of life. Positive coping strategies included logical analysis, problem-solving coping strategies, information seeking, affective (emotional) regulation, approach coping, and, most significantly, social support. The literature reflected the fact that the higher the levels of social network size, activity, and satisfaction, the better the perceived quality of life for caregivers, especially within the domains of life satisfaction, and mental and physical health. In other words, caregivers who had a robust social network were less likely to experience a decline in health, a change in physical function, or an increase in depression and related mental illness (Lim & Zebrack, 2004). In Sautter et al. (2014), the authors determined that, although caregiver burden remained relatively stable throughout a patient's illness, caregivers benefitted positively from referrals to social resources early in the course of the patient’s illness.

Gap in the Literature

What these studies don’t distinguish is the specific relationship between patient and caregiver. Specifically, they don’t identify how many caregivers were patients’ partners or spouses. For the caregiver who is also the spouse, a robust social network could mean self-defining activities and interactions that do not solely rely on their disabled partner for validation. Thus, a caregiver with good support outside of the marriage would be able to provide the emotional and physical support that the ill partner needs to manage their illness.

Caregiving and Marital Satisfaction

How does the role of the caregiver and the burden of care that the caregiver assumes affect the marital satisfaction with their patient-partner? Several studies attempt to address this issue.

In a study of marital satisfaction and resilience in caregivers of spouses with dementia by Fitzpatrick and Vacha-Hasse (2010), an increase in caregiver burden resulted in lower marital satisfaction. However, older caregivers, independent of burden, were found to have increased marital satisfaction. A similar study by Simonelli et al. (2007) involving caregiver spouses of Alzheimer's patients identified a negative correlation between caregiver burden and marital satisfaction.

In a study of relationship satisfaction among people with Parkinson's Disease and their caregiver-partners by Heine et al. (2021), it was found that patients' and caregivers’ sense of marital and relationship satisfaction closely paralleled each other and was correlated with low caregiver burden and low presentation of depression.

Two studies explore caregiver marital satisfaction with patient-partners who have multiple sclerosis. Tzitzika et al. (2020) observed that in a sample group of 909 Greek caregivers, most participants reported a high level of marital satisfaction and also a high level of marital commitment. The study also found that, among caregivers who reported a high level of marital satisfaction and commitment, the perception of caregiver burden was low. This was in contrast to previous studies that showed that many caregivers faced high levels of caregiver burden with low levels of marital satisfaction. The conclusion of the study is caregivers who have a high perceived level of marital satisfaction are at lower risk of experiencing caregiver burnout and related concerns, such as fatigue, depression, and anxiety. The question that the study poses is, does the positive attitude towards the caregivers’ marriage alleviate their burden of care? Or does the low level of caregiving burden translate to greater marital satisfaction?

In a smaller study of caregiver marital satisfaction by Perrone et al. (2006), 40 caregiver spouses found that couples who engaged in positive marital interaction – i.e. physical intimacy and positive communication – reported higher marital satisfaction and lower caregiver burden.

A study by Notari et al. (2017), of caregiver-partners of women with breast cancer, demonstrated that caregivers who reported significant caregiver burden at the beginning of the course of an illness eventually reported decreased burden as the course of the disease resolved itself, coupled with an inverse increase in marital satisfaction over time. In addition, this research showed that caregivers with high marital dissatisfaction at the beginning of the course of chronic illness were especially vulnerable to the stress of caregiving.

Min et al. (2019) explored the role of depressive symptoms among caregivers of spouses with chronic illnesses in Korea. The results showed that the type of chronic illness of the spouse affected the impact of depression on the caregiver. For example, symptoms of depression were significantly higher for caregivers of spouses who were diagnosed with cancer or stroke, but not for other chronic diseases. In addition, marital satisfaction at the beginning of the disease course was also a mitigating factor for depression. Lastly, gender also presented as a significant factor, as men seemed to experience fewer symptoms of depression than women. Interestingly enough, when compared to similar studies done in the United States, the results were generally the same, though the authors pointed out that disease-by-disease comparisons were difficult since the studies conducted in the U.S. did not differentiate between different illnesses. Differences in how husbands and wives viewed marital satisfaction and caregiver burden were also compared in a study conducted by Korporaal et al. (2013) which confirmed many of the findings made by earlier studies: that marital satisfaction had a negative correlation to caregiver burden, that caregiver burden could be predicted depending on the level of marital satisfaction at the beginning of the disease course, and that there was a distinction between how male caregivers and how female caregivers viewed their burden of care.

In a PhD dissertation by Leszko (2014), the role of intimacy as a mediator between caregiver burden and marital satisfaction was explored. The results were that caregivers and their patient-partners who reported satisfaction from physical and emotional intimacy were more likely to report lower caregiver burden and higher marital satisfaction. However marital satisfaction declined and caregiver burden increased when caregivers reported decreased satisfaction from intimacy. Older couples, who may tend to have less physical intimacy, reported a decrease in marital satisfaction and an increase in caregiver burden. This is negated, however, if the burden of care is shifted to another party, such as a relative or professional caregiver. The study concludes that physical and emotional intimacy is important for the emotional well-being of both the patient and spouse, regardless of who is providing care. This conclusion was also confirmed by a study conducted by Wright and Aquilino (1998) who confirmed that the emotional exchange between husband and wife, regardless of who was the patient and the caregiver, was critical to the emotional well-being of both partners.

Finally, Wilson-Genderson et al. (2009) explored the role of caregiver burden and how it affected marital and emotional satisfaction for both caregivers and patients with chronic kidney disease. They concluded that caregiver burden had a stronger negative effect on emotional satisfaction, but little impact on caregiver satisfaction. They also found that caregiver burden had little impact on the patient's emotional status.

Conclusion

Upon review of the literature, several major themes emerge. The first is that marital satisfaction is clearly negatively correlated to caregiver burden (Carter et al., 2004; Danenker et al., 2001; DesRosier, et al., 1992; Fitzpatrick & Vacha-Hasse, 2010; Heine et al., 2021; Khaira et al., 2012; Korporaal et al., 2013; Lee et al., 2015; Leszko, 2014; Lim & Zebrack, 2004; Min et al., 2020; Notari et al., 2016; Perrone et al., 2006; Pruchno et al., 2009; Reese et al., 2001; Sautter et al., 2014; Simonelli et al., 2007; Tzitzika et al., 2020; Wang et al., 2014; Wilson-Genterson et al., 2009; Wright & Aquilino, 1998). As a patient's health burden increases, and the spouse assumes a greater proportion of the caregiver duties for their partner, marital satisfaction is impacted and it usually declines throughout the illness. Additionally, the burden of caregiving impacts male and female caregivers in distinctly different ways (Wang et al., 2014; Reese et al., 2001; Lee et al., 2015; Lim & Zebrack, 2004; Min et al., 2019; Korporaal et al., 2013).

However, several significant factors can mitigate this decline and possibly prevent marital conflict and caregiver burnout. One is positive marital satisfaction before the onset of chronic illness. Reese et al. (2001) reports that caregivers with high marital satisfaction view the responsibility of caregiving as giving them a sense of meaning and purpose, as well as increasing self-esteem and emotional regard towards their partners. Another is access to emotional supports outside of the marriage, such as through close friends, family, and support groups. Caregivers who isolate tend to have lower self-esteem, higher rates of depression, and lower marital satisfaction (Reese et al., 2001; DeRosier et al., 1992; Lee et al., 2015; Carter et al., 2004; Lim & Zebrack, 2004; Fitzpatrick & Vacha-Hasse, 2010; Simonelli et al., 2007; Heine et al., 2021; Notari et al., 2017).. A third factor is access to community resources as well as help and support in the home – this can reduce the level of burden for caregivers, spread the responsibility for caregiving among a group of people rather than just the partners, and help to avoid costly and impersonal institutional care for the patients (Lim & Zebrack, 2004; Sautter et al., 2014).

The following chapters will explore approaches and interventions that can positively impact these factors on a micro, mezzo, and macro level. For example, what would be some effective interventions to create positive marital satisfaction before the onset of a major illness, and how can couples best prepare, emotionally and socially, for the possibility of a catastrophic illness? How can both members of a marital dyad create healthy support networks before and during the onset of a major illness? How can couples facing the challenges of a major illness have access to adequate and appropriate community resources so that the burden of care is spread out among formal and informal caregivers?

When implementing interventions, how can we take into consideration the differences in how male and female caregivers experience burden?

Finally, as Social Workers, how can we implement these interventions on the micro (direct interventions with the patient and caregiver), mezzo (interventions and resources targeted to couples and families), and macro levels (community and government support/assistance programs)? A successful strategy will mean higher rates of marital satisfaction, lower rates of caregiver burnout, lower rates of depression and correlated health concerns of the caregiver, lower rates of institutionalization, and, ultimately, a lower burden of cost to the community

CHAPTER THREE

METHODS

Introduction

This researcher has determined that the most appropriate methodology for this research project is a scoping review. This methodological approach will enable the researcher to systematically explore the breadth and depth of the available literature on the topic, providing a comprehensive overview of existing research. By using the scoping review, the researcher will map out the extent of the available evidence and also analyze and synthesize the findings to offer a clear picture of the current state of knowledge of evidence-based therapeutic interventions for marital dyads where one spouse is diagnosed with a chronic illness.

A scoping review is particularly well-suited for this project as it allows the researcher to investigate a wide range of studies, identify key trends, and highlight gaps in the literature. This approach will facilitate the exploration and identification of relevant interventions, enabling the researcher to present a detailed analysis of the therapeutic approaches currently employed to support couples in this situation. The scoping review will allow the researcher to identify critical factors that could shape the development of future social work interventions, particularly those that address caregiver burden, marital satisfaction, and emotional well-being in the context of chronic illness.

In this chapter, the researcher will provide an in-depth examination of the study designs employed in the reviewed literature, the sampling strategies used for data collection, and the tools and methodologies applied to gather the data. The researcher will also outline the procedures followed in these studies, including any measures taken to protect human subjects, and describe the data analysis processes employed. By thoroughly reviewing and synthesizing this information, the researcher will present a clear and comprehensive summary of the available evidence and its implications for social work practice. This will include a discussion of how these findings can inform clinical practice, enhance policy development, and improve support for marital dyads facing the challenges of chronic illness.

Study Design

This exploratory research project will employ a scoping review to gather, evaluate, and synthesize existing studies on the impact of caregiving within a marital dyad where one partner is diagnosed with a chronic illness. The primary objective of this research is to identify evidence-based therapeutic interventions that have the potential to alleviate symptoms of depression and burnout experienced by caregivers in such partnerships. The researcher will conduct a thorough search of academic databases to locate articles that meet predetermined selection criteria. Following this, a detailed review of the literature will be performed to uncover key trends, patterns, and themes related to caregiving within this context.

The significance of this research for the field of social work will be explored, particularly in terms of its potential to inform clinical practice, guide therapeutic interventions, and shape support services for caregivers and couples managing chronic illness. The scoping review has been selected as the most appropriate methodology for this research because it does not involve human subjects and allows for a comprehensive examination of existing studies. Additionally, this method provides an opportunity to expand upon and synthesize available research, thereby contributing to the development of effective interventions specifically tailored to the needs of marital dyads facing chronic illness.

To ensure a robust and wide-ranging review, the researcher will utilize scholarly databases such as One Search, EBSCOhost, JSTOR, PsychINFO, SAGE Journals Online, and Google Scholar, focusing on studies published between the years 2000 and 2024. To identify the most up-to-date research findings, the researcher may face some limitations in assessing certain articles or journals due to restrictions on access permissions. However, the scoping review will aim to incorporate as many relevant sources as possible in order to provide a comprehensive analysis of the interventions that can support caregivers in mitigating emotional distress and enhancing overall well-being within the marital relationship.

Sampling

Inclusion criteria for this study will be carefully defined to ensure that only relevant sources are considered. Eligible articles must meet the following conditions: they must be peer-reviewed and available on one of the previously identified search databases. The articles must not require any purchase or subscription fees to view. The selected studies must have been published between the years 2000 and 2024 and must specifically reference a marital dyad in which one partner has been diagnosed with a chronic illness. The articles should focus on evidenced-based and data-driven interventions that target caregivers within these relationships, and they must address aspects of marital or couple satisfaction as part of their analysis.

Exclusion criteria will ensure that studies falling outside the scope of this research are omitted. Articles that are not peer-reviewed, those not available in the identified search databases, and articles requiring purchase for access will be excluded. Any articles published prior to 2000, as well as articles that have not yet been published, will not be considered. The research will also exclude gray literature, literature reviews, and articles that do not specifically reference both a marital dyad and the diagnosis of a chronic illness.

Data Collection and Instruments

The researcher will conduct an extensive search for data relevant to this study by utilizing scholarly databases to identify peer-reviewed journal articles, following a well-defined set of inclusion and exclusion criteria. These databases will be accessed through the California State University, San Bernardino library, which provides comprehensive resources for academic research. The initial phase of the search will involve reviewing abstracts of the identified articles to determine their relevance and suitability based on the established criteria for further inclusion.

Once the abstracts have been screened, the researcher will systematically categorize the articles, documenting key details such as author(s), year of publication, country of origin, research methods, type and purpose of the study, population characteristics and sample size, types of interventions implemented, and the outcomes and results reported. This structured categorization process ensures that each study is thoroughly evaluated for its contribution to the research question.

Following this, the researcher will read through each selective article in its entirety to ensure that it fully aligns with the eligibility criteria for inclusion in the scoping review. This comprehensive reading is essential to validate that the article provides valuable data and meets the necessary academic and methodological standards.

To facilitate an organized and consistent data collection process, the researcher will utilize a data collection instrument modeled after the framework developed by George and Laitano (2023). This tool will assist in systematically gathering, analyzing, and interpreting the data, ensuring accuracy and rigor in the review process. Once articles have passed the full review, they will be included in the final scoping review, which will provide a comprehensive overview of evidence-based therapeutic interventions relevant to the study's focus on marital dyads where one spouse is diagnosed with a chronic illness.

Procedures

The researcher will employ a carefully curated set of specific keywords and phrases to guide the search for peer review articles relevant to the study. These keywords have been selected to ensure a comprehensive exploration of literature pertinent to key themes and variables under investigation. The chosen keywords will include, but are not limited to: chronic illness, caregiver burden, marital satisfaction, depression, self-esteem, quality of life, caregiver spouse, intimate partner, domestic partner, partnership, gender differences, evidenced-based interventions, intervention effectiveness, and evidence-based practice. These terms are strategically designed to capture a wide range of research findings that relate to the experiences of individuals and couples where one spouse is managing a chronic illness, with a particular focus on the psychosocial and relational dynamics within such partnerships.

It is important to note that this research will exclusively focus on quantitative studies, thereby excluding qualitative research from the scope of the review. The rationale behind this decision is to prioritize studies that provide measurable data on intervention effectiveness and outcomes. By using these keywords, the researcher will identify robust, empirical supportive studies that can inform the analysis and contribute to a well-rounded understanding of the evidence-based therapeutic interventions available for supporting marital dyads affected by chronic illness.

Protection of Human Subjects

This study does not involve the direct participation of human subjects as all data will be sourced from previously published research and existing studies. However, to guarantee full compliance with Institutional Review Board (IRB) protocols and uphold the highest ethical standards throughout the research process, the study will still be subjected to a preliminary review. Specifically, it will undergo an initial Collaborative Institutional Review Board Training Initiative (CITI) review. This step ensures that all aspects of the project align with the ethical considerations mandated for research involving human subjects, even though no new data will be collected directly from individuals. By adhering to these guidelines, the study will maintain the necessary integrity and ethical responsibilities required within academic and research settings.

Data Analysis

After gathering and thoroughly reviewing all relevant data, the researcher will proceed to systematically extract key components from each study. This will include detailed information about the participants, such as the total number of participants, their ages, gender, medical diagnosis, ethnicity, race, and country of origin. In terms of interventions, the researcher will document the type of treatment administered, the number and frequency of encounters, the duration of the intervention program, and the specific methodology employed. This includes the study's purpose, source of participant recruitment, publication source, outcome measures, year of publication, the setting and location where the study was conducted, and the overall study design.

Next, the researcher will meticulously select the most relevant studies for further review. These studies will be systematically analyzed and presented in comprehensive tables. Each table will be structured to categorize and outline key aspects of this research, including the type of study (e.g., randomized, controlled trial, cohort study), the methodologies utilized (quantitative or mixed methods), the specific interventions applied (e.g., counseling, cognitive-behavioral therapy, support groups), the characteristics of the target population, and the measured effectiveness of the interventions.

This in-depth review will highlight a variety of evidence-based therapeutic approaches that are available for marital dyads in which one spouse is managing a chronic illness. Moreover, the findings will not only focus on the clinical effectiveness of these interventions, but also explore their implications for the broader field of social work. The researcher will examine how these interventions can inform clinical practice, guide policy development, and influence the provision of support services for couples who are dealing with the challenges posed by chronic illness. By identifying and analyzing the most effective therapeutic approaches, this research will contribute to the development of targeted, evidence-based interventions that can significantly improve the quality of life for both caregivers and their partners.

Summary

This study aims to investigate the range of available evidence-based interventions designed to support marital dyads in which one spouse is diagnosed with a chronic illness. The primary focus will be on interventions that have been shown to reduce caregiver burden, alleviate depression, and enhance marital satisfaction. In addition to evaluating the effectiveness of these interventions, the study will systematically examine the existing literature to identify gaps in the research, highlight key concepts and findings from earlier studies, and assess the broader implications for the field of social work.

This chapter detailed the design and methodology employed in the scoping review, offering a clear framework for how the study will be conducted. The researcher has chosen to utilize a scoping review as the methodological approach for this study because it allows for a broad and comprehensive analysis of the literature without the need for human subject participation. Data will be sourced from previously conducted research, eliminating the ethical and logistical complexities involved in direct data collection from individuals.

The scoping review methodology provides several key advantages, including the ability to examine a larger number of studies across a wide range of topics, offering a more expansive understanding of the research landscape. This approach allows the researchers to thoroughly explore the existing body of knowledge, identifying not only effective interventions but also areas where further research is needed. By synthesizing these findings, this study will offer valuable insight into how social work practitioners can better support couples navigating the challenges of chronic illness. The review will also address how these findings can be applied in social work practice to inform therapeutic interventions, policy development, and the creation of support services aimed at enhancing the well-being of both spouses in such relationships.

APPENDIX A

DATA COLLECTION AND EXTRACTION SPREADSHEET

Data Charting

EVIDENCE-BASED THERAPEUTIC INTERVENTIONS AVAILABLE FOR MARITAL DYADS WHERE ONE SPOUSE IS DIAGNOSED WITH A CHRONIC ILLNESS:
A SCOPING REVIEW
Based on George and Laitano's (2023) instrument

Data Extraction Tool	
A. Person responsible for the extraction	
B. Bibliographical Data Author Year of publication of article Country of origin where study was published Country of origin where study was conducted	
C. Methodology Type of research used Purpose of the study	
D. Population Number of persons involved Inclusionary criteria of the study Exclusionary criteria of the study Demographic characteristics	
E. Interventions Intervention type(s) Intervention category(ies) Number of interventions used Duration of interventions used	
F. Outcomes Overall research findings of study	
G. Key findings Key findings that relate to the scoping review question	

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