

AMERICAN UNIVERSITY OF BEIRUT

PREDICTORS OF PHYSICAL AND PSYCHOLOGICAL
QUALITY OF LIFE IN INFORMAL CAREGIVERS OF
PATIENTS LIVING WITH CHRONIC ILLNESSES

by
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ABSTRACT OF THE PROJECT OF

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Title: Predictors of Physical and Psychological Quality of Life in Informal Caregivers of Patients Living with Chronic Illnesses

Background: About 700 million individuals aged 65 years or older currently populate the world and this number is expected to double to 1.5 billion by 2050. Lebanon and the Middle East and North Africa region are expected no different with prevalence rates expected to reach 17.8% by 2050. Aging is coupled with a rise in chronic illnesses and hence the role of informal caregivers [ICs] becomes ever so important. This burden and a lack formal support for caregivers has led to an increased prevalence of caregiver burden, contributing to a decline in both physical and psychological quality of life [QOL].

Aim: The primary purpose of this secondary analysis is to determine predictors of physical and psychological QOL in ICs of patients living with chronic illnesses in Lebanon.

Methods: Guided by an integration of the Informal Caregiving Integrative Model and using data from a sequential exploratory mixed methods study design, we recruited dyads from a major tertiary medical center in Lebanon. QOL was measured using the Arabic translated version of World Health Organization QOL–BREF and was studied across several predictors.

Results: Our sample included 104 ICs [82.7% females; mean age 54.43 years]. QOL of ICs was moderate with means of 63.29 ± 20.34 for the physical, 65.14 ± 16.99 for the psychological, 58.25 ± 21.14 for the social, and 63.61 ± 17.66 for the environmental. A lower negative impact from caregiving [denoting lower personal feeling of being stressed in caregiving], a higher psychological and environmental QOL, and a lower family wellbeing explained about 62.4% of the variance in the IC physical QOL. A higher IC physical and social QOL, better IC coping, and higher duration of caregiving explained about 55.5% of the variance in the IC's psychological QOL.

Discussion: Our study provides insights into the QOL of ICs caring for patients with chronic illnesses in Lebanon, revealing a complex interplay of factors influencing their well-being. The findings underscore the need for tailored support interventions addressing caregiver burden, coping mechanisms, and the dynamics of caregiving relationships to enhance ICs' QOL and overall caregiving experience.

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Keywords: Informal Caregivers, Quality of Life, Patients with Chronic Diseases, Mental Health, Physical Health, Psychological Distress.

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CHAPTER 1

INTRODUCTION

1.1. Background

About 700 million individuals aged 65 years or older currently populate the world and this number is expected to double to 1.5 billion by 2050 (United Nations, 2019). Lebanon and the Middle East and North Africa (MENA) region are expected to be no different with prevalence rates expected to reach 17.8% by 2050 (Yount & Sibai, 2009). Aging is coupled with a rise in chronic debilitating illnesses and hence the role of self and home care becomes imperative. Home care can be provided in a formal or informal manner (Albin, 2011). Informal care refers to the unpaid care given by family, friends, or volunteers and is critical in supporting individuals with chronic non-communicable illnesses or disabilities (Roth et al., 2015).

Informal Caregiving is key to resilient healthcare systems and the need for it will grow exponentially in the coming decades because of an increasingly aging population living with complex chronic illnesses (Schulz et al., 2020). When the IC is providing this care, the patient-caregiver is referred to as a dyad. Informal caregiving encompasses a broad spectrum of tasks, ranging from simple support with everyday tasks and assistance in providing personal care for the care recipient to guiding them through the intricate healthcare and social service systems (Schulz et al., 2020). This type of caregiving has become prevalent, and its demand is rising globally due to multiple inevitable reasons (Silva et al., 2013).

With an aging population comes myriad of factors that predispose older adults to needing assistance from others in performing activities of daily living. Limitations in

physical and mental health and functioning are among the main reasons. Developing chronic health conditions, such as heart disease, diabetes, arthritis, and dementia require ongoing home-based care and management, which can be difficult for older adults to handle on their own. Thus, living longer often means living with impairments that can hinder one's ability to carry out daily tasks. As individuals age, they are more prone to develop physical or cognitive impairments that impact their ability to function independently during which ICs play a crucial role in supporting and helping them to maintain their independence and QOL (Adams et al., 2013; Wolff & Jacobs, 2015).

However, this does not happen without a cost. This caregiving role and a lack of formal support for ICs has led to an increased prevalence of caregiver burden, contributing to a decline in both physical and psychological QOL. Studies showed that ICs taking care of chronically ill patients were more likely to have poorer QOL and greater psychological problems than the care recipients (Hodges et al., 2005; McCorkle et al., 2007), and they are more prone to experience anxiety and depression than the general population (Karabekiroğlu et al., 2018). Additionally, increased caregiving responsibilities raise the likelihood of caregiver fatigue and places the caregiver at an elevated risk of experiencing declines in both physical and mental health (Burton et al., 1997).

1.2. Significance and Aim

Providing care for patients living with chronic illnesses has repercussions on the lives and daily routines of those providing the care and can lead to negative effects on both physical and mental well-being. Studies have shown that a rise in caregiving responsibilities elevates the likelihood of caregiving fatigue, thereby increasing the risk

of both physical and mental health decline for the IC (Burton et al., 1997; Yang et al., 2012). ICs who suffer from caregiver burden or strain have a 63% elevated risk of mortality compared to those not in caregiving roles (Schulz & Sherwood, 2008). A substantial body of research shows that ICs have higher rates of psychological distress (anxiety or depressive symptoms) than their counterparts who do not provide care to a sick family member (Karabekiroğlu, 2018; Yıkılkan et al., 2014).

Across illness contexts, patients and ICs influence each other's health outcomes (Cipolletta et al., 20220) making it relevant to focus on the patient and IC simultaneously, as a unit or dyad, to optimize their QOL. Few previous studies have explored the health statuses and factors associated with the QOL life in individuals providing care for older adults. However, this was never the case in Lebanon or the Middle East/North Africa (MENA) region. Additionally, studies in the Arab context rarely focused on mental health and QOL of ICs. Thus, approaching illness from a dyadic perspective provides a more practical representation of how patients and their ICs live through and cope with the illness (Lyons et al., 2015). This underscores the significance of considering the interpersonal aspect of illness (Thompson & Walker, 1982). Dyadic research acknowledges that the patient and their IC are an interdependent entity working together within the same life context, and their shared appraisal of the illness can impact how they manage the disease (Lyons & Lee, 2018). Because patients living with chronic illnesses face difficulties in carrying out self-care, the involvement of ICs is essential. However, this involvement may be a causative factor for poor physical and psychological QOL in ICs.

In this analysis we aim to identify predictors of physical and psychological QOL in ICs of patients living with chronic illnesses in Lebanon. Knowledge from this analysis

will help position ICs QOL at the core of caregiving processes. By preventing or addressing poor QOL, healthcare providers can enhance positive outcomes of ICs, control dyadic dependence, and maintain the patients' and their ICs' psychological and physical well-being.

CHAPTER 2

LITERATURE REVIEW

ICs play a crucial role in supporting individuals living with chronic illnesses within an aging population (Schulz et al., 2020). These are key elements in the lives of people they care for and essential components of the whole health care system, yet their significance to society has newly been recognized and valued (Del Castillo, 2023). As the prevalence of chronic conditions rises with age, those caregivers, often family members or friends, become integral to the overall well-being of the affected individuals. They provide essential emotional, physical, and practical assistance, contributing to the management of symptoms and enhancing the QOL for those with chronic illnesses (Schulz et al., 2020). ICs also help alleviate the burden on formal healthcare systems by offering personalized, continuous care (Schulz et al., 2020). Recognizing and supporting the efforts of ICs is essential for promoting the health and resilience of an aging society grappling with the challenges of chronic conditions.

2.1. Informal Caregivers in Lebanon and the Arabic Speaking MENA Region

Based on past demographic information from the Lebanese Ministry of Social Affairs, individuals aged 65 or older accounted for 8% of the Lebanese population (Abyad, 2001). Projections indicate that by 2025, this age group is anticipated to constitute 13% of the population (Sibai et al., 2004). Most elderly individuals in Lebanon reside with their families (Shideed et al., 2013). Within such living arrangements, family members typically offer the primary assistance and care needed when their older relative is experiencing functional or cognitive impairments.

Few research studies have been conducted in Lebanon exploring the health of family caregivers and the challenges they face when caring for patients with chronic illnesses. One study by Dumit and colleagues studied ICs of cardiac patients in Lebanon shedding the light on the challenges they faced in this context (Dumit et al., 2015). It revealed that family caregivers feel a strong sense of duty and obligatory responsibility towards their ill family member, and they offer various forms of support and care. In Lebanon, ICs felt a strong sense of duty and emotional responsibility to stay close to their loved ones and provide care, regardless of whether the patients could manage their disease on their own (Dumit et al., 2015). Another study explored the lived experiences of nine ICs of cancer patients, eight themes emerged: dealing with fears and uncertainty, loss of happiness, added responsibility, living in an emergency state, sharing the pain, navigating truth-telling dilemmas, coping with pity, and relying on God. Authors suggest that nurses should be aware of the challenges faced by family caregivers (Dumit et al., 2008).

Research from the region, although not exclusively focused on QOL, provides valuable insights into the experiences of informal caregiving in the MENA region. One study investigated the QOL of family caregivers in Saudi Arabia who provided care for patients with chronic diseases, including cardiovascular disease, diabetes, cancer, and other illnesses, amidst the COVID-19 pandemic (Aljuaid et al., 2022). The study, involving 1081 ICs, utilized the World Health Organization Quality of Life Assessment tool (WHOQOL-BREF) questionnaire to measure QOL. Results showed that ICs of cancer patients reported the highest QOL levels, followed by those caring for diabetes and cardiovascular disease patients, with the lowest reported by ICs of patients with other diseases. The study highlights the importance of incorporating QOL assessments

for caregivers of chronically ill patients and recommends regular psychological and physical health evaluations for caregivers within the healthcare system. It also calls for further research to identify factors influencing health outcomes for caregivers and patients at personal, organizational, and national levels, aiming to enhance overall well-being in caregiving contexts.

In a Jordanian mixed-method study researchers aimed to gain a deeper understanding of the mental health experiences of ICs and to propose potential social work interventions (AlMakhamreh, 2017). Results showed that most ICs are adult females who face challenges such as stress, domestic violence, social exclusion due to their caregiving responsibilities, and concerns about stigma. It emphasized the importance of considering cultural and religious factors in addressing the caregiving role effectively. The implications of these findings suggest the need for social work practices at a community level, focusing on familial and support-group interventions that are sensitive to gender and religious considerations. This approach aimed to provide more tailored and effective support for ICs in managing their mental health and well-being.

Additionally, a study conducted on the unmet needs of ICs, caring for cancer patients receiving chemotherapy on an outpatient basis, highlighted how cultural factors specific to Jordanians and Arabs contribute to these unmet needs and increase their feelings of burden (Al-Jauissy, 2010). The study noted that Jordanian and Arabic cultures emphasize a strong sense of duty and dedication towards the ill, which manifests in intentions, verbal affirmations, and actions. This cultural expectation drives caregivers to strive for perfection in meeting their obligations, ultimately amplifying their burden across these three levels.

2.2. Essential Support in Daily Life and Emerging Challenges

Informal care refers to unpaid care given by family, friends, or volunteers and is critical in supporting individuals with chronic non-communicable illnesses or disabilities (Roth et al., 2015). When the IC is assisting in the care of a patient, the couple (patient-caregiver) is referred to as a dyad. Informal caregiving encompasses a broad spectrum of tasks, ranging from simple aiding with everyday tasks and assisting in providing personal care for the care recipient to guiding them through intricate healthcare and social service systems (Schulz et al., 2020).

Assisting an older individual dealing with persistent health issues demands the IC to maintain optimal physical and mental well-being. This is crucial due to the substantial physical and emotional challenges associated with caregiving, encompassing tasks such as aiding with personal hygiene, ensuring the fulfillment of medical requirements, and addressing the daily uncertainties related to the individual's prognosis (Penning & Wu, 2016; Stanley et al., 2017). This type of caregiving has become prevalent, and its demand is rising in various countries due to multiple unescapable reasons (Silva et al., 2013). Other than the advanced age, limitations in physical health and functioning, mental health, and/or cognitive functioning are the main reasons why older adults require assistance from others.

Developing chronic health conditions, such as heart disease, diabetes, arthritis, and dementia, require ongoing care and management. This can be difficult for older adults to handle on their own and can impact their ability to manage household tasks and run errands, leading to increased reliance on ICs. These physical limitations can result in increased feelings of loneliness and depression, which can be mitigated through social interaction and support from ICs (Stone, 2015). Therefore, living a longer life

frequently entails dealing with challenges that may impede one's capacity to perform everyday activities and sometime this is accompanied with impairments but without implying that all older individuals are physically or mentally impaired. Thus, assisting elderly individuals with daily activities should not be considered a natural consequence of aging (Stone, 2015).

2.3. Effects of Informal Caregiving on Caregiver's Well-Being and Quality of Life

As individuals age, they are more prone to develop physical or cognitive impairments that impact their ability to function independently during which ICs play a crucial role in supporting and helping them to maintain their independence and QOL (Adams et al., 2013; Wolff & Jacobs, 2015). However, this does not happen without a cost. As those elderly individuals age, their ICs gradually age too. Thus, ICs are progressively more susceptible to developing chronic conditions, leading to various consequences (Penning & Wu, 2016; Stanley et al., 2017).

QOL is defined as a person's insight of his or her position in life in the context of the culture and value systems in which they live and in relation to one's own goals, expectations, standards, and concerns. It comprises various domains such as the person's physical, psychological, and social well-being, personal beliefs, level of independence, and environmental relationships (Bužgová et al., 2009).

Studies have shown that those ICs were more likely to have poorer QOL and greater psychological problems than the care recipients (McCorkle et al., 2007; Hodges, Humphris, & Macfarlane, 2005), and they are more prone to experience psychological distress, anxiety, and depression than the general population (Karabekiroğlu et al.,

2018). Therefore, identifying the predictors of the to better understand and address ICs' physical and psychological distress if of paramount importance.

2.4. Exploring the Complexities of Informal Caregiving

A substantial body of evidence found that increased levels of psychological distress was reported in cancer patients and their ICs as compared to the general population (Northouse, 1989; Oberst et al., 1989). In one study done in Turkey, symptoms of depression and anxiety in ICs were linked to lower caregiver QOL (Yıkılkan et al., 2014). More than half of the ICs had depressive symptoms and 12.7% were suffering from severe depression. Detrimental consequences of IC's health and QOL significantly decreases their ability to deliver care for their patients. Consequently, the attention and support that caregivers can offer to the older adults they are looking after will be diminished if they prioritize their own health requirements (Bužgová et al., 2009).

In a study conducted in Singapore, authors referred to ICs as the hidden patients and reported that more than half of ICs faced chronic had physical (58.6%) and psychological (52.6%) issues (Sambasivam et al., 2019). Interestingly, ICs tended to experience higher emotional exhaustion and a sense of reduced personal accomplishment compared to professional caregivers like nurses, physicians, and social workers (Almberg et al., 1997; Takai et al., 2009). A considerable amount of research has delved into the challenges faced by ICs of individuals with depression, including work limitations (Stjernsward & Ostman, 2008), social isolation, family dynamic changes (Highet et al., 2004), abandonment of leisure activities, and financial struggles (Skundberg-Kletthagen et al., 2014; Gbiri, Olawale, & Isaac, 2015). A cross-sectional

study on 345 ICs of cancer patients showed that anxiety and burden were experienced by 34.1% of ICs mainly spouses and parents (Rumpold et al., 2016). Chan and Ng (2022) suggested that anxiety in ICs was associated with depression and with lower ICs' perception of their physical and psychological inability to meet the care recipients' demands. It's crucial to note that while informal caregiving is often associated with experiences, many ICs view it as a positive aspect of their lives (Yamamoto-Mitani et al., 2004). In fact, families develop a sense of equilibrium, a consistent dynamic and rhythm, that often change when a family member is diagnosed with a long-term illness. These diagnoses alter familial roles and duties and can evoke feelings of sadness, depression, anxiety, and hopelessness (Golics et al., 2013).

2.5. Exploring the Complexities of Informal Caregiving

2.5.1. Gender, Age, Family Dynamics, and Care Recipient Characteristics

A large body of literature studied potential predictors of psychological morbidity and poor psychological QOL in ICs. Consistent with Karabekiroğlu et al.'s (2018) findings, being female (Morgan et al., 2016; Given et al., 2004; Valeberg & Grov, 2013) and older (Marwit & Meuser, 2002) render ICs more prone to develop psychological illnesses. Likely, spousal dyadic relation type is more predisposed to depression as compared to other family members (Rumpold et al., 2016; Fasse et al., 2015; Götze et al., 2014) and adult children (Given et al., 2004).

Moreover, characteristics of care recipients affect well-being and QOL in ICs. ICs of younger patients (Tang et al., 2013), those showing psychological maladjustment (Götze et al., 2014), and patients with physical impairments (Valeberg & Grov, 2013) are more likely to have higher psychological suffering. Areia and colleagues suggested

that primary as well as nonprimary caregivers are at close probability to develop psychological distress, depression, somatization, and anxiety (2019).

2.5.2. Caregiver Burden, and Relationship Quality in the Context of Health-Related Quality of Life

IC's burden is linked to many adverse effects on their physical, social, and psychological well-being (Morimoto et al., 2003). The extent of the caregiving burden might be connected to the morbidity and comorbidity of the patient. Individuals providing care for patients with multiple chronic illnesses are likely to experience more significant consequences of caregiving compared to those caring for patients with only a single chronic illness (Sherwood et al., 2005). Factors such as chronic physical health issues and comorbidities, psychological distress, and having a secondary education level were linked to reduced physical QOL. Similarly, psychological distress, younger age, primary education status, and increased caregiving duration were associated with lower mental QOL (Sambasivam et al., 2019).

A favorable quality of the relationship between a patient and caregiver serves as a protective factor against the adverse effects of illness. Patients and caregivers who view their relationship more positively generally experience better outcomes (Hooker et al., 2013). Various other attributes of caregivers are linked to their Health-Related QOL. For instance, women in caregiving roles have indicated lower levels of well-being and health status, especially concerning mental health, along with heightened experiences of depression compared to their male counterparts (Arnsberger et al., 2012; Pinquart & Sörensen, 2006). Conversely, male caregivers frequently reported superior physical and mental well-being in comparison to female caregivers (Gibbons et al., 2014; Tommis et al., 2007). Additionally, female caregivers are more prone to comorbidities and chronic

illnesses, irrespective of the specific ailment or disease affecting the care recipient (Neri et al., 2012; Wang et al., 2014).

2.5.3. Family Functioning, Appraisal, Social Support, and Cultural Influences on Quality of Life

Areia and colleagues (2019) concluded that the quality of family functioning is closely correlated with the impact of a terminal disease on family carers, suggesting that poor family functioning is more likely to negatively impact the caregivers' psychological wellbeing. It was also found that ICs who negatively appraise their caregiving experience are more likely to perceive their tasks as demanding and stressful, whereas those who positively appraise their experience tend to express improved performance motivation and perceive their tasks to be less stressful and burdensome (Muldary, 1983).

Additionally, Karabekiroğlu et al. (2018) found that ICs receiving social support with their caregiving roles are less prone to psychological distress as their psychological and physical burden would be significantly reduced. Similarly, the QOL for ICs tending to individuals with chronic diseases and functional limitations is positively influenced by enhanced support from others, a more favorable self-assessment of their health, and increased caregiving experience. Likewise, it was found in a study conducted in Lebanon including 319 primary caregivers that the ICs' wellbeing is positively correlated with the informal emotional support that they receive ($p < 0.001$), and an insufficient emotional support is linked to an increase in role strain ($p < 0.001$) (Séoud et al., 2007). Moreover, social support, mainly family support emerged as a crucial factor influencing the self-care habits of Lebanese cardiac patients too. Regardless of the patients' own capabilities, their family members actively assisted

them with self-care tasks. Interestingly, the patients welcomed this assistance from their families, while the family members themselves felt a strong sense of responsibility for their loved ones' health and well-being (Dumit et al., 2015).

Conversely, a rise in depressive symptoms among care recipients is linked to a decline in the QOL for the caregivers (Ślusarska et al., 2019). Additionally, caregiving preparedness; defined as the caregiver's perception of their readiness to attend to a patient's physical and emotional needs, handle emergency situations, and provide general healthcare for the patient (Archbold et al., 1990), causes improvement in anxiety, depression, hope, mental health, role strain, overall QOL, and sense of reward in ICs (Henriksson & Kristofer, 2013; Schumacher, Stewart, & Archbold, 2007). Furthermore, the study conducted in Turkey by Yıkılkan et al. (2014) highlighted that the lack of support groups and community programs that assist the caregiver and their patients is a major issue that need to be addressed.

Moreover, culture plays a pivotal role throughout the process of caregiving. Pharr et al., (2014) found that the ICs' experiences of caregiving vary greatly among different cultural and ethnic groups. The cultural context and embeddedness of caring also affects whether it is seen as a voluntary act or a required obligation. Besides, the perception of the caregiving role as an expected aspect of one's life course was influenced by cultural values and traditions. Family values like familism and family devotion severely discouraged caregivers from refusing to take on the caregiving obligations and even enforced them (Pharr et al., 2014). In nations like Lebanon and the MENA region, this is anticipated to be the case.

Previous studies largely examined many predictors of physical and psychological QOL among ICs addressing the concepts social support, anxiety,

depression, age, gender, culture, caregiving preparedness, and IC's medical history.

These predictors are considered deleterious to ICs QOL. There are no similar studies in the literature conducted in the Arab context. Thus, this will be the first Arab study to address ICs psychological distress and as such it is expected to raise awareness about ICs state of mental and physical health and their overall QOL.

CHAPTER 3

THEORETICAL FRAMEWORK

This study was guided by the Informal Caregiving Integrative Model (see Appendix A), which combines elements of the Job Demands-Resources Model from studies on occupational burnout and the Caregiving Stress and Burden Model from health literature.

This model focuses on the aspects that impact caregiver burnout, including the caregiving environment (primary stressors and secondary elements), caregiver attributes and characteristics (such as sociodemographic factors, preparedness, and physical condition), and the sociocultural context (including social support and caregiver decision-making) (Gérain & Zech, 2019). Burnout serves as a critical link connecting these factors to overall outcomes like anxiety, depression, and poor QOL. Additionally, the model suggests that the impact of these factors on burnout is influenced by how caregivers appraise their caregiving experience (both positively and negatively), and the quality of their relationship quality with the person they care for (Gérain & Zech, 2019). Coping strategies are viewed as mediators between burnout and how caregivers appraise their caregiving experience, as well as quality of the dyadic relationship.

The measured dyadic concepts encompass the QOL, and general health outcomes of ICs (Lyons & Lee, 2018; Pucciarelli et al., 2017).

CHAPTER 4

METHODS

4.1. Study Design

This is a quantitative correlational analysis of a sequential exploratory mixed methods study on: Appraisal, Burnout, and Coping in Dyads Living with Chronic Illness: The ABCs of Informal Caregiving. The primary study was a mixed methods study with the primary purpose of exploring QOL, family relationships, and health outcomes of dyads living with chronic illnesses. This analysis is done with a primary purpose of exploring the predictors of physical and psychological QOL of ICs of patients living with chronic illnesses in Lebanon.

4.2. Population, Sample, and Setting

The sample was a convenience sample that included 104 patient-caregiver dyads recruited from the adult non-oncology inpatient units and outpatient clinics at Lebanon's biggest tertiary medical center. Assuming a medium anticipated effect size of 0.15, a desired statistical power level of 0.8, a significance level of 0.05 for a multiple regression with 8 predictors, a minimum sample size of 104 subjects was needed.

Patients were included in this study if they spoke Arabic, were 30 years or older, lived with one or more chronic illness such as cardiovascular, pulmonary, and/or renal disease for more than 6 months prior to inclusion in the study, and at the time of data collection had an IC who assisted them with their self-care. They were excluded from the study if they were clinically unstable, in an acute exacerbation, had a concomitant

terminal illness, and/or documented dementia. ICs needed to meet the following eligibility criteria: identified by the patient as the primary caregiver, not paid for the care, someone who provided care on a regular basis (over a minimum of 5 hours per week), were present with the patient in the hospital/clinic visit and was willing to provide consent to participate in the study.

4.3. Protection of Human Participants

The initial study was as submitted to the institutional review board [IRB] for approval before starting the data collection phase. Confidentiality of data was maintained all throughout the data collection phase. Information that identified participants directly was not collected. Questionnaires were stored in a locked cabinet in the primary investigator's office and electronic files will be stored in the primary investigator's password protected computer.

4.4. Measures

Medical record review and a semi-structured interview were used to obtain information on age, gender, education, place of residence, marital status, living status, number of persons in the household, annual income, occupational status, disease indices of the care-recipient including any chronic illness and the number of comorbid medical conditions, duration of the illness that required the intervening of an IC in years, and the recipient's number of hospitalizations in the last year. Please check Appendix B for concepts and methods of measurement.

4.5. Data Analysis

Quantitative data was analyzed using descriptive statistics performed using IBM SPSS Statistics version 29.0 for Windows. The data was checked for distribution, skewness, and linearity. The level of significance for statistical tests was set at $p < 0.05$. Descriptive statistics was used to summarize ICs' QOL as well as sociodemographic characteristics of patients and their ICs and caregiving setting. The QOL of ICs, this analysis's main outcome, will be described using frequencies, means, and standard deviations.

Descriptive statistics of various possible determinants of QOL of ICs will be provided. This includes prevalence analysis (count and percentage) of anxiety, depression, and coping in patients and ICs and caregiver preparedness, social support, and caregiver burnout among ICs of patients living with chronic illnesses.

Scores for ICs' physical and psychological QOL, measured using the World Health Organization QOL–BREF, will be used as the main study outcome. QOL scores will be compared across demographic and caregiving characteristics using independent sample t test and analysis of variance tests or Pearson r as appropriate for the level of measurement of the variables. An analysis of potential baseline covariates identified in the literature was conducted to identify a comprehensive set of covariates associated with ICs' physical and psychological QOL ($p < 0.05$) without collinearity concerns.

Finally, multiple regression analysis will be used to study the associations with the physical and psychological QOL among ICs, and to determine the strength and significance of the relationships between the predictor variables and the outcome variables in the previously mentioned sample considering a broader set of variables and potential interactions.

CHAPTER 5

RESULTS

5.1. Sample Characteristics

Data collection took place over a 15-month period commencing in May 2023. One hundred and four participants were recruited from the non-oncology inpatient units and outpatient clinics at a tertiary medical center in Lebanon. Patient participants had a mean age of 73.43 ± 9.56 years with 77.9% married, and 41.3% females. IC participants had a mean age 54.43 ± 13.54 years and 82.7% of them were males with 73.1% married. Almost half of the ICs and less than one fifth of the patients were employed. Most of the ICs had a high school or university degree [please refer to Table 1 for Sample Characteristics].

Table 1. Patient and Caregiver Characteristics.

Variable	Mean \pm SD or n [%]	
	Caregiver	Patient
Age in years	54.43 \pm 13.54	73.43 \pm 9.56
Female Gender	86 [82.7]	43 [41.3]
Education		
Illiterate	2 [1.9]	4 [3.8]
Intermediate	2 [1.9]	8 [7.7]
High School	28 [26.9]	37 [35.6]
University Degree	70 [67.3]	36 [34.6]
Marital Status		
Single	23 (22.1)	2 [1.9]
Married	76 [73.1]	81 [77.9]
Widowed	1 [1.0]	20 [19.2]
Divorced	4 [3.8]	1 [1.0]
Income		
Less than \$6,000	46 (44.2)	44 [45.9]
Between \$6 and 12,000	24 [23.1]	24 [24.5]
Between \$12 and 15,000	14 [13.5]	11 [11.2]
More than \$15,000	17 [16.3]	18 [18.4]
Employment Status [Employed]	49 [47.1]	20 [19.2]

5.2. Caregiver Setting

ICs in this sample were mostly spouses [46.2%] or children [47.1%] of patients they cared for and provided care for an average of 11.4 years and for a mean of 3.24 ± 1.01 hours per week. About 80% of the dyads lived in the same household. The majority of ICs reported having an often or always good relationship with the person they cared for, while 97.1% of patients reported having an often or always good relationship with their caregiver.

More than half of the ICs reported that the care was collaborative or complementary, that is both members of the dyad assumed care of the patient's health together or took care of different aspects of patient's health jointly. A mere 4% reported that the care is done purely by the patient while 39.8% of the ICs reported that the care is done solely by them. A big percentage [47.1%] of the dyads in this sample were considered discordant and did not agree on how and by whom the care is being provided.

An alarming 68% of the caregivers in this sample reported a high level of care burden which is the degree of responsibility or effort, and the intensity and complexity of care needed to meet the patient's physical, emotional, and social needs [please refer to Table 2 for Caregiving Setting].

Table 2. Caregiving Setting.

Caregiving Setting	Median [IQR]; Mean \pm SD; n [%]
Living Status	
In the same household	80 [77.7]
Different households/same building	4 [3.9]
Within walking distance	4 [3.9]
Within a 10-minute drive	8 [7.8]
Within a 30-minute drive	3 [2.9]
Within a 1-hour drive	1 [1.0]
More than an hour drive	3 [2.9]

Presence of Other Dependents [Yes]	10.6 [97.8]
Other Family Obligations [Yes]	51 [49.5]
Availability of Help [Yes]	76 [73.1]
Duration of Caregiving [years]	11.4 ± 10.32
Number of Caregiving Hours/ Week	
0 to 8 hours	8 [7.8]
9 to 20 hours	19 [18.4]
21 to 40 hours	16 [15.5]
41 hours or more	60 [58.3]
Dyad Relationship Type	
Spouse	48 [46.2]
Sibling	5 [4.8]
Children	49 [47.1]
Relative	1 [1.0]
Non-Relative	1 [1.0]
Availability of Other Caregivers	
Family Members/Friends	53 [51]
Paid Help	5 [4.8]
Family Members/Friends and Paid Help	11 [10.6]
Caregiving Choice [Yes]	80 [79.2]
Level of Care Burden	
Low	21 [20.4]
Moderate	12 [11.7]
High	70 [68]
Caregiver Perceived Quality of the Dyad Relationship	
Poor	6 [5.8]
Strong	98 [94.2]
Dyadic Type [Discordant]	
Patient Oriented	4 [3.9]
Caregiver Oriented	41 [39.8]
Collaborative or Complementary	58 [56.3]
Caregiver Preparedness [range 0 to 4; higher scores indicating greater preparedness]	3.79 [0.29]

5.3. Outcome Variables

Physical, psychological, social, and environmental QOL was assessed using the World Health Organization Quality of Life–BREF [WHOQOL-BREF] with higher scores indicating better QOL in each dimension. The findings reveal varying levels of health among caregivers across different domains. On average, ICs scored relatively highest in psychological health and lowest in social health. While ICs reported relatively strong psychological, physical, and environmental well-being, there may be

challenges in social interactions that could impact their overall QOL and caregiving experience [please refer to Table 3 for Caregiver Strain].

Table 3. Informal Caregivers Quality of Life

	N	Mean ± SD
Physical Health	104	63.29 ± 20.34
Psychological Health	104	65.14 ± 16.99
Social Health	104	58.25 ± 21.14
Environmental Health	104	63.61 ± 17.66

Caregiver psychological QOL variable followed a normal distribution [Shapiro-wilk $p=0.21$]. Regardless of a p -value < 0.005 for the caregiver physical QOL ($p=0.038$), the distribution was considered normal as the skewness value was within normal range [Skewness = -0.303].

5.4. Identifying Predictor Variables of Caregivers' physical and psychological QOL

Scores on physical and psychological QOL were compared across patient and caregiver demographic and clinical characteristics using independent t test and analysis of variance tests as appropriate [please refer to Table 4 for Predictor Variables]. The availability of other individuals who helped the caregiver while taking care of their patient significantly affected the caregiver psychological QOL. Caregivers receiving Paid Help reported significantly lower psychological health scores compared to those not receiving paid help [45.83 ± 17.67 versus 68.33 ± 16.48 ; $F(3, 100) = 3.464$, $p = 0.019$].

Likely, IC's dyadic typology significantly predicted IC's psychological QOL with IC's in a collaborative relationship having higher psychological QOL scores than ICs in a caregiver-oriented typology [69.17 ± 16.17 versus 59.25 ± 16.47 ; $F(3, 99) = 2.979$, $p = 0.035$].

Burden of care as perceived by the caregivers significantly affected their physical QOL. High caregiver burden significantly decreased IC's physical QOL compared to caregivers who had low burden [60.05 ± 20.73 versus 74.83 ± 13.38; F(2, 100) = 4.653, p = 0.012].

Table 4. Predictor Variables.

	IC Physical QOL	Psychological QOL
Availability of Other Caregivers [Mean ± SD]		
None	67.96 ± 17.80	68.33 ± 16.48*
Family Members/Friends	61.19 ± 20.52	66.27 ± 15.63*
Paid Help	56.43 ± 28.05	45.83 ± 17.67*
Family Members/Friends and Paid Help	61.69 ± 23.47	58.33 ± 19.27*
Dyadic Type [Discordant]- Caregiver		
Patient Oriented	71.43 ± 24.04	66.67 ± 23.81*
Caregiver Oriented	56.71 ± 21.60	59.25 ± 16.47*
Collaborative	67.07 ± 17.48	69.17 ± 16.17*
Complementary	70.54 ± 23.74	70.31 ± 16.28*
Burden Categorical		
Low	74.83 ± 13.38*	70.63 ± 12.80
Moderate	60.71 ± 22.43*	62.50 ± 21.39
High	60.05 ± 20.73*	63.51 ± 16.83
Caregiver Quality of Life [Pearson's r]		
Physical	--	0.65*
Psychological	0.65*	--
Social Relationships	0.42*	0.53*
Environment	0.66*	0.54*
Patient Quality of Life [Pearson's r]		
Physical	0.24*	0.25*
Psychological	0.02	0.15
Social Relationships	0.18	0.18
Environment	0.33*	0.22*
Duration of Caregiving in years [Pearson's r]	-0.09	0.20*
Dyadic Coping Inventory [Pearson's r]		
Patient	-0.20*	0.02
Caregiver	0.07	0.26*

Burnout [Pearson's r]		
Emotional Exhaustion	-0.63*	-0.59*
Depersonalization	-0.33*	-0.34*
Personal Accomplishment	0.09	0.29*
Caregiver Social Support Scale [Pearson's r]		
Negative Impact Subscale	-0.52*	-0.43*
Quality of Support Subscale	0.1	0.32*
Anxiety [Pearson's r]		
Caregiver	-0.46*	-0.49*
Patient	-0.01	-0.09
Depression [Pearson's r]		
Caregiver	-0.54*	-0.61*
Patient	-0.22*	-0.23*
Caregiver Preparedness [Pearson's r]		
	0.11	0.30*
Family Appraisal of Caregiving [Pearson's r]		
FACS caregiving distress	-0.026	0.007
FACS positive appraisal	-0.06	0.06
FACS caregiver distress	0.13	0.07
FACS Family Wellbeing	-0.258*	-0.09

*: p-value < 0.05

Pearson correlation was used to ascertain correlations between QOL and variables such as IC's perceived social support; caregiving duration; ICs and patients' dyadic coping; IC's burnout particularly emotional exhaustion, depersonalization, and personal accomplishment, ICs and patients' depression and anxiety; caregiver preparedness; and IC's Appraisal of Caregiving.

Higher levels of care burden were significantly associated with lower physical and psychological QOL in ICs [Pearson's $r = -0.26$ and -0.19 ; $p = 0.006$ and 0.045 respectively].

Higher IC psychological, social, and environmental QOL were significantly associated with higher IC physical QOL [$r = 0.65$, 0.42 , and 0.66 respectively; $p < 0.001$]. Likewise, higher caregiver physical, social, and environmental QOL were

significantly associated with higher caregiver psychological QOL [$r = 0.65, 0.53,$ and 0.54 respectively; $p < 0.001$].

COPE Index's negative impact scale that relates to the IC's personal feeling of being stressed in caregiving was significantly associated with lower physical and psychological QOL in ICs [Pearson's $r = -0.52$ and -0.43 respectively; $p < 0.001$].

Similarly, higher emotional exhaustion was negatively correlated with IC's physical and psychological QOL [$r = -0.63$ and -0.59 respectively; $p < 0.001$].

Presence of symptoms of depression, in ICs and patients, affected ICs physical and psychological QOL in this sample. Higher depression scores [in ICs and patients] yielded lower physical [$r = -0.54$ and $-0.22,$ $p = 0.00$ and 0.002 respectively] and psychological QOL [$r = -0.61$ and $-0.23,$ $p = 0.00$ and 0.015 respectively]. Similarly, the higher the IC's anxiety the lower was their physical and psychological QOL [$r = -0.46$ and -0.49 respectively; $p < 0.001$].

5.5. Predictor Variables of Caregivers' Physical and Psychological QOL

Different variables were associated with IC's physical and psychological QOL (please refer to table 3). To explore relationships within the data more thoroughly, the IC's physical and psychological QOL were used as the outcome variables to create the best regression model using significant variables from the univariate analyses [please refer to Table 5 for Regression Analysis]. All possible predictors were entered in the regression test. A stepwise approach was utilized Predictors were retained in the regression model if they contributed significantly to the model or were conceptually relevant and did not negatively affect the variance.

Although the bivariate correlation between burnout (mainly EE and depersonalization) was statistically significant with both aspects' of QOL, burnout did not contribute significantly to the regression in the two models.

5.5.1. Caregiver Physical Quality of Life

A lower negative impact from caregiving [denoting lower personal feeling of being stressed in caregiving], a higher psychological and environmental QOL, and a lower family wellbeing explained about 62.4% of the variance in the IC physical QOL (please refer to table 5).

5.5.2. Caregiver Psychological Quality of Life

A higher IC physical and social QOL, better IC coping, and higher duration of caregiving explained about 55.5% of the variance in the caregiver psychological QOL (please refer to table 5).

Table 5. Regression Analysis for Quality of Life.

Regression Analysis Physical Quality of Life	Adjusted R2	F	Sig.	Unstandardized β	Standardized β	t	Sig.
Constant	.624	40.821	<0.001	62.99		4.14	<.001
FACS Family Wellbeing				-7.93	-0.22	-3.49	<.001
IC WHO Psychological Health				0.39	0.32	4.09	<.001
IC WHO Environment				0.40	0.35	4.63	<.001

Negative Impact Subscale				-1.10	-0.27	-3.76	<.001
Regression Analysis Psychological Quality of Life	Adjusted R2	F	Sig.	Unstandardized β	Standardized β	t	Sig.
Constant	.555	28.791	<0.001	-0.93		-0.10	0.919
IC WHO Physical Health				0.47	0.56	7.31	0.00
IC WHO Social				0.17	0.21	2.68	0.007
IC Dyadic Coping				0.16	0.19	2.60	0.01
Duration of Caregiving in years				0.36	0.21	2.99	0.004

CHAPTER 6

DISCUSSION

We evaluated the physical and psychological QOL among ICs of patients living with chronic illnesses and identified QOL predictors through analysis of a cross-sectional study that looked at dyadic determinants of self-care. To our knowledge, this is the first study to address QOL in ICs of patients living with diverse chronic illnesses in collectivist societies such as those in the MENA region. QOL was average in this sample of ICs. The mean score on all 4 domains of QOL was above 50, suggesting a moderate overall QOL in all domains of the scale (Fatoye et al. 2006).

In our study, most ICs were females consistent with the literature (Sharma et al., 2016). This can be explained by several contextual factors. In the Lebanese cultural context, there is a strong cultural expectation for females to take on caregiving responsibilities within families (Dumit et al., 2015). Additionally, societal norms and expectations mostly dictate that males primarily engage in activities outside the home, such as work or running errands, leaving females more available for caregiving tasks (Sharma et al., 2016). Furthermore, the observed gender distribution could also reflect the specific dynamics of the sample population in Lebanon. It's possible that certain socioeconomic factors or familial structures in Lebanon contribute to a higher prevalence of female ICs reflecting how cultural norms and societal expectations shape caregiving dynamics in this setting. Additionally, the mean age of ICs (54.4 years) was consistent with the literature denoting that ICs who care for older people tend to be around the same age (Wakefield et al., 2012; Camargos et al., 2012).

In our study, 67.3% of the ICs had more than high school education. However, this level of education had no significant impact on their overall QOL. This finding

contradicts previous studies which found an association between those factors. In their research, Basheer and colleagues observed a comparable pattern, indicating that individuals with higher level of education achieved higher scores across all four dimensions of QOL (Basheer et al., 2015). Similarly, Tasi et al. (2018) reported analogous findings, suggesting that increased levels of education correlate with a deeper comprehension of the illness and its implications. Our findings may be explained by the presence of a Lebanese support network in families that transcends educational levels. Individuals, irrespective of their educational background, often receive significant support from extended family members, neighbors, or local community organizations. This strong support system plays a crucial role in alleviating the burden of caregiving, ultimately contributing to similar QOL outcomes across diverse education levels.

We found that most of the ICs were married but the marital status was not correlated with QOL. Literature highlights that providing care for a terminally ill patient places an additional weight on individuals who are already dedicated to familial obligations, particularly for married individuals who must balance caring for both their family and their sick patient (Alrashed, 2017). In Lebanon, familial responsibilities are deeply ingrained, and the expectation to care for family members, particularly during times of illness, transcends educational attainment or marital status. Married individuals may have additional support from their spouses in caregiving responsibilities, which could help offset some of the challenges associated with caregiving.

In our study, IC's employment status and income did not significantly affect the overall QOL while other studies reported that ICs with better financial stability experienced a better QOL (Vincent-Onabanjo et al., 2013), and vice versa, ICs who reported financial difficulties experienced a lower QOL compared to those without

financial issues (Karakas & Pehlivan, 2020). Financial security enables ICs to opt for optimal medical care and rehabilitation strategies for their patients, as well as access a wider range of treatment options. Conversely, ICs facing financial constraints struggle to cover the medical expenses of their patients and afford the needs of their families. This challenge can negatively impact their QOL and exacerbate the burden of caregiving (Basheer et al., 2015; Vincent-Onabajo et al., 2013). The absence of an association in our study between IC's employment status and income and their QOL could be due to factors such as Lebanon's economic instability, strong social support networks, equitable healthcare access, cultural norms emphasizing familial duty and their financial contribution towards the sick family member, and potential government support programs. These elements may have mitigated the financial burden on ICs, leading to similar QOL outcomes regardless of income or employment status.

ICs in our study had high scores of caregiver preparedness, but the majority felt burdened by caregiving. Despite the burdensome experience of caregiving, the QOL of the study participants was good overall. Similar findings were established by a study conducted by Aljuaid et al. (2022) in Saudi Arabia whereby the ICs have similar QOL. The findings of our study may be explained by Anderson & White (2018) study. Although it is claimed that caregiving often represents a profound, challenging, and transformative journey for many ICs, Anderson and White outlined three significant aspects of the rewarding nature of caregiving experience which contribute positively to their overall well-being and improve their QOL. These include: (1) the appreciation felt for the ability to assist those in need, (2) a sense of achievement, and (3) an awareness of the importance of good health.

Surprisingly, ICs who did not receive any help in caregiving exhibited a higher QOL compared to those who received assistance, whether it's paid or from family and friends. This suggests that while support is typically considered beneficial, its presence may introduce additional stressors or complexities for ICs. It could be that those who manage independently experience a sense of autonomy and mastery over their caregiving responsibilities, leading to greater psychological and physical well-being. This finding underscores the importance of understanding the nuanced dynamics of caregiving relationships and tailoring support interventions to suit individual needs and preferences.

It's widely acknowledged that the bond between family ICs and the individuals they look after significantly influences the QOL for ICs (Morishita-Kawahara et al., 2022). In this study we found an association between QOL of ICs and their relationship to patients. The complementary dyadic relationship between the IC and the patient yields the highest psychological QOL in ICs. In a complementary relationship between the dyad, there's likely a harmonious and mutually supportive dynamic. This type of relationship may involve effective communication, understanding, and cooperation between the IC and the patient. As a result, ICs in such relationships may feel more fulfilled, valued, and appreciated, leading to a higher psychological QOL. Moreover, they may feel that they are making a meaningful difference in the patient's life and that their efforts are recognized and reciprocated. This sense of fulfillment can also contribute positively to their psychological well-being.

Our results show that depression and anxiety in ICs negatively correlate with their physical and mental QOL. Previous literature highly supports this established correlation. Evidence shows that caregiving can have detrimental impacts on the

physical health of ICs, manifesting in significant burden (Roth et al., 2013), psychological stress, and the onset of depression (Chow et al., 2011; Adelman et al., 2015).

It is suggested that, for ICs, emotional exhaustion refers to a situation in which the IC feels unable to continue and is emotionally drained; depersonalization refers to disconnected responses in the caregiving relationship that can lead to the objectification of the person being cared for; and the reduced personal accomplishment refers to the lack of a positive experience in fulfilling the role (Gérain, & Zech, 2019). Our findings show that emotional exhaustion has the highest negative correlation with physical and psychological QOL in ICs followed by depersonalization, and personal achievement has its lowest positive effect on the discussed 2 domains of QOL. Similar findings were established in a previous study. It was found that the relationship between caregiving satisfaction and psychological, environmental, and spiritual QOL in ICs was influenced by emotional exhaustion, depersonalization, and personal accomplishment acting together in a study conducted over 92 cancer patients ICs in Portugal (Blom et al., 2023). Specifically, emotional exhaustion alone had a notable impact on this relationship, and thus negatively impacting ICs' QOL.

No previous articles discussed the association between family wellbeing and the physical QOL of ICs. This could be attributed to the support and resources available within the family unit. This may be explained by the fact that high family wellbeing often requires ICs to devote substantial time and effort to caring for their loved ones. This increased caregiving responsibility can lead to physical exhaustion, lack of time for self-care activities, and neglect of personal health needs, ultimately impacting the IC's physical QOL. Additionally, even though family wellbeing may be high in terms of

emotional support and solidarity, ICs often experience significant emotional stress due to witnessing their loved one's suffering, dealing with uncertainty about the illness's progression, and managing complex medical and caregiving tasks. Chronic stress can manifest in physical symptoms such as fatigue, headaches, and muscle tension, contributing to a lower physical QOL.

High scores on the negative impact subscale for social support may indicate maladaptive coping mechanisms or a lack of effective coping strategies, which can contribute to poorer physical QOL. These scores indicate increased stress levels related to caregiving responsibilities, which can lead to fatigue, sleep disturbances, and overall decreased physical well-being (Oleas Rodríguez et al., 2024). Additionally, ICs with high negative impact scores may lack effective coping strategies and resources, neglecting self-care practices and facing financial strain, which limits access to healthcare services and exacerbates existing health issues (Hawken et al., 2018). Furthermore, the absence of adequate support networks and proper care services for ICs can result in feelings of isolation, burnout, and further deterioration of physical health (Liu et al., 2020).

Similarly, four predictors were significantly important to predict psychological QOL among ICs: WHO physical health caregiver, WHO social relationships caregiver, dyadic coping inventory total score caregiver, and duration of caregiving in years.

A high DCI score indicates effective coping strategies within the caregiving relationship, including open communication and mutual support, which help ICs manage stress and challenges (Muijres et al., 2023). This, in turn, reduces ICs burden and feelings of overwhelm or burnout (Muijres et al., 2023). Additionally, the collaborative nature of dyadic coping fosters increased social support between ICs and

care recipients, providing emotional and practical assistance that supports ICs well-being (Ferraris et al., 2022). Furthermore, effective dyadic coping promotes a sense of purpose and fulfillment in ICs and builds resilience, enabling them to navigate the caregiving journey with greater psychological well-being and satisfaction overall (Lim et al., 2014).

Extended periods of caregiving are linked to increased stress, depressive symptoms, and anxiety, resulting in poorer health self-assessment and diminished QOL for ICs (Castora-Binkley et al., 2011). Rodrigues et al.'s (2016) study validates that the longer someone serves as a caregiver, the lower their QOL scores and the more negative their health self-assessment becomes.

All the WHO QOL domains; physical, social, environmental, and psychological, are related to one another and have effect on each other (Blom et al., 2023).

6.1. Limitations

This secondary analysis shares typical constraints associated with this type of analysis including limitations inherited from the parent study like the cross-sectional design, convenience sampling, susceptibility to social desirability bias in self-reporting, and recruitment from both inpatient settings with heightened patient needs and outpatient settings with lower caregiving demands.

Despite these constraints, the study possesses notable strengths, notably being an original examination of ICs QOL in societies where caregiving is rooted in a collectivist concept involving both the patient and their family. In these contexts, caregiving is perceived not as a voluntary choice but rather as a social expectation. Thus, this cultural context provides new insights to what is known about caregiving and ICs QOL.

Caregiving norms, expectations, and perceptions of caregiving may vary significantly across cultures, and the findings might not be universally applicable. Additionally, health disparities among the caregivers themselves may exist and impact their ability to cope with caregiving strain, and thus affecting their QOL.

6.2. Conclusion

In conclusion, this study sheds light on the physical and psychological QOL among informal ICs patients living with chronic illnesses in a collectivist society like Lebanon. To our knowledge, this is one of the first studies of its kind in the MENA region, focusing on diverse chronic illnesses and their impact on ICs' QOL. The study's findings indicate that while the overall QOL among ICs was good, there were several nuanced factors influencing their QOL outcomes. Despite facing significant caregiving burdens, most ICs reported a good QOL, particularly in psychological health. This could be attributed to various factors such as a strong sense of family duty and support systems within the Lebanese cultural context.

Our study also explored the demographic and clinical predictors of ICs' QOL. We found that factors such as gender, education level, marital status, employment, and income did not significantly impact ICs' overall QOL. This suggests that in the context of caregiving in Lebanon, societal and cultural norms may play a more significant role in shaping caregiving experiences and outcomes than individual demographic characteristics.

Interestingly, the study revealed that receiving assistance in caregiving, whether from family, friends, or paid help, was not necessarily correlated with a higher QOL among ICs. This challenges the conventional notion that support always leads to better

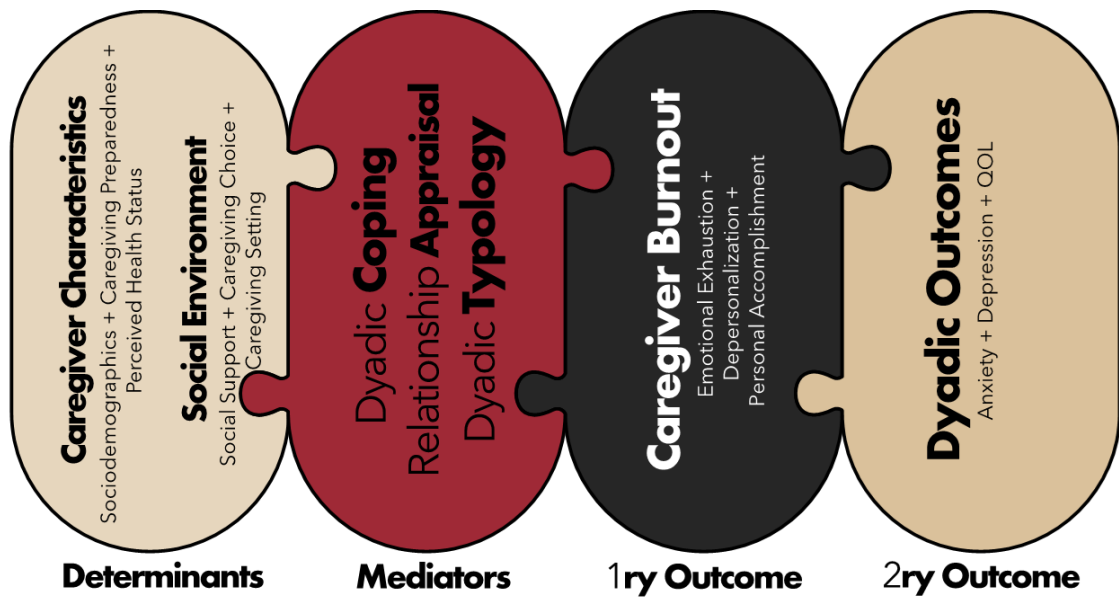
outcomes and highlights the importance of individual coping mechanisms and preferences in caregiving dynamics.

Furthermore, our findings underscore the importance of understanding the dyadic relationship between ICs and care recipients. Collaborative and complementary dyadic relationships were associated with higher psychological QOL among ICs, emphasizing the role of effective communication, mutual support, and shared responsibility in caregiving.

The study also identified significant negative correlations between ICs' QOL and factors such as depression, anxiety, emotional exhaustion, depersonalization, and reduced personal accomplishment. These findings emphasize the need for targeted interventions and support services aimed at addressing ICs' mental health and coping strategies

APPENDIX 1

INFORMAL CAREGIVING INTEGRATIVE MODEL



APPENDIX 2

CONCEPTS AND METHODS OF MEASUREMENT

Concept	Method of Measurement	Details
Sociodemographics Patient and Caregiver	Researcher developed tool. Medical record review and Face-to-Face Interview	Age; Gender; Marital Status; Education Level; Income; and Employment.
Caregiving Setting: Caregiver	Researcher developed tool. Medical record review and Face-to-Face Interview	Living Status; Number of persons in the household; Number of rooms beside bathroom and kitchen; Other Family Obligations; Availability of help; Relationship between Patient and Caregiver [parent, spouse, children, sibling, relative, or non-relative].
Caregiving Duration: Caregiver	Researcher developed tool. Medical record review and Face-to-Face Interview	Time since start of caregiving; Number of Caregiving Hours/Week
Caregiver Preparedness: Caregiver	Caregiver Preparedness Scale [CPS]	CPS defines preparedness as the caregiver's perceived readiness to attend to the patient's physical and emotional needs (Archbold, 1990). In a Swedish study on ICs of patients with life threatening conditions, the CPS have shown concurrent validity with the Rewards of Caregiving Scale [r= 0.76; p < 0.001] and the Caregiver Competence Scale

		[$r = 0.34$; $p < 0.001$] (Henriksson, 2021). In addition, internal consistency reliability tested with Cronbach's alpha was adequate at 0.94, as well as test-retest reliability (0.70) between the baseline and the 6-week follow-up.
Social Support: Caregiver	Carers of Older People in Europe Index [COPE Index]	Carers of Older People in Europe Index [COPE Index] was used to measure caregivers' social support (Balducci et al., 2008). This is a 15-item instrument that measures the positive and negative impacts of caregiving as well as the quality of social support received. The internal reliability, assessed through Cronbach's alpha (α), yielded a score of 0.86 for factors indicating a negative impact, 0.76 for the five items gauging support quality, and 0.64 for the positive values subscale. Test-retest reliability, assessed via Spearman's rank order correlation, demonstrated good consistency across all three factors (Moholt et al., 2018).
Quality of Dyad Relationship and Typology: Caregiver	Dyadic Typology	One question was asked to address the quality of the dyadic relationship: "Do you have a good relationship with the person who cares for you?" (Buck et al., 2013).
Dyadic Type: Patient and Caregiver	Dyadic Typology	Caregivers were asked to choose what best describes their relationship with their counterpart in terms of how they take care of the disease. Four categories will be used: Patient Oriented, Caregiver Oriented, Collaborative, and Complementary Categories.

		<p>The first two categories exist when the patient or the caregiver takes exclusive responsibility for illness care and the other member of the dyad is only compliant. In the collaborative and complementary categories, the dyad manages illness care equally and together or where both members take care of different aspects of the chronic illness (Buck et al., 2013).</p>
<p>Anxiety/Depression: Patient and Caregiver</p>	<p>Hospital Anxiety and Depression Scale [HADS-A and HADS-D]</p>	<p>Caregiver Hospital Anxiety and Depression Scale [HADS-A and HADS-D] was utilized to measure anxiety/depression in ICs (Zigmond & Snaith, 1983). The HADS is divided into an anxiety subscale (HADS-A) and a depression subscale (HADS-D). Total scores for each subscale range from 0 (optimal) to 21 (worst) points. Psychometric properties of the Arabic version revealed Cronbach's alpha of 0.75 for the HADS anxiety subscale and 0.82 for the HADS depression subscale (Al-Gamal, 2017) rendering the tool a reliable and valid instrument for the assessment of anxiety and depression in Arabic speaking patients with COPD.</p>
<p>Appraisal: Caregiver</p>	<p>Family Appraisal of Caregiving [FACS]</p>	<p>IC's appraisal of caregiving will be measured using the multi-dimensional Family Appraisal of Caregiving Questionnaire for Palliative Care [FACQ] (Cooper et al., 2006).</p>

		<p>This is a 25-item measure consists of four theoretically derived subscales: caregiver strain, positive caregiving appraisals, caregiver distress, and family well-being. For each scale, the score ranges from 0 to 5 points with higher scores indicating a greater amount of the variable being measured.</p> <p>Cronbach's alpha was .86, .73, .75, and .78 for the caregiver strain, positive caregiving appraisals, caregiver distress, and family well-being subscales respectively.</p> <p>The correlations between the four subscales and indicators of family functioning, positive and negative emotions, and subjective burden supported both convergent and discriminant validity.</p>
<p>Burnout: Caregiver</p>	<p>Maslach Burnout Inventory [MBI]</p>	<p>The MBI measures burnout as three separate components: emotional exhaustion, depersonalization, and reduced personal accomplishment (Bakker et al., 2002). A high score on the preceding burnout dimensions indicates increased burnout tendencies. The responses will be obtained on a 7-point Likert scale that measured the frequency of feelings and anchored from 0 (never) to 6 (everyday).</p> <p>The internal reliability of these scales is adequate. They</p>

		<p>reported Cronbach alpha coefficients between 0.84 and 0.90 for exhaustion, 0.74 to 0.84 for cynicism, and 0.70 to 0.78 for professional efficacy (Duan et al., 2023).</p>
<p>Quality of Life: Patient and Caregiver</p>	<p>World Health Organization Quality of Life–BREF</p>	<p>This is a 26-item WHOQOL-BREF instrument that measures QOL in the following 4 dimensions: physical (the ability to perform activities of daily living); psychological (negative/positive feelings); (3) social (personal relationships), and (4) environmental (financial resources). Scores are transformed to a 0 to 100 scale, with higher scores indicating better QOL in each dimension. Cronbach’s alpha values for physical health, psychological health, social relationships, and environmental health were 0.65, 0.77, 0.52, and 0.79, respectively. The average item-to-total correlations were 0.76, 0.73, 0.62, and 0.78 for physical health, psychological health, social relationships, and environmental health, respectively. For each WHOQOL-BREF, factor analysis yielded only one factor. Collectively, these results confirm the uni-dimensionality of the four scales and the local independence of items within each scale (Vahedi, 2010).</p>

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