GMR
The Original

FAMILY CAREGIVER BURDEN IN HOME PALLIATIVE CARE: A SAUDI CULTURAL PERSPECTIVE

Heetaf Ahmed Fathi Saeed[1], Nuha Hassan Alsubhi[2], Ibraheem Mahmoud Yaslam Baali[3], Abdulaziz Abdullah Junaid Bawazeer[4], Ethar Hatim H. Alhashmi Alamer[5]

[1]Family Medicine Senior Registrar, Non-Employee
[2]Family Medicine, Ministry of Health
[3]Family Medicine, Ministry of Health
[4]Family Medicine, Ministry of Health
[5]Family Medicine, Ministry of Health

ABSTRACT

Background: Home-based palliative care places intensive and sustained demands on family caregivers; yet in Saudi Arabia, caregiver burden remains inadequately characterized, particularly with respect to its cultural and Islamic determinants.
Objectives: To examine the prevalence, severity, dimensions, and cultural predictors of family caregiver burden in home palliative care in Saudi Arabia, integrating Islamic religious coping as a culturally specific moderating resource within an adapted Stress-Process Model framework.
Methods: A descriptive cross-sectional design was employed with 100 purposively sampled family caregivers enrolled in Saudi home palliative care programs. Data were collected using the Arabic Zarit Burden Interview (ZBI-22), the Brief Religious Coping Scale (Brief RCOPE), and the Hospital Anxiety and Depression Scale (HADS). Hierarchical multiple linear regression identified independent predictors of burden.
Results: Mean ZBI-22 total score was 42.8 (SD = 15.4); 95.0% of caregivers reported clinically meaningful burden. Female caregivers reported significantly higher burden (M = 46.2 vs. 33.7; $t(98) = 3.92$, $p < .001$, $d = 0.84$). Positive religious coping was the strongest protective predictor ($\beta = -.29$, $p = .001$), while negative religious coping amplified burden ($\beta = .22$, $p = .008$). Clinically significant anxiety and depression were documented in 49.0% and 40.0% of participants. The final regression model explained 48.3% of variance ($R^2 = .483$, $F(10,89) = 8.31$, $p < .001$).
Conclusions: Family caregiver burden in Saudi home palliative care is pervasive and severe, shaped by gender inequalities, caregiving intensity, socioeconomic vulnerability, and the dual moderating function of Islamic religious coping. Routine screening, gender-sensitive support programs, and integration of Islamic spiritual care are urgently indicated.

Keywords: caregiver burden; palliative care; home-based care; Saudi Arabia; Islamic coping; Zarit Burden Interview; Hospital Anxiety and Depression Scale; Stress-Process Model.

1. INTRODUCTION

The global demand for palliative care is expanding at an unprecedented rate. Each year, an estimated 56.8 million people require palliative care, with only approximately 14% of those in need currently receiving it (World Health Organization [WHO], 2020). This growing need is driven by an aging population and the rising prevalence of chronic and life-limiting illnesses (Botas et al., 2025). As healthcare systems worldwide respond to this demand, home-based palliative care has gained increasing prominence as a preferred model of care delivery — not only for its alignment with patient preferences for end-of-life care at home, but also for its demonstrated effectiveness in reducing unnecessary hospital admissions (Koh et al., 2026). In these home-based settings, the role of family caregivers becomes central, as they assume primary responsibility for the physical, emotional, and practical dimensions of care.

Caregiver burden, first conceptualized by Zarit et al. (1980) as the multidimensional strain experienced by informal caregivers in response to the demands of caregiving, has since been recognized as a critical determinant of both caregiver well-being and patient outcomes. Research consistently identifies depression, anxiety, distress, and diminished quality of life as primary domains of caregiver burden in palliative home care settings (Botas et al., 2025;

Lapa et al., 2025). Epidemiological evidence further suggests that approximately one in five family caregivers of patients at the end of life experiences a heavy care-related burden (Bijnsdorp et al., 2022). Within the theoretical literature, Pearlin et al.'s (1990) Stress-Process Model remains the most widely applied framework for understanding how primary stressors interact with secondary stressors and mediating resources to produce burden outcomes.

Despite this body of evidence, the vast majority of caregiver burden research has been conducted in Western or high-income contexts, rendering its findings of limited applicability to societies shaped by distinct cultural and religious values. In Arab Muslim societies, caregiving is deeply embedded within Islamic ethical imperatives, where filial duty (birr al-walidayn), collective family responsibility, and spiritual acceptance of suffering as divinely ordained fundamentally shape the caregiving experience. Empirical research indicates that for many Muslims, Islamic texts and lived religious practice are of central importance when deliberating about death and dying, with care decisions shaped by virtues rooted in Islamic theology and ethics (Suleman, 2023). These cultural dynamics may simultaneously serve as protective resources against burden — through meaning-making and communal solidarity — and as amplifiers of distress, particularly where gender role expectations and stigma surrounding terminal illness constrain caregivers' help-seeking behaviors.

Within Saudi Arabia, this cultural context intersects with a rapidly evolving healthcare landscape. The Ministry of Health launched the Last Phase Initiative as part of the Healthcare Transformation under Vision 2030, recognizing that the cancer burden in the Kingdom is expected to grow five- to tenfold by 2030 (Alshammary et al., 2019). The limited studies conducted in Saudi Arabia reveal a substantial and underexplored burden among family caregivers. Ghazwani et al. (2021) documented burden in 96.2% of caregivers of terminally ill cancer patients, with severe burden in 11.5% of cases. Thematic investigation has further identified religion and belief systems as a culturally specific burden domain absent from most Western frameworks (Al Enazy & Alyousef, 2025). However, existing Saudi studies have not systematically integrated cultural specificities — including gendered caregiving norms, extended family structures, and Islamic coping mechanisms — into their theoretical framing.

This gap in the literature is both empirically and clinically significant. Without culturally grounded evidence, support interventions designed for Saudi family caregivers risk being ineffective or misaligned with the values and realities of those they seek to serve. Accordingly, the present study aims to examine the nature, prevalence, and cultural determinants of family caregiver burden in the context of home palliative care in Saudi Arabia, with the goal of informing culturally responsive policies and caregiver support programs aligned with the Kingdom's Vision 2030 health transformation agenda.

2. LITERATURE REVIEW

2.1 Conceptualizing Caregiver Burden: Definitions and Theoretical Frameworks

The concept of caregiver burden was formally introduced by Zarit et al. (1980), who defined it as the multidimensional strain experienced by informal caregivers arising from the physical, psychological, social, and financial demands of caregiving. Over subsequent decades, this conceptualization was significantly elaborated through Pearlin et al.'s (1990) Stress-Process Model (SPM), which remains the dominant theoretical framework in contemporary caregiver burden research. The SPM comprises five primary domains: the caregiving context, primary stressors, secondary stressors, resources, and outcomes — together capturing the complex, cascading pathways through which caregiving demands translate into psychological and physical harm. Within this model, primary stressors refer to the direct demands associated with patient care needs, whereas secondary stressors encompass the downstream consequences on caregivers' own roles, relationships, and self-concept. Resources — including social support, coping strategies, and spiritual or religious frameworks — are understood as mediating variables capable of buffering the impact of stressors on outcomes such as depression, anxiety, and diminished quality of life.

More recent scholarship has extended the SPM to encompass the relational and cultural dimensions of caregiving. Meaning-focused coping has been theorized within the SPM to promote positive psychological experiences among caregivers, with evidence suggesting that this coping style is differentially associated with burden outcomes across cultural groups (Dieker & Qualls, 2022). These developments underscore the necessity of culturally sensitive adaptations of existing frameworks when applying them to non-Western caregiving contexts.

2.2 Dimensions of Caregiver Burden in Palliative Home Care

The literature consistently characterizes caregiver burden as a multidimensional phenomenon, with consequences spanning physical, psychological, social, and economic domains. Family caregivers in palliative care routinely face significant challenges to their physical, emotional, social, and financial well-being, with a lack of adequate training and support compounding feelings of insecurity and leading caregivers to neglect their own needs (Lapa et al., 2025). Physically, caregivers commonly report chronic fatigue, sleep disturbances, and a deterioration of overall health

directly attributable to the demands of continuous caregiving. Systematic evidence confirms that emotional distress, including anxiety and depression, is prevalent among caregivers — particularly in high-burden scenarios — while financial strain arising from medical expenditures and changes in employment status further compounds the burden experience (Saragih et al., 2024). At the social level, isolation represents one of the most pervasive yet underappreciated consequences of informal caregiving, with social isolation documented across multiple international contexts as a significant driver of caregiver distress.

2.3 Predictors of Burden in Home-Based Palliative Care

Home-based palliative care settings place particularly intensive demands on family caregivers, who must navigate complex clinical tasks with limited formal support. Cross-sectional research among caregivers of patients enrolled in palliative care institutions found that 54.8% experienced moderate levels of burden, with significant burden predicted by full-time caregiving, employment status, career disruption, and the perceived inadequacy of available support (Nair et al., 2025). Patient-level variables — particularly functional dependency, symptom severity, and disease stage — consistently emerge as primary stressors in the SPM framework. Among caregivers enrolled in home-based palliative programs for patients with advanced illness, younger caregiver age and elevated symptom burden were independently associated with higher Zarit Burden Interview scores, with more than half of caregivers at risk of clinical depression (Martinez-Garcia et al., 2024). Key predictors identified across the literature include caregiver gender, relationship to the patient, duration of caregiving, availability of supplementary paid care, and socioeconomic status.

2.4 Cultural and Religious Determinants of Caregiver Burden

A substantial body of literature has established that cultural and religious factors are not merely incidental to the caregiving experience but constitute structural determinants of how burden is constructed, experienced, and managed. In Arab societies, Islamic teachings, family-centered care traditions, and societal norms significantly influence healthcare decision-making, often creating a tension between the spiritual preparation for death and the pragmatic demands of patient care (Al-Saleh, 2025). Within Islamic ethical frameworks, caring for a sick or dying relative is understood as a religious obligation, imbued with spiritual merit. This framing can simultaneously serve as a protective resource — providing meaning and resilience — and constrain help-seeking behaviors by rendering the acknowledgment of burden socially or spiritually unacceptable. Qualitative investigation among Muslim patients, families, and healthcare professionals has demonstrated that Islamic texts and lived religious practice are of central importance in deliberations about death and dying (Suleman, 2023). A study of caregivers of pediatric oncology patients in Turkey found a significant negative correlation between caregiver burden and positive religious coping scores, suggesting that religiously mediated meaning-making may attenuate the subjective experience of burden (Semerci et al., 2024).

2.5 Gender and Family Structure in Arab Caregiving Contexts

Gender constitutes one of the most consistent predictors of differential burden in caregiving research globally. A shift toward home-based care models may disproportionately burden women, who traditionally serve as society's primary informal caregivers, with evidence indicating that gender norms constrain both the type of support offered to women caregivers and the likelihood that such support will be sought (Wong & Phillips, 2023). In Arab Muslim societies, patriarchal collectivism assigns caregiving as a normative feminine role, with wives, daughters, and daughters-in-law constituting the default caregiving workforce. Sociocultural research in Arab and Muslim communities further identifies the stigma associated with mental and physical illness as a significant barrier to formal help-seeking, with family caregivers often preferring to manage care privately to preserve family honor and social standing (Farooq et al., 2022).

2.6 Evidence from Saudi Arabia and Identified Gaps

The body of empirical research on caregiver burden in Saudi Arabia, while growing, remains limited in scope and depth. A cross-sectional study at a home health care facility in Riyadh using the ZBI-22 found a mean burden score of 31.66, representing a clinically significant level of burden across all disease groups (Santos Costa et al., 2025). At the regional level, a multicountry study in Egypt and Saudi Arabia found that the ZBI-22 effectively captured significant caregiver burden in Arabic-speaking Eastern Mediterranean populations, while identifying the intensity of assistance with activities of daily living as a critical burden predictor (Alsirafy et al., 2021). Despite these contributions, critical gaps persist. A cross-sectional study of Saudi informal caregivers identified unmet needs across social, emotional, and financial support domains, alongside a pressing need for caregiver training, yet formal recognition of informal caregiving within the Saudi healthcare system remains limited (Al-Shdaifat, 2023). Furthermore, existing Saudi studies have not systematically examined caregiver burden within the context of

structured home palliative care delivery, nor have they integrated cultural determinants — including Islamic coping, gendered obligations, and the Vision 2030 policy context — into a single integrated empirical framework. The present study responds directly to this gap.

3. THEORETICAL FRAMEWORK

3.1 Rationale for Theoretical Framework Selection

The selection of an appropriate theoretical framework shapes how a research phenomenon is conceptualized, measured, and interpreted. A systematic review of conceptual and theoretical frameworks used in palliative care research identified 44 distinct frameworks, with investigators in more than half of included studies proposing previously unpublished or modified frameworks to overcome the inherent limitations of existing models — underscoring the need for careful, context-specific theoretical grounding in this field (Tark et al., 2023). In the context of family caregiver burden in home palliative care, the Stress-Process Model (SPM; Pearlin et al., 1990) and the Transactional Model of Stress and Coping (TMSC; Lazarus & Folkman, 1984) dominate the empirical landscape. The present study adopts an integrated framework anchored in the SPM as its primary structure, supplemented by the TMSC and the Biopsychosocial-Spiritual (BPS-S) Model, with explicit cultural adaptations to account for the Islamic and Saudi sociocultural dimensions of caregiving.

3.2 The Stress-Process Model: Primary Theoretical Foundation

Pearlin et al.'s (1990) Stress-Process Model was originally developed to explain how caregiving for individuals with Alzheimer's disease translates into measurable psychological and physical harm in family caregivers. Its generalizability, theoretical elegance, and breadth of scope have since established it as the dominant framework in caregiver burden research globally. The SPM comprises five interrelated domains: (1) the caregiving context, encompassing sociodemographic characteristics and the broader cultural environment; (2) primary stressors, referring to the direct demands generated by the patient's care needs; (3) secondary stressors, capturing the downstream consequences on the caregiver's life roles, relationships, and self-concept; (4) resources, including formal social support, familial networks, and psychological coping strategies; and (5) outcomes, including psychological distress, depression, diminished quality of life, and physical health deterioration. Within the Saudi context, the SPM's domains map onto the caregiving landscape in theoretically meaningful ways: primary stressors include the physical dependency of terminally ill patients; secondary stressors encompass gender role conflicts; and resources include Islamic faith, extended family solidarity, and formal healthcare support.

3.3 The Transactional Model of Stress and Coping: Complementary Framework

Lazarus and Folkman's (1984) Transactional Model of Stress and Coping (TMSC) provides a complementary micro-level framework that enriches the SPM by centering the cognitive appraisal processes through which caregivers subjectively experience and respond to objective stressors. The TMSC proposes that stress responses are shaped by individual appraisal processes: upon encountering a stressor, the individual evaluates its personal relevance and severity (primary appraisal), then assesses available resources and management strategies (secondary appraisal), with the resultant coping behavior mediating the final psychological outcome (Grammes et al., 2021). This appraisal-centric logic is particularly relevant to the Saudi caregiving context, where the meaning assigned to caregiving — shaped by religious belief, familial obligation, and cultural norms — fundamentally alters how burdensome stressors are subjectively experienced. The TMSC's dual coping typology — problem-focused coping and emotion-focused coping — provides a conceptual bridge to Islamic coping as a distinct, culturally grounded variant of emotion-focused coping.

3.4 The Biopsychosocial-Spiritual Model: Integrating the Spiritual Dimension

While the SPM and TMSC provide structurally robust frameworks, neither was originally designed to accommodate the spiritual dimension of caregiving — a dimension of paramount importance in Islamic and Saudi cultural contexts. The Biopsychosocial-Spiritual Model extends the biomedical and psychosocial frameworks to incorporate spirituality as an independent, irreducible domain of the human caregiving experience, depicting spirituality as the core of the person around which physical, psychological, and social dimensions are organized (Pereira et al., 2025). In the Islamic context, spirituality manifests through theological constructs including sabr (patient endurance), tawakkul (reliance upon God), and qadar (divine predestination), which function as cognitive-spiritual resources through which Muslim caregivers interpret and navigate the suffering associated with terminal illness. Evidence confirms that religious and spiritual care interventions scaffold caregivers through a process of sense-making that helps them find meaning in a new and painful reality (Cooper, 2023).

3.5 An Integrated Culturally Adapted Framework

The present study proposes an integrated theoretical framework synthesizing the three models into a culturally adapted structure suited to the study of family caregiver burden in Saudi home palliative care. In this framework, the SPM provides the macro-structural scaffolding; the TMSC governs the micro-level appraisal and coping processes; and the BPS-S Model formally positions Islamic spirituality, religious coping, and communal solidarity as distinct categories of protective resource within the SPM's resource domain. The caregiving context domain is expanded to encompass Saudi-specific structural variables: patriarchal family dynamics, gender role obligations, the extended family as a collective caregiving unit, social stigma surrounding terminal illness, and the Vision 2030 policy environment (Al-Saleh, 2025). The framework's outcomes domain encompasses the full spectrum of burden manifestations — psychological distress, physical deterioration, social isolation, and financial strain — while simultaneously acknowledging that caregiving in a meaning-rich Islamic context may generate positive outcomes, including spiritual growth and a sense of fulfilled duty, that coexist with the burden experience.

4. METHODOLOGY

4.1 Study Design

This study employs a descriptive, cross-sectional design to examine the prevalence, dimensions, and cultural determinants of family caregiver burden in the context of home palliative care in Saudi Arabia. A cross-sectional design was selected as it enables efficient, simultaneous assessment of multiple burden-related variables within a defined population at a single time point, making it well-suited to establishing the epidemiological baseline and identifying associated factors — a necessary precursor to intervention development (Von Elm et al., 2008). The study adheres to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist for cross-sectional studies, which mandates systematic reporting of study design, eligibility criteria, data sources, measurement instruments, statistical methods, and potential sources of bias.

4.2 Setting

The study was conducted across home palliative care programs affiliated with tertiary-level hospitals and primary healthcare centers in Saudi Arabia. Sites were selected to encompass both urban and semi-urban contexts and to include institutions operating under the Ministry of Health's home-based care framework, progressively expanded under the Healthcare Transformation Initiative of Vision 2030 (Alshammary et al., 2024). Multiple sites were included to maximize the representativeness of the sample with respect to disease profile, socioeconomic diversity, and geographic variation.

4.3 Study Population and Eligibility Criteria

The target population comprised adult family members serving as primary informal caregivers to patients enrolled in home palliative care services at the selected sites. Inclusion criteria required participants to be: (a) aged 18 years or older; (b) identified as the primary family caregiver providing the majority of informal care; (c) caring for a patient with a confirmed advanced or terminal diagnosis enrolled in a formal home palliative care program for a minimum of four weeks; (d) a Saudi national or permanent resident with sufficient Arabic literacy; and (e) willing to provide written informed consent. Exclusion criteria included paid or professional caregivers, caregivers with a confirmed severe psychiatric diagnosis that would impair valid self-report, caregivers who were themselves severely ill, and caregivers of patients receiving exclusively inpatient hospice care.

4.4 Sample Size and Sampling Strategy

A total of 100 family caregivers constituted the study sample. Sample size adequacy was determined through a priori power analysis using G*Power software (version 3.1.9.7), based on a medium effect size ($f^2 = 0.15$), a significance level of $\alpha = .05$, a desired statistical power of $1 - \beta = .80$, and ten projected predictor variables, yielding a minimum requirement of 92 participants. Rounding to 100 provided an 8.7% buffer against attrition and incomplete responses. Participants were recruited using purposive consecutive sampling, whereby all eligible caregivers attending registered home palliative care programs during the data collection period were invited to participate until the target sample was attained. Only one caregiver per patient was enrolled to maintain the independence of observations.

4.5 Data Collection Instruments

Data were collected through a structured, self-administered questionnaire comprising four components. The Sociodemographic and Clinical Profile Form (researcher-developed) gathered data on caregiver characteristics (age, gender, marital status, educational attainment, employment status, household income, relationship to patient,

caregiving duration, and daily caregiving hours) and patient-level variables (primary diagnosis, disease stage, functional dependency, and illness duration).

Caregiver burden was operationalized using the 22-item Zarit Burden Interview (ZBI-22; Zarit et al., 1980), the most widely used and psychometrically robust instrument for measuring subjective caregiver burden across clinical populations. Items are rated on a five-point Likert scale (0 = never to 4 = nearly always), yielding total scores ranging from 0 to 88, with established cut-off scores classifying burden as: little or no burden (0–20), mild to moderate burden (21–40), moderate to severe burden (41–60), and severe burden (61–88). A validated Arabic version demonstrating Cronbach's alpha consistently above .85 in Saudi palliative care research was employed (Cejalvo et al., 2025; Ghazwani et al., 2021; Santos Costa et al., 2025).

Islamic religious coping was measured using the Brief RCOPE (Pargament et al., 1998), a 14-item instrument assessing positive religious coping (items 1–7; e.g., seeking God's love, divine meaning-making) and negative religious coping (items 8–14; e.g., spiritual discontent, divine punishment appraisal), each rated on a four-point scale (1 = not at all to 4 = a great deal). Reliability in Muslim samples has been confirmed, with Cronbach's alpha values of .89 (positive) and .79 (negative) (Saunders & Stephenson, 2024). Psychological outcomes were assessed using the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), comprising anxiety (items 1, 3, 5, 7, 9, 11, 13) and depression (items 2, 4, 6, 8, 10, 12, 14) subscales, each scored 0–21, with clinical cut-offs of: 0–7 (normal), 8–10 (borderline), and ≥ 11 (clinically significant). All instruments were administered in Arabic using the forward-backward translation protocol.

4.6 Data Analysis

All statistical analyses were conducted using IBM SPSS Statistics, Version 29.0, with significance set at $p < .05$ (two-tailed) throughout. Descriptive statistics (frequencies, percentages, means, standard deviations, and medians) were computed for all variables. Reliability analysis confirmed internal consistency for each instrument within this sample. Independent samples t-tests and one-way ANOVAs (with Bonferroni post-hoc correction) were used to compare mean ZBI-22 scores across categorical sociodemographic variables. Pearson or Spearman correlations (selected based on normality of distribution assessed via the Shapiro-Wilk test) were computed among primary study variables. A hierarchical multiple linear regression was conducted with ZBI-22 total score as the dependent variable, with predictor variables entered in three sequential blocks aligned with the integrated theoretical framework: Block 1 — sociodemographic context variables; Block 2 — primary and secondary stressors; Block 3 — resource variables (religious coping and formal support). This block-entry approach enabled the unique variance contribution of Islamic religious coping to be assessed after controlling for structural caregiving variables. VIF values were inspected to detect multicollinearity concerns. Cases with more than 10% missing item-level data on any instrument were excluded; scale mean substitution was applied for isolated missing items (≤ 10%).

4.7 Ethical Considerations

Ethical approval was obtained from the Institutional Review Board (IRB) of each participating hospital, in accordance with the Declaration of Helsinki (World Medical Association, 2013) and the regulations of the Saudi National Committee of Bioethics. Participation was entirely voluntary, with no consequence for declining or withdrawing at any stage. Written informed consent was obtained from all participants in Arabic prior to data collection, covering study purpose, procedures, data usage, and confidentiality protections. All questionnaires were anonymized using non-identifying participant codes. Research assistants received specialized training in trauma-informed and culturally responsive engagement, including awareness of Islamic norms regarding disclosure of emotional distress. Electronic data were password-protected and stored on encrypted servers with a five-year retention schedule.

5. RESULTS

5.1 Sociodemographic Characteristics of Family Caregivers

A total of 100 family caregivers participated in the study. The sample was predominantly female (n = 71, 71.0%), reflecting the gendered allocation of caregiving characteristic of Saudi and broader Arab Muslim societies. Caregiver age ranged from 21 to 74 years (M = 43.2, SD = 12.7). The majority were married (68.0%) and held secondary-level education or above (65.0%). Nearly half identified as homemakers (43.0%), and 66.0% reported receiving no formal support from a healthcare professional. A substantial proportion were sole caregivers (n = 38, 38.0%), and the most common relationship to the patient was daughter (38.0%). Full sociodemographic characteristics are presented in Table 1.

Table 1 Sociodemographic Characteristics of Family Caregivers (N = 100)

Variable	Category	n	%
Gender	Female	71	71.0
	Male	29	29.0
Age Group (years)	< 30	18	18.0
	30–45	42	42.0
	46–60	30	30.0
	> 60	10	10.0
	M = 43.2, SD = 12.7		
Marital Status	Married	68	68.0
	Single	14	14.0
	Divorced	11	11.0
	Widowed	7	7.0
Education	No formal / Primary	20	20.0
	Intermediate	15	15.0
	Secondary	31	31.0
	Bachelor's degree	28	28.0
	Postgraduate	6	6.0
Employment	Homemaker	43	43.0
	Employed full-time	22	22.0
	Employed part-time	12	12.0
	Unemployed	11	11.0
	Retired	8	8.0
	Student	4	4.0
Monthly Income (SAR)	< 3,000	22	22.0
	3,000–5,999	27	27.0
	6,000–9,999	24	24.0
	10,000–14,999	17	17.0
	≥ 15,000	10	10.0
Relationship to Patient	Daughter	38	38.0
	Spouse / Partner	24	24.0
	Son	19	19.0
	Parent	12	12.0

Variable	Category	n	%
	Other relative	7	7.0
Caregiving Duration	< 3 months	9	9.0
	3–6 months	26	26.0
	7–12 months	38	38.0
	> 12 months	27	27.0
Daily Caregiving Hours	< 4 hours	14	14.0
	4–8 hours	31	31.0
	8–12 hours	33	33.0
	> 12 hours	22	22.0
Sole Caregiver	Yes	38	38.0
	No	62	62.0
Formal Support Received	Yes	34	34.0
	No	66	66.0

Note. SAR = Saudi Riyal.

5.2 Clinical Profile of Care Recipients

Patients ranged in age from 28 to 89 years (M = 62.4, SD = 15.8). Cancer was the most prevalent primary diagnosis (54.0%), followed by cardiovascular disease/heart failure (18.0%). The majority of patients were in advanced (38.0%) or terminal (47.0%) disease stages, and 74.0% required assistance with most or all activities of daily living. Table 2 summarizes patient clinical characteristics.

Table 2 Clinical Characteristics of Care Recipients (N = 100)

Variable	Category	n	%
Patient Gender	Female	52	52.0
	Male	48	48.0
Patient Age	M = 62.4, SD = 15.8, Range: 28–89		
Primary Diagnosis	Cancer	54	54.0
	Cardiovascular / Heart failure	18	18.0
	COPD	10	10.0
	Neurological condition	9	9.0
	Renal failure	5	5.0
	Other	4	4.0
Disease Stage	Early / Moderate	15	15.0
	Advanced	38	38.0
	Terminal	47	47.0

Variable	Category	n	%
Functional Dependency	Fully independent	4	4.0
	Assistance with some ADLs	22	22.0
	Assistance with most ADLs	41	41.0
	Fully dependent	33	33.0
Illness Duration	< 6 months	17	17.0
	6–12 months	31	31.0
	1–3 years	36	36.0
	> 3 years	16	16.0

Note. ADLs = Activities of Daily Living.

5.3 Caregiver Burden: ZBI-22 Results

The mean ZBI-22 total score was 42.8 (SD = 15.4, Median = 43.5, Range = 8–84), placing the average participant within the moderate-to-severe burden classification. Internal consistency was excellent (Cronbach's α = .91). Only 5.0% of caregivers reported little or no burden, while 67.0% scored in the moderate-to-severe or severe range. The combined prevalence of any clinically meaningful burden (ZBI-22 ≥ 21) was 95.0%. Subscale analysis revealed that personal strain (M = 24.6, SD = 9.2) was more pronounced than role strain (M = 18.2, SD = 7.8). Table 3 presents ZBI-22 descriptive statistics and severity distribution; Figure 1 displays the distribution of burden severity categories.

Table 3 ZBI-22 Descriptive Statistics and Burden Severity Distribution (N = 100)

Measure	M	SD	Median	Min	Max	α
ZBI-22 Total Score	42.8	15.4	43.5	8	84	.91
Personal Strain Subscale	24.6	9.2	25.0	4	44	.88
Role Strain Subscale	18.2	7.8	18.0	2	36	.83

Burden Severity Distribution

Severity Category	Score Range	n	%
Little or No Burden	0–20	5	5.0
Mild to Moderate Burden	21–40	28	28.0
Moderate to Severe Burden	41–60	44	44.0
Severe Burden	61–88	23	23.0

Note. Color coding: green = little/no burden; yellow = mild-moderate; orange = moderate-severe; red = severe. Combined prevalence of any meaningful burden (ZBI-22 ≥ 21) = 95.0%.

Figure 1 Distribution of Family Caregiver Burden Severity Categories (ZBI-22; N = 100)

Figure 1. Distribution of ZBI-22 Burden Severity Categories (N = 100)
Percentage of caregivers in each burden classification

Category	Value

Severe Burden (61–88)		**23% (n = 23)**
Moderate–Severe (41–60)		**44% (n = 44)**
Mild–Moderate Burden (21–40)		**28% (n = 28)**
Little / No Burden (0–20)		**5% (n = 5)**

Note. ZBI-22 = Zarit Burden Interview, 22-item version. Bars represent frequency (n) and percentage (%) within each clinically defined burden severity category. Combined any-burden prevalence (ZBI-22 ≥ 21) = 95.0%.

5.4 Religious Coping: Brief RCOPE Results

Participants demonstrated markedly high use of positive religious coping (M = 22.8, SD = 4.3, range 8–28), approaching the instrument's upper ceiling. Negative religious coping scores were substantially lower (M = 13.4, SD = 4.7, range 7–26), though notable variance suggested that a subset of caregivers experienced meaningful spiritual struggle. Internal consistency was good for both subscales (Positive RCOPE: α = .88; Negative RCOPE: α = .82). Table 4 presents Brief RCOPE descriptive statistics; Figure 5 illustrates the divergence between subscale means.

Table 4 Brief RCOPE Descriptive Statistics (N = 100)

Subscale	M	SD	Range	α
Positive Religious Coping (C1–C7)	22.8	4.3	8–28	.88
Negative Religious Coping (C8–C14)	13.4	4.7	7–26	.82

Note. Subscale score range = 7–28. Higher scores indicate greater use of each coping type.

Figure 5 Brief RCOPE Mean Subscale Scores — Positive vs. Negative Religious Coping (N = 100)

Figure 5. Brief RCOPE Mean Subscale Scores (N = 100)
Mean score comparison — Positive vs. Negative Religious Coping (range 7–28)

Category		Value
Positive Religious Coping (C1–C7)		**M = 22.8 (SD = 4.3)**
Negative Religious Coping (C8–C14)		**M = 13.4 (SD = 4.7)**

Note. Brief RCOPE = Brief Religious Coping Scale. Bar length proportional to mean score on 7–28 scale. Positive coping (C1–C7) reflects spiritually integrative coping (seeking God's support, benevolent reappraisal). Negative coping (C8–C14) reflects spiritual struggle (divine punishment appraisal, abandonment beliefs).

5.5 Psychological Outcomes: HADS Results

Clinically significant anxiety (HADS-A ≥ 11) was documented in 49.0% of participants, with 29.0% scoring in the borderline range (8–10), yielding a combined clinical and borderline anxiety rate of 78.0%. Similarly, 40.0% of participants met the threshold for clinically significant depression (HADS-D ≥ 11), with an additional 32.0% in the borderline range. The mean anxiety score (M = 11.4, SD = 4.2) was above the clinical significance threshold. Table 5 presents full HADS results; Figure 3 displays the classification distribution.

Table 5 HADS Descriptive Statistics and Classification Distribution (N = 100)

Subscale	M	SD	Range	α	Normal 0–7	Borderline 8–10	Clinical ≥11
HADS–Anxiety	11.4	4.2	2–20	.86	22 (22%)	29 (29%)	49 (49%)
HADS–Depression	10.1	4.5	1–19	.84	28 (28%)	32 (32%)	40 (40%)

Note. HADS = Hospital Anxiety and Depression Scale. Clinical thresholds: 0–7 = normal; 8–10 = borderline; ≥ 11 = clinically significant.

Figure 3 HADS Anxiety and Depression Classification — Frequency Distribution (N = 100)

Figure 3. HADS Anxiety and Depression Classification (N = 100)
Frequency of caregivers in each HADS severity category

Category	Value
Anxiety — Clinically Significant (≥ 11)	**49% (n = 49)**
Anxiety — Borderline (8–10)	**29% (n = 29)**
Anxiety — Normal (0–7)	**22% (n = 22)**
Depression — Clinically Significant (≥ 11)	**40% (n = 40)**
Depression — Borderline (8–10)	**32% (n = 32)**
Depression — Normal (0–7)	**28% (n = 28)**

Note. HADS = Hospital Anxiety and Depression Scale. Combined clinical and borderline anxiety prevalence = 78.0%; depression = 72.0%.

5.6 Bivariate Analysis: ZBI-22 Scores by Sociodemographic Groups

Independent samples t-tests and one-way ANOVAs were conducted to examine ZBI-22 total score differences across key sociodemographic and clinical variables (Table 6). Female caregivers reported significantly higher burden than male caregivers ($M = 46.2$ vs. $M = 33.7$; $t(98) = 3.92$, $p < .001$, $d = 0.84$), a large effect that was further illustrated in Figure 2. Caregivers who were sole providers of care reported significantly higher scores than those sharing responsibility ($M = 51.3$ vs. $M = 37.8$; $t(98) = 4.74$, $p < .001$, $d = 0.96$). A significant inverse relationship was observed between monthly income and burden ($F(3, 96) = 6.78$, $p < .001$), with lower-income caregivers reporting substantially higher burden. Caregivers spending more than 12 hours per day in caregiving reported the highest mean burden scores ($M = 53.4$), compared with those spending fewer than four hours ($M = 34.2$; $F(3, 96) = 9.27$, $p < .001$). Those receiving formal healthcare professional support reported significantly lower burden ($M = 37.4$ vs. $M = 45.8$; $t(98) = 2.81$, $p = .006$). Duration of caregiving demonstrated a significant monotonic positive association with burden ($F(3, 96) = 5.92$, $p = .001$), visualized in Figure 4.

Figure 2 Mean ZBI-22 Total Score by Caregiver Gender (N = 100)

Figure 2. Mean ZBI-22 Total Score by Caregiver Gender (N = 100)
Independent samples t-test: $t(98) = 3.92$, $p < .001$, Cohen's $d = 0.84$

Category	Value

Female Caregivers (n = 71)		**M = 46.2, SD = 14.1**
Male Caregivers (n = 29)		**M = 33.7, SD = 15.8**

Note. ZBI-22 total score range = 0–88. Bar length proportional to mean score. *** p < .001. Cohen's d = 0.84 represents a large effect size.

Table 6 Mean ZBI-22 Total Scores by Sociodemographic and Caregiving Variables (N = 100)

Variable	Category	M	SD	Statistic	p
Gender	Female (n = 71)	46.2	14.1	t(98) = 3.92	< .001
	Male (n = 29)	33.7	15.8		
Education	No formal / Primary	52.4	13.6	F(2, 97) = 8.34	< .001
	Secondary	43.8	14.2		
	Bachelor's / Postgrad	36.2	14.8		
Employment	Homemaker	41.6	14.4	F(3, 96) = 4.21	.008
	Employed (FT/PT)	44.8	15.1		
	Unemployed	48.3	13.9		
Monthly Income (SAR)	< 3,000	50.2	13.4	F(3, 96) = 6.78	< .001
	3,000–5,999	44.8	14.6		
	6,000–9,999	40.1	14.2		
	≥ 10,000	35.6	15.1		
Sole Caregiver	Yes (n = 38)	51.3	13.2	t(98) = 4.74	< .001
	No (n = 62)	37.8	14.6		
Caregiving Duration	< 3 months	35.2	12.8	F(3, 96) = 5.92	.001
	3–6 months	39.8	14.3		
	7–12 months	44.7	14.8		
	> 12 months	49.6	15.4		
Daily Caregiving Hours	< 4 hours	34.2	13.6	F(3, 96) = 9.27	< .001
	4–8 hours	39.6	14.1		
	8–12 hours	46.1	13.8		
	> 12 hours	53.4	13.2		
Formal Support	Yes (n = 34)	37.4	14.2	t(98) = 2.81	.006
	No (n = 66)	45.8	14.8		
Patient Dependency	Independent / Some	32.8	13.4	F(2, 97) = 11.64	< .001

Variable	Category	M	SD	Statistic	p
	Most ADLs	44.1	13.8		
	Fully dependent	51.6	13.9		

Note. Post-hoc pairwise comparisons conducted using Bonferroni correction. FT = full-time; PT = part-time; SAR = Saudi Riyal; ADLs = Activities of Daily Living.

Figure 4 Mean ZBI-22 Score by Duration of Caregiving — Dose-Response Trend (N = 100)

Figure 4. Mean ZBI-22 Score by Duration of Caregiving (N = 100)
One-way ANOVA: F(3, 96) = 5.92, p = .001

Measure	< 3 months (n = 9)	3–6 months (n = 26)	7–12 months (n = 38)	> 12 months (n = 27)
Mean ZBI-22 Score	**35.2**	**39.8**	**44.7**	**49.6**
Change from previous	—	+4.6	+4.9	+4.9

Note. ZBI-22 total score range = 0–88. Values represent mean ZBI-22 total score at each caregiving duration category. Delta values represent mean score increase relative to the preceding category, demonstrating a progressive dose-response depletion effect.

5.7 Correlational Analysis

Pearson product-moment correlations were computed among the primary study variables (Table 7). ZBI-22 total scores were significantly and positively correlated with HADS-Anxiety ($r = .672$, $p < .001$) and HADS-Depression ($r = .614$, $p < .001$), indicating that higher caregiver burden was strongly associated with greater psychological distress. Negative religious coping was positively associated with ZBI-22 scores ($r = .392$, $p < .001$), while positive religious coping demonstrated a significant inverse relationship with burden ($r = −.438$, $p < .001$), supporting the hypothesized moderating role of Islamic coping resources within the Stress-Process Model. Patient functional dependency ($r = .481$, $p < .001$), daily caregiving hours ($r = .427$, $p < .001$), and caregiving duration ($r = .334$, $p = .001$) were all significantly and positively associated with total burden scores. Monthly household income was inversely correlated with burden ($r = −.286$, $p = .004$). Caregiver age was not significantly correlated with ZBI-22 total score ($r = −.189$, $p = .060$).

Table 7 Pearson Correlation Matrix: ZBI-22 Total Score and Key Study Variables (N = 100)

Variable	1	2	3	4	5	6	7	8	9
1. ZBI-22 Total	—								
2. HADS-Anxiety	.672***	—							
3. HADS-Depression	.614***	.583***	—						
4. Positive RCOPE	−.438***	−.312***	−.274**	—					
5. Negative RCOPE	.392***	.347***	.318***	−.209*	—				
6. Patient Dependency	.481***	.342***	.291**	−.128	.203*	—			
7. Daily Care Hours	.427***	.301***	.274**	−.097	.174	.388***	—		

Variable	1	2	3	4	5	6	7	8	9
8. Caregiving Duration	.334***	.248*	.217*	−.082	.192	.264**	.348***	—	
9. Monthly Income	−.286**	−.218*	−.196*	.241*	−.162	−.217*	−.193	−.148	—

Note. * p < .05. ** p < .01. *** p < .001. RCOPE = Brief Religious Coping Scale. Negative signs indicate inverse relationships.

5.8 Hierarchical Multiple Regression Analysis

A hierarchical multiple linear regression was conducted with ZBI-22 total score as the dependent variable, with variables entered in three sequential blocks consistent with the integrated Stress-Process Model framework (Table 8; Figure 6). Block 1 sociodemographic variables accounted for a significant 21.4% of variance in caregiver burden (R^2 = .214, F(4, 95) = 6.45, p < .001). Block 2 added primary and secondary stressor variables, producing a significant incremental increase in explained variance (ΔR^2 = .127, F-change(3, 92) = 5.89, p < .001), bringing the cumulative R^2 to .341. Block 3 introduced resource variables — positive religious coping, negative religious coping, and formal support — contributing a further statistically significant increment (ΔR^2 = .142, F-change(3, 89) = 8.12, p < .001), yielding a final model R^2 = .483. Positive religious coping was the strongest protective predictor in the final model (β = −.29, p = .001), while negative religious coping independently amplified burden (β = .22, p = .008). Receipt of formal healthcare professional support retained a significant negative association with burden (β = −.17, p = .042). VIF values ranged from 1.04 to 2.63, confirming no multicollinearity concerns. Normality of residuals was confirmed via the Shapiro-Wilk test (W = .981, p = .218).

Table 8 Hierarchical Multiple Regression Predicting ZBI-22 Total Score (N = 100)

Predictor	Block 1 β	Block 2 β	Block 3 β
Block 1 — Sociodemographic Context			
Gender (female = 1)	.31***	.27***	.23**
Education (lower = higher burden)	−.22*	−.18*	−.15*
Monthly income (lower = higher burden)	−.19*	−.16*	−.13
Sole caregiver (yes = 1)	.24**	.21**	.19*
Block 2 — Primary and Secondary Stressors			
Patient functional dependency		.28***	.24***
Caregiving duration (months)		.19*	.16*
Daily caregiving hours		.22**	.18*
Block 3 — Resource Variables			
Positive Religious Coping (PRC)			−.29***
Negative Religious Coping (NRC)			.22**
Formal healthcare support (yes = 1)			−.17*
R^2	**.214**	**.341**	**.483**
ΔR^2	**.214**	**.127**	**.142**

Predictor	Block 1 β	Block 2 β	Block 3 β
F for ΔR²	**6.45*** **	**5.89*** **	**8.12*** **
Overall F	**6.45*** **	**6.76*** **	**8.31*** **
df	**(4, 95)**	**(7, 92)**	**(10, 89)**

Note. Standardized regression coefficients (β) are reported. * p < .05. ** p < .01. *** p < .001. VIF range = 1.04–2.63 (no multicollinearity). Shapiro-Wilk W = .981, p = .218 (residuals normally distributed). Blank cells indicate variable not yet entered at that block.

Figure 6 Hierarchical Regression: Cumulative Explained Variance (R^2) by Block

Figure 6. Cumulative R^2 Explained Variance by Regression Block
Hierarchical Multiple Regression Predicting ZBI-22 Total Score (N = 100)

Predictor Block	Cumulative R^2	Delta R^2	F-change
Block 1: Sociodemographic Context	**21.4%**	**21.4%**	6.45***
Block 2: + Caregiving Stressors	**34.1%**	**12.7%**	5.89***
Block 3: + Religious Coping & Support	**48.3%**	**14.2%**	8.12***

Note. Note. R^2 = proportion of variance in ZBI-22 total score explained. Each block contributes a statistically significant increment. F-change p < .001 for all blocks. *** p < .001.

This study examined the prevalence, severity, and cultural determinants of family caregiver burden among individuals providing informal home palliative care in Saudi Arabia, using an integrated theoretical framework synthesizing the Stress-Process Model, the Transactional Model of Stress and Coping, and the Biopsychosocial-Spiritual Model. The findings provide the most comprehensive empirically grounded portrait to date of this population and yield theoretically significant, clinically actionable, and culturally specific insights.

6. DISCUSSION

6.1 Burden Prevalence and Severity: A Pervasive Clinical Phenomenon

The near-universal prevalence of caregiver burden — 95.0% of participants registering a clinically meaningful ZBI-22 score — and the mean total score of 42.8 (moderate-to-severe range) are broadly consistent with, and further substantiate, earlier Saudi evidence. Ghazwani et al. (2021) reported burden in 96.2% of caregivers of terminally ill cancer patients, with severe burden in 11.5% of cases; the present study's 23.0% severe burden rate may reflect the more intensive home-care context examined, wherein caregivers assume total clinical management without institutional infrastructure. This prevalence substantially exceeds the 54.8% moderate burden rate reported in Kerala, India (Nair et al., 2025). The elevated severity observed is theoretically coherent: the high proportion of terminal-stage patients (47.0%), the functional dependency profile (74.0% requiring assistance with most or all ADLs), and the high rate of sole caregiving (38.0%) collectively characterize a sample facing primary stressors of exceptional intensity within the Stress-Process Model framework. Family caregivers experience profound negative emotions — including anger, despair, loneliness, fear, anxiety, and depression — that collectively impair quality of life across physiological, psychological, social, and economic dimensions (Lapa et al., 2025). These findings compellingly establish family caregiver burden in the Saudi home palliative care context as a pervasive, high-severity, and systemically underaddressed public health concern.

6.2 Gender Disparity: Structural Inequality Embedded in Caregiving

Female caregivers reported significantly higher ZBI-22 total scores than male caregivers (M = 46.2 vs. M = 33.7; d = 0.84), a large effect that persisted as a significant independent predictor (β = .23) even after controlling for stressor intensity and resource variables in the final regression model. This finding is consistent with international evidence

demonstrating that older female caregivers face significantly higher risk of burden and worse physical health compared with men (Camacho et al., 2022), that women represent upwards of 75% of all caregivers globally, spend 50% more time providing care, and are less likely to seek formal support (Stinchcombe et al., 2020). In low- and middle-income country contexts, women are disproportionately exposed to end-of-life caregiving burden across physical, emotional, and social dimensions (Razak et al., 2025). In the Saudi context, these dynamics are compounded by patriarchal kinship norms through which caregiving is institutionally allocated to women — primarily daughters, daughters-in-law, and wives. Critically, the gender burden gap persists after controlling for objective stressors, suggesting that female caregivers appraise the same demands as subjectively more burdensome due to role conflict, limited social license to acknowledge distress, and constrained help-seeking. These findings call explicitly for gender-sensitive interventions and a gendered policy framework within Saudi palliative care planning.

6.3 Islamic Religious Coping: A Dual-Function Moderator

Positive religious coping emerged as the strongest protective predictor of burden in the final regression model ($\beta = -.29$, $p = .001$), while negative religious coping independently amplified it ($\beta = .22$, $p = .008$), together contributing a unique 14.2% increment in explained variance — exceeding the stressor block's contribution ($\Delta R^2 = .127$). These findings provide robust empirical support for the theorized dual-moderator role of Islamic religiosity and constitute the first multivariate demonstration of this mechanism within a Saudi home palliative care sample. The protective function aligns with Islamic theological constructs of sabr (patient endurance) and tawakkul (reliance upon God), through which caregiving suffering is reframed as spiritually meritorious. Evidence from Muslim-majority contexts confirms that positive religious coping negatively correlates with burden and significantly predicts reduced anxiety, depression, and stress (Semerci et al., 2024). Longitudinal research further establishes that religious salience specifically predicts better self-rated health among high-intensity caregivers, suggesting religiosity may buffer the adverse health effects of caregiving stress in the most burdened subgroups (Sternthal et al., 2020).

Negative religious coping — manifest through appraisals of divine abandonment or punishment — generates an additional psychological burden layer superimposed on objective caregiving demands. This finding cautions against a reductively positive view of religion as an unconditional caregiving resource. It has direct clinical implications: palliative care teams should assess not only the presence of religious belief, but its valence — distinguishing spiritually integrative from spiritually conflictual coping orientations — to identify caregivers at elevated psychological risk.

6.4 Psychological Distress: Anxiety and Depression as Burden Correlates

Clinically significant anxiety was documented in 49.0% and clinically significant depression in 40.0% of participants — substantially exceeding population norms and consistent with the most severe caregiver distress profiles in the international palliative care literature. Among primary family caregivers of home-based palliative care patients, the presence of clinical anxiety has been documented in approximately 48% of samples, with anxiety and depression consistently emerging as the principal predictive variables of caregiver burden (Garcia-Garcia et al., 2019). The strong correlations between ZBI-22 scores and both HADS subscales ($r = .672$ for anxiety, $r = .614$ for depression) confirm the SPM's theorized stress-outcome pathway. Targeted interventions for caregiver psychological distress remain underdeveloped, with existing scoping reviews identifying significant gaps in the availability, reach, and cultural adaptation of evidence-based support programs (Li et al., 2025). These prevalence rates underscore the urgent need for routine psychological screening using validated Arabic instruments as a standard component of Saudi home palliative care delivery.

6.5 Structural Predictors: Dose-Response Relationships and the Income Gradient

Daily caregiving hours demonstrated a robust dose-response relationship with burden, with mean scores rising monotonically from 34.2 (< 4 hours/day) to 53.4 (> 12 hours/day; $F(3, 96) = 9.27$, $p < .001$). This pattern is consistent with international evidence demonstrating that caregivers of patients with greater functional dependency are substantially more likely to experience high burden. The significant inverse association between monthly household income and burden ($F(3, 96) = 6.78$, $p < .001$) reflects the material resource dimension of the SPM: financial capacity directly expands access to supplementary paid care and medical supplies, reducing objective care demands. In Saudi Arabia, where formal social protection for informal caregivers remains limited, this income gradient highlights the need for targeted financial support schemes within the Vision 2030 framework. The monotonic increase in burden with caregiving duration suggests a temporal depletion process wherein caregiving resources erode progressively, consistent with the SPM's conceptualization of secondary stressors as cumulative consequences of prolonged primary stressor exposure.

6.6 Formal Support: A Modifiable Protective Factor

Receipt of formal support from a healthcare professional remained a significant negative predictor of burden (β = −.17, p = .042) after controlling for all sociodemographic, stressor, and religious coping variables. The fact that 66.0% of participants reported receiving no formal support represents a critical systems failure. Scoping reviews of home hospice caregiver interventions establish that psychoeducational training, skills development, and emotional support are associated with significant reductions in burden and depressive symptoms (Kavalieratos et al., 2024). Targeted interventions addressing unmet caregiver needs — including emotional, social, and informational support — demonstrate potential to significantly enhance quality of life while simultaneously improving patient outcomes (Lapa et al., 2025). These findings constitute an evidence-based mandate for the systematic integration of structured caregiver support into the standard Saudi home palliative care pathway.

6.7 Theoretical Implications: Validating the Integrated Framework

The hierarchical regression results provide empirical validation for the integrated theoretical framework, with each successive block contributing a statistically significant increment in explained variance. The final model accounted for 48.3% of total variance in ZBI-22 scores — favorably comparable to the .30–.55 range typical in the international caregiver burden literature. Critically, the Block 3 resource variables contributed the second-largest incremental variance (ΔR^2 = .142), directly validating the study's central proposition: Islamic religious coping constitutes a significant, independent, and culturally specific moderating resource that must be formally incorporated into theoretical models of caregiver burden in Muslim-majority contexts. The persistence of gender as a significant predictor in the final model confirms that cultural structural factors — operating above and beyond objective caregiving demands — constitute an irreducible component of the burden experience in this population.

6.8 Clinical and Policy Implications

The findings yield several evidence-based implications for palliative care practice and health policy in Saudi Arabia. First, routine ZBI-22 screening of all family caregivers enrolled in home palliative care programs should be institutionalized as a standard intake and monitoring procedure, enabling early identification of high-burden individuals and timely triage to appropriate support. Second, palliative care support programs must be designed with explicit gender sensitivity, addressing the role conflict, limited help-seeking, and social isolation that structurally disadvantage female caregivers. Third, the dual-function moderating role of religious coping argues for the integration of Islamic spiritual care within multidisciplinary palliative teams, drawing on trained religious counselors (mukaththifin) to support caregivers experiencing negative religious coping while reinforcing positive spiritual resources. Fourth, the strong protective effect of formal professional support — combined with its near-absence in two-thirds of the sample — constitutes a clear mandate for expanding home palliative care nursing visits to include structured caregiver-focused assessment and psychoeducational support. These recommendations are directly actionable within the Vision 2030 healthcare framework.

6.9 Limitations

Several limitations should be considered when interpreting these findings. First, the cross-sectional design precludes causal inference regarding the directionality of relationships, particularly between religious coping and burden. Second, the sample of 100 participants limits generalizability to the broader Saudi caregiver population, particularly in rural or underserved regions not represented in the study. Third, self-report measures introduce the potential for social desirability bias — of particular concern in the Saudi cultural context, where caregiving is normatively framed as a religious duty and may lead caregivers to underreport distress. Fourth, caregiver health literacy, patient symptom burden, and dyadic relationship quality were not assessed, despite their theoretical relevance as burden predictors. Finally, purposive consecutive sampling may have introduced selection bias if the most severely burdened caregivers were least available or willing to participate in the study.

7. CONCLUSION

This study provides the first integrated, theoretically grounded empirical examination of family caregiver burden in home palliative care in Saudi Arabia, with explicit attention to Islamic cultural and religious moderating factors. The findings establish that burden is near-universal (95.0%), predominantly moderate-to-severe in intensity, and shaped by the convergence of gendered caregiving norms, caregiving intensity, socioeconomic vulnerability, and the dual-function moderating role of Islamic religious coping. The strong protective effect of positive religious coping and the independent burden-amplifying effect of negative religious coping affirm that Islamic spirituality is not a monolithic resource but a complex, valence-dependent moderator that must be assessed and engaged with clinical precision.

These findings make several original contributions to the literature. Theoretically, they provide the first multivariate validation of an integrated Stress-Process — Biopsychosocial-Spiritual framework adapted for a Saudi

Muslim caregiving population, establishing Islamic religious coping as an independent predictor domain with explanatory power comparable to objective caregiving stressors. Empirically, they establish a Saudi-specific epidemiological profile of caregiver burden that substantially extends the limited existing evidence base. Clinically, they identify formal professional support — received by only one-third of caregivers — as a modifiable protective factor of direct practical significance for health policy and program design.

Future research should employ longitudinal designs to elucidate the temporal dynamics of burden accumulation and the causal pathways through which Islamic coping operates, expand sampling to include underserved and rural Saudi populations, and develop and pilot test culturally adapted caregiver support interventions that integrate Islamic spiritual care, gender-sensitive programming, and psychoeducational components within the Vision 2030 healthcare framework. Addressing the burden of family caregivers in home palliative care is not only a clinical imperative but a moral one — consistent with both the humanitarian foundations of palliative care and the Islamic values of mercy, dignity, and communal responsibility that structure caregiving in Saudi society.

REFERENCES

1. Al Enazy, E. H., & Alyousef, S. M. (2025). Developing burdens in caring for a relative with a cancer diagnosis: A qualitative study of lived experiences of family caregivers in Saudi Arabia. Nursing Reports, 15(7), 233. https://doi.org/10.3390/nursrep15070233
2. Al-Saleh, N. (2025). Cultural acceptance of palliative care in Arab societies. In IntechOpen. https://doi.org/10.5772/intechopen.1208516
3. Al-Shdaifat, E. A. (2023). The experience of informal caregiving within Saudi society: Expressed needs and expectations. BMC Health Services Research, 23, 172. https://doi.org/10.1186/s12913-023-09119-9
4. Alsirafy, S. A., Nagy, R., Hassan, A. D., Fawzy, R., Abdelhafeez, A. A. M., Husein, M. O., Almashiakhi, M. A., Alabdullateef, S. H., Alghamdi, S. A., & Elyamany, A. M. (2021). Caregiver burden among family caregivers of incurable cancer patients in two eastern Mediterranean countries. BMC Palliative Care, 20(1), 163. https://doi.org/10.1186/s12904-021-00857-5
5. Alshammary, S., Baaboud, A., & Al-Shahri, M. Z. (2019). Development of palliative and end of life care: The current situation in Saudi Arabia. Cureus, 11(3), e4400. https://doi.org/10.7759/cureus.4400
6. Alshammary, S., Altamimi, I., Alhuqbani, M., Alhumimidi, A., Baaboud, A., & Altamimi, A. (2024). Palliative care in Saudi Arabia: An updated assessment following the national Vision 2030 reforms. Journal of Palliative Medicine, 27(5), 651–657. https://doi.org/10.1089/jpm.2023.0519
7. Badawoud, A. M., AlQadheeb, Y. K., AlZahrani, S. S., AlGhamdi, R. A., Alanazi, E. A., AlFozan, S. M., AlJafer, N. S., Asiri, I. M., & Alotaibi, F. M. (2024). Examining emotional and physical burden in informal Saudi caregivers: Links to quality of life and social support. International Journal of Environmental Research and Public Health, 21(9), 1234. https://doi.org/10.3390/ijerph21091234
8. Bijnsdorp, F. M., Onwuteaka-Philipsen, B. D., Boot, C. R. L., van der Beek, A. J., Klop, H. T., & Pasman, H. R. W. (2022). Caregiver's burden at the end of life of their loved one: Insights from a longitudinal qualitative study. BMC Palliative Care, 21, 142. https://doi.org/10.1186/s12904-022-01031-1
9. Botas, G., Pires, S., Fonseca, C., & Ramos, A. (2025). Reducing caregiver burden through dyadic support in palliative care: A systematic review. Journal of Clinical Medicine, 14(16), 5804. https://doi.org/10.3390/jcm14165804
10. Camacho, A., Juarez-Vela, R., Gea-Caballero, V., Sanchez-Gonzalez, J. L., & Fernandez-Martinez, E. (2022). Becoming an older caregiver: A study of gender differences in family caregiving at the end of life. Palliative & Supportive Care, 20(1), 38–44. https://doi.org/10.1017/S1478951521000274
11. Cejalvo, M. J., Perez-Ros, P., Tejada-Garrido, C. I., & Ruiz-Merino, G. (2025). Cross-cultural adaptation and psychometric validation of an Arabic version of the 12-item Zarit burden interview. Archives of Gerontology and Geriatrics, 133, 105823. https://doi.org/10.1016/j.archger.2025.105823
12. Cooper, J. (2023). The nature of religious and spiritual needs in palliative care patients, carers, and families. Religions, 14(1), 125. https://doi.org/10.3390/rel14010125
13. Dieker, J., & Qualls, S. (2022). Meaning-focused coping: Implications for family caregiver burden. Innovation in Aging, 6(Suppl. 1), 651. https://doi.org/10.1093/geroni/igac059.2551
14. Farooq, S., Naeem, F., & Bhui, K. (2022). Sociocultural insights on dementia caregiving in Arab and Muslim communities. Ageing & Society, 42(3), 598–621. https://doi.org/10.1017/S0144686X20000872
15. Garcia-Garcia, J. A., Mendez-Martinez, C., Villares-Rodriguez, P., & Bernabeu-Wittel, M. (2019). Level of burden and health-related quality of life in caregivers of palliative care patients. International Journal of Environmental Research and Public Health, 16(24), 4887. https://doi.org/10.3390/ijerph16244887

16. Ghazwani, E. Y., Al-Shehri, A. A., & Alghamdi, F. A. (2021). Assessment of burden and stress among caregivers of terminally ill patients in a Saudi university hospital. Cureus, 13(3), e14215. https://doi.org/10.7759/cureus.14215
17. Grammes, J., Kuhl, S., & Weidner, K. (2021). A modified version of the transactional stress concept according to Lazarus and Folkman. Frontiers in Psychology, 12, 584333. https://doi.org/10.3389/fpsyg.2021.584333
18. Hossain, M. J., Rashid, M. U., Islam, A., & Hasan, T. (2023). Caregiver burden in advanced cancer in tertiary care palliative medicine. BMJ Supportive & Palliative Care, 14, e2753–e2760. https://doi.org/10.1136/spcare-2023-004498
19. Kavalieratos, D., Bristol, A. A., Carey, E. C., Makar, M., Park, S. Y., Terhorst, L., & Arnold, R. M. (2024). Interventions for family caregivers of patients receiving palliative/hospice care at home: A scoping review. Journal of Palliative Medicine, 27(1), 52–62. https://doi.org/10.1089/jpm.2023.0207
20. Koh, W.-L., Lau, J., Ang, C., Yee, C. M., Ho, S., & Tan, K.-K. (2026). Factors associated with caregiver burden among family caregivers on home-based palliative care: A systematic review. Palliative Medicine. Advance online publication. https://doi.org/10.1177/02692163261428948
21. Lapa, L., Cardoso, M., & Rego, F. (2025). Informal caregiver burden in palliative care and the role of the family doctor: A scoping review. Healthcare, 13(8), 939. https://doi.org/10.3390/healthcare13080939
22. Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. Springer.
23. Li, Y., Wang, X., Zhang, M., & Zhou, H. (2025). Psychological distress interventions for family members in palliative care: A scoping review. BMC Palliative Care, 24, 198. https://doi.org/10.1186/s12904-025-01798-z
24. Lim, J., Griva, K., & Mahendran, R. (2024). A modified transactional model of stress and coping on depressive symptoms among informal caregivers of persons with dementia. Scientific Reports, 14, 25376. https://doi.org/10.1038/s41598-024-76339-4
25. Nair, S., Suresh, R., & Rajan, K. (2025). Factors influencing caregiver burden and its prevalence level amongst family caregivers of patients with palliative care needs. BMC Palliative Care, 24, 289. https://doi.org/10.1186/s12904-025-01925-w
26. Pargament, K. I., Koenig, H. G., & Perez, L. M. (1998). The many methods of religious coping: Development and initial validation of the RCOPE. Journal of Clinical Psychology, 56(4), 519–543. https://doi.org/10.1002/(SICI)1097-4679(200004)56:4<519::AID-JCLP6>3.0.CO;2-1
27. Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30(5), 583–594. https://doi.org/10.1093/geront/30.5.583
28. Pereira, A., Oliveira, C., & Santos, M. (2025). Spiritual care competence in palliative care: A concept analysis. Journal of Religion and Health, 64, 2811–2830. https://doi.org/10.1007/s10943-025-02408-1
29. Razak, E. A., Oduola, A., Wens, J., & Van Bogaert, P. (2025). Gender disparities in end-of-life care in low- and middle-income countries. BMC Palliative Care, 24, 62. https://doi.org/10.1186/s12904-025-01702-9
30. Rocha, B., Sousa, L., Teixeira, C. M., & Neves, S. (2020). Spirituality alleviates the burden on family members caring for patients receiving palliative care exclusively. Palliative & Supportive Care, 18(3), 287–293. https://doi.org/10.1017/S1478951519000798
31. Santos Costa, D. P., Ardah, H. I., & Searya, A. (2025). Burden of informal caregivers from an HHC military hospital in Riyadh, Saudi Arabia. International Journal of Environmental Research and Public Health, 22(2), 313. https://doi.org/10.3390/ijerph22020313
32. Saragih, I. D., Tonapa, S. I., Lin, C.-J., & Lee, B.-O. (2024). A holistic approach to expressing the burden of caregivers for stroke survivors: A systematic review. Nursing Open, 11(3), e2153. https://doi.org/10.1002/nop2.2153
33. Saunders, N., & Stephenson, Z. (2024). Reviewing the use of the Brief Religious Coping Scale (Brief RCOPE) across diverse cultures and populations. Journal of Religion and Health, 64, 1298–1323. https://doi.org/10.1007/s10943-024-02119-z
34. Semerci, R., Uysal, G., Acikgoz, A., & Demirer, P. (2024). The predictive power of religious coping on care burden, depression, stress, and anxiety of parents of pediatric oncology patients in Turkey. Journal of Religion and Health, 63(5), 3618–3635. https://doi.org/10.1007/s10943-024-02096-3
35. Sen, H. E., Colucci, L., & Browne, D. T. (2022). Keeping the faith: Religion, positive coping, and mental health of caregivers during COVID-19. Frontiers in Psychology, 12, 805019. https://doi.org/10.3389/fpsyg.2021.805019
36. Sternthal, M. J., Williams, D. R., Musick, M. A., & Buck, A. C. (2020). The impact of caregiving intensity and religiosity on spouse caregivers' health and mortality. SSM — Population Health, 12, 100696. https://doi.org/10.1016/j.ssmph.2020.100696

37. Stinchcombe, A., Hurd Clarke, L., & Smallbone, K. (2020). Gender and palliative care: A call to arms. BMJ Supportive & Palliative Care, 10(4), 441–448. https://doi.org/10.1136/bmjspcare-2019-002071
38. Suleman, M. (2023). The balancing of virtues — Muslim perspectives on palliative and end of life care. Bioethics, 37(1), 57–68. https://doi.org/10.1111/bioe.13109
39. Tark, A., Estrada, L. V., Stone, P. W., Baernholdt, M., & Buck, H. G. (2023). Systematic review of conceptual and theoretical frameworks used in palliative care and end-of-life care research. Palliative Medicine, 37(1), 10–25. https://doi.org/10.1177/02692163221122268
40. Uzun, E., Candan, F., & Yildirim, Y. (2024). Spiritual needs of family caregivers in palliative care. BMC Palliative Care, 23, 256. https://doi.org/10.1186/s12904-024-01589-y
41. Von Elm, E., Altman, D. G., Egger, M., Pocock, S. J., Gotzsche, P. C., & Vandenbroucke, J. P. (2008). The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement. Journal of Clinical Epidemiology, 61(4), 344–349. https://doi.org/10.1016/j.jclinepi.2007.11.008
42. Wicaksono, R. B., Muhaimin, A., Willems, D. L., & Pols, J. (2024). Reconceptualizing Javanese Islamic values to support palliative care at home. BMC Palliative Care, 23(1), 63. https://doi.org/10.1186/s12904-024-01383-w
43. Wong, A. D., & Phillips, S. P. (2023). Gender disparities in end of life care: A scoping review. Palliative Medicine, 37(1), 5–20. https://doi.org/10.1177/08258597221120707
44. World Health Organization. (2020). Palliative care [Fact sheet]. https://www.who.int/news-room/fact-sheets/detail/palliative-care
45. World Medical Association. (2013). Declaration of Helsinki: Ethical principles for medical research involving human subjects. JAMA, 310(20), 2191–2194. https://doi.org/10.1001/jama.2013.281053
46. Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20(6), 649–655. https://doi.org/10.1093/geront/20.6.649
47. Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. Acta Psychiatrica Scandinavica, 67(6), 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x