

# PSYCHOLOGICAL DISTRESS AND COPING MECHANISMS AMONG FAMILIES OF PATIENTS WITH CHRONIC ILLNESSES ATTENDING DIVISIONAL HEADQUARTERS TEACHING HOSPITAL MIRPUR AJK: A CROSS-SECTIONAL STUDY

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## ABSTRACT

Chronic illnesses impose deep emotional, financial, and social demands not only on patients but also on their families, who often serve as primary caregivers. Despite their critical role, caregivers' psychological well-being remains underexplored in Pakistan, particularly in semi-urban regions such as Azad Jammu and Kashmir (AJK). This cross-sectional study assessed psychological distress and coping mechanisms among family caregivers of patients with chronic illnesses attending the Divisional Headquarters Teaching Hospital, Mirpur. A cross-sectional study was conducted using consecutive sampling. A total of 410 caregivers were enrolled. Psychological distress was measured with the Kessler-10 (K10), while coping strategies were evaluated through the Brief COPE Inventory. Data was analyzed in spss version 26. More than half of the participants (56.3%) experienced clinically significant distress, with 33.2% in the severe category. Independent predictors of moderate-to-severe distress includes female gender (AOR 1.9, 95% CI 1.2–3.1), monthly household income <PKR 40,000 (AOR 2.3, 95% CI 1.4–3.7), and caregiving duration exceeding 12 months (AOR 2.6, 95% CI 1.5–4.2). Coping responses were predominantly adaptive, with religious coping (88%), seeking emotional support (73%), and acceptance (70.5%) most frequently reported, while maladaptive strategies such as denial (21.7%) and substance use (7%) were less common. Findings highlight that caregivers in AJK are a vulnerable yet neglected population, and their psychological health must be integrated into chronic illness management through culturally sensitive interventions, psychosocial support, and financial assistance programs.

## I. INTRODUCTION

Chronic illnesses such as cardiovascular diseases, cancers, diabetes, and chronic respiratory conditions represent a global epidemic with immense public health consequences. According to the World Health Organization (WHO), non-communicable diseases (NCDs) account for approximately 41 million deaths annually, which constitutes nearly three-quarters of all global mortality (World Health Organization, 2023). The burden is disproportionately borne by low- and middle-income countries (LMICs), where more than 85% of premature deaths (ages 30–69

years) from NCDs occur (WHO, 2020). Pakistan, as an LMIC, faces a rising epidemic of NCDs, with an estimated 58% of annual mortality attributable to such conditions (Nishtar et al., 2013). In this context, attention has primarily been directed towards disease prevention, clinical management, and health system strengthening. However, an equally critical yet underexplored dimension is the impact of chronic illness on family members who assume caregiving responsibilities. Caregiving is an inherently demanding role, requiring family members to provide continuous emotional, financial, and physical support to chronically ill patients. This role, while socially valued and culturally expected in South Asian societies, can impose substantial psychological, social, and economic burdens (Adelman et al., 2014). Evidence demonstrates that caregivers of chronically ill patients experience higher rates of depression, anxiety, sleep disturbances, and reduced quality of life compared with non-caregivers (Schulz & Sherwood, 2008; Pinquart & Sörensen, 2003). Long-term caregiving has also been linked with negative physical health outcomes, including cardiovascular morbidity and immune dysfunction, mediated by chronic stress pathways (Vitaliano et al., 2003; Miller et al., 2007). The “hidden patient” phenomenon where caregivers themselves develop health problems as a result of caregiving is now increasingly recognized as a public health priority (Zarit et al., 1980).

The concept of psychological distress encompasses a spectrum of emotional suffering, including anxiety, depressive symptoms, and perceived stress, that arises when demands exceed coping resources (Drapeau et al., 2012). Caregivers of patients with chronic illnesses are particularly vulnerable due to the long-term, unpredictable, and resource-intensive nature of care. The degree of psychological distress varies with caregiver characteristics (e.g., age, gender, marital status), patient characteristics (e.g., illness severity, functional dependence), and contextual factors (e.g., healthcare accessibility, financial strain) (Chou, 2000). Studies have consistently found female caregivers, those with limited financial resources, and individuals providing care over prolonged periods to be at greater risk of mental health problems (Qadir et al., 2013). Coping strategies play a central role in determining how individuals adapt to the stress of caregiving. Lazarus and Folkman’s stress-appraisal model defines coping as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands” (Lazarus & Folkman, 1984). Adaptive strategies such as acceptance, problem-solving, planning, and seeking social or emotional support are associated with improved psychological outcomes, while maladaptive strategies such as denial, avoidance, or substance use exacerbate distress (Carver & Connor-Smith, 2010). Importantly, coping behaviors are shaped by cultural and religious contexts. In Muslim-majority countries like Pakistan, religious coping—including prayer, recitation of the Holy Quran, and reliance on faith is a predominant mechanism for managing stress (Pargament et al., 1998). This underscores the need for culturally sensitive research that explores coping in local populations rather than extrapolating findings from Western contexts.

Globally, there has been growing recognition of caregiver burden. A systematic review of caregivers of cancer patients found that nearly 40% experienced significant psychological morbidity, and those with lower social support had worse outcomes (Northouse et al., 2010). Similarly, studies from Europe and North America have documented that caregiving burden is strongly linked with reduced life satisfaction and poorer physical health outcomes (Cooper et al., 2007; Schulz & Beach, 1999). In contrast, literature from South Asia remains limited. In India, a study among caregivers of chronic kidney disease patients reported that 56% suffered from moderate-to-severe psychological distress, primarily linked to financial strain and social isolation (Chavan et al., 2017). In Pakistan, available studies are few and largely confined to tertiary hospitals in major cities. For example, caregivers of psychiatric patients in Karachi were reported to have high levels of depression and anxiety, with financial hardship and caregiving duration being major risk factors (Qureshi et al., 2011). Similarly, research from Lahore demonstrated substantial caregiver distress in families of oncology patients (Ashraf et al., 2019). However, these studies have focused on specific diseases and urban populations, leaving district-level and semi-urban caregivers largely unexamined. The Divisional Headquarter (DHQ) Teaching Hospital in Mirpur, Azad Jammu and Kashmir (AJK) provides a unique context to investigate this issue. AJK’s semi-urban and rural population faces several challenges, including limited access to specialized healthcare, financial constraints, and reliance on family-based caregiving (Shaikh et al., 2012). Cultural norms in the region strongly emphasize family responsibility, with caregiving duties often falling disproportionately on women, who are already burdened with household and childcare responsibilities. These socio-cultural and economic factors likely exacerbate caregiver stress while also shaping their coping strategies. Despite this, no published research to date has systematically explored the psychological distress and coping behaviors of caregivers of chronic illness patients in AJK.

The absence of local data is particularly concerning given Pakistan's recent policy efforts to integrate mental health services into the broader public health system (Government of Pakistan, 2022). Evidence shows that caregiver well-being directly affects patient care; distressed caregivers may be less effective in medication adherence monitoring, appointment follow-up, and emotional support provision (Bevans & Sternberg, 2012). Thus, neglecting caregiver mental health can undermine patient outcomes and health system efficiency. Generating empirical evidence from district-level hospitals is essential to inform policy, develop caregiver support interventions, and strengthen family-centered care approaches. The objectives of the study are:

1. To determine the level of psychological distress among family caregivers of patients with chronic illnesses attending Divisional Headquarter Teaching Hospital, Mirpur, and AJK.
2. To identify coping mechanisms adopted by caregivers in response to caregiving stress.
3. To find the association between psychological distress and caregiving-related factors.

## II. METHOD

This cross-sectional study was conducted at the Divisional Headquarters (DHQ) Teaching Hospital, Mirpur, Azad Kashmir, a tertiary-level institution that functions as the main referral center for both urban and rural populations in the region. The study population comprised family members providing unpaid care to patients with chronic illnesses, including cardiovascular diseases, diabetes, cancers, and chronic respiratory or renal conditions, attending inpatient and outpatient departments. Eligible participants were adult ( $\geq 18$  years) family members who had been providing unpaid and regular caregiving—either daily or weekly—for at least three months and were willing to provide informed consent. Paid or professional caregivers, caregivers with pre-existing psychiatric diagnoses, and those unwilling to participate were excluded.

### Participants

The sample size was calculated using OpenEpi (v3) based on a proportion estimate. Assuming a prevalence of 50% (in the absence of prior data from Azad Kashmir), a 95% confidence level, and 5% precision, the minimum required sample size was 384. To account for a potential 10% non-response rate, the final targeted sample size was increased to 422 participants. A consecutive sampling strategy was employed, whereby all eligible caregivers presenting to the inpatient and outpatient departments during the study period were invited to participate. Recruitment continued until the required sample size was achieved. Data collection took place over six months, from March 1 to August 31, 2024.

### Measures

Data were collected using a structured, interviewer-administered questionnaire, developed in English and translated into Urdu. The tool comprised of three sections: (1) sociodemographic characteristics (age, gender, marital status, education, income, relationship to the patient, and caregiving duration); (2) psychological distress, assessed with the Kessler Psychological Distress Scale (K10) (Kessler et al., 2002), a validated 10-item instrument scored on a scale of 10–50, with cutoffs of 10–19 (low/none), 20–24 (moderate), 25–29 (high), and  $\geq 30$  (severe); and (3) coping strategies, assessed using the Brief COPE<sup>26</sup>, a 28-item tool with 14 subscales rated on a four-point scale. Religious coping was analyzed as a separate subscale. The instruments were pretested on 30 participants in a similar setting, yielding Cronbach's alpha values exceeding 0.80 for both scales, confirming internal reliability. Trained health professionals conducted the interviews in private hospital areas to ensure confidentiality. Each interview lasted approximately 25–30 minutes. The primary outcome variable was psychological distress, measured by K10 scores, which were categorized as none/low, moderate, high, or severe. For regression analysis, psychological distress was dichotomized as low ( $\leq 19$ ) versus moderate-to-severe ( $\geq 20$ ). Independent variables included sociodemographic characteristics, caregiving-related factors, and coping strategies.

### Procedure

Data entry and analysis were performed using SPSS version 26. Descriptive statistics (means, standard deviations, frequencies, and percentages) were generated. Bivariate associations were assessed using chi-square tests and independent sample t-tests, with variables demonstrating  $p < 0.20$  considered for multivariable analysis. Multivariable logistic regression was conducted to identify independent predictors of psychological distress, and

results were reported as adjusted odds ratios (AOR) with 95% confidence intervals (CI). Statistical significance was defined as  $p < 0.05$ . Ethical approval was obtained from the Institutional Review Board of DHQ Teaching Hospital, Mirpur (approval number: DHQ/IRB/2024/217). Written informed consent was obtained from all participants after providing a detailed explanation of the study objectives, confidentiality protocols, and the voluntary nature of participation. The research was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki.

III.RESULTS

Out of 422 targeted participants, 410 caregivers completed the study (response rate: 97.1%). The mean age of participants was  $38.7 \pm 12.5$  years (range: 18–72 years). Females comprised 59.3% (n=243). A majority was married (71.7%) and resided in urban areas (62.4%). Nearly half (48.0%) reported monthly household income below PKR 40,000. Demographic details of the participants are outlined in Table 1 (Insert table 1 here)

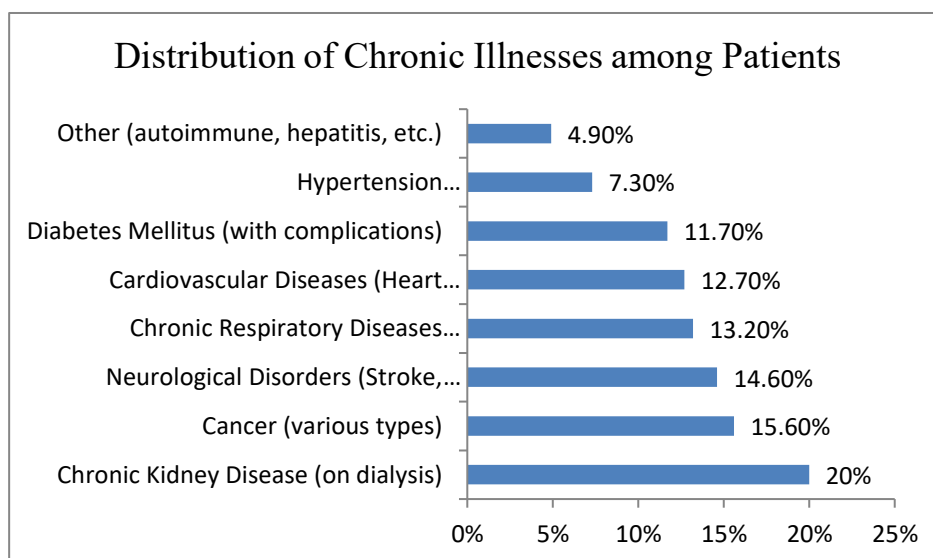
Table 1: Sociodemographic Characteristics of Family Caregivers (n=410)

| Variable                | Frequency (n) | Percentage (%) |
|-------------------------|---------------|----------------|
| Age (years)             |               |                |
| 18–30                   | 122           | 29.8           |
| 31–45                   | 176           | 42.9           |
| 46–60                   | 84            | 20.5           |
| >60                     | 28            | 6.8            |
| Gender                  |               |                |
| Male                    | 167           | 40.7           |
| Female                  | 243           | 59.3           |
| Marital Status          |               |                |
| Single                  | 82            | 20.0           |
| Married                 | 294           | 71.7           |
| Widowed/Divorced        | 34            | 8.3            |
| Education Level         |               |                |
| Illiterate              | 48            | 11.7           |
| Primary–Matric          | 106           | 25.9           |
| Intermediate–Bachelor   | 176           | 42.9           |
| Master and above        | 80            | 19.5           |
| Monthly Income (PKR)    |               |                |
| <20,000                 | 102           | 24.9           |
| 20,000–40,000           | 95            | 23.2           |
| 40,001–70,000           | 124           | 30.2           |
| >70,000                 | 89            | 21.7           |
| Relationship to Patient |               |                |
| Spouse                  | 134           | 32.7           |
| Parent                  | 96            | 23.4           |
| Child                   | 84            | 20.5           |
| Sibling                 | 56            | 13.7           |
| Other                   | 40            | 9.8            |
| Duration of Caregiving  |               |                |
| <6 months               | 76            | 18.5           |
| 6–12 months             | 144           | 35.1           |
| >12 months              | 190           | 46.4           |

The most frequent chronic illnesses requiring caregiving were chronic kidney disease (20.0%), cancer (15.6%), and neurological disorders (14.6%). A considerable proportion also had chronic respiratory diseases (13.2%) and advanced cardiovascular conditions (12.7%). Hypertension and diabetes were present but contributed less

significantly to caregiver burden, especially when not associated with complications. Overall, families caring for patients with cancer, neurological diseases, and chronic kidney disease reported higher levels of psychological distress compared to those managing fewer disabling conditions.

**Figure I: Distribution of Chronic Illnesses among Patients**



### Psychological Distress Levels

Based on Kessler-10 (K10) scores, 62 (15.1%) caregivers had low, 117 (28.5%) had moderate while **56.3%** of caregivers (high + severe) experienced clinically significant levels of psychological distress. Distress varied significantly across demographic factors (Table :2)

- Female caregivers reported higher distress (**65.0%**) compared to males (**44.3%**) ( $\chi^2 = 17.24$ ,  $p < 0.001$ ).
- Caregivers with monthly household income below PKR 40,000 showed greater distress (**69.0%**) compared to those earning  $\geq 40,000$  (**44.6%**) ( $\chi^2 = 21.88$ ,  $p < 0.001$ ).

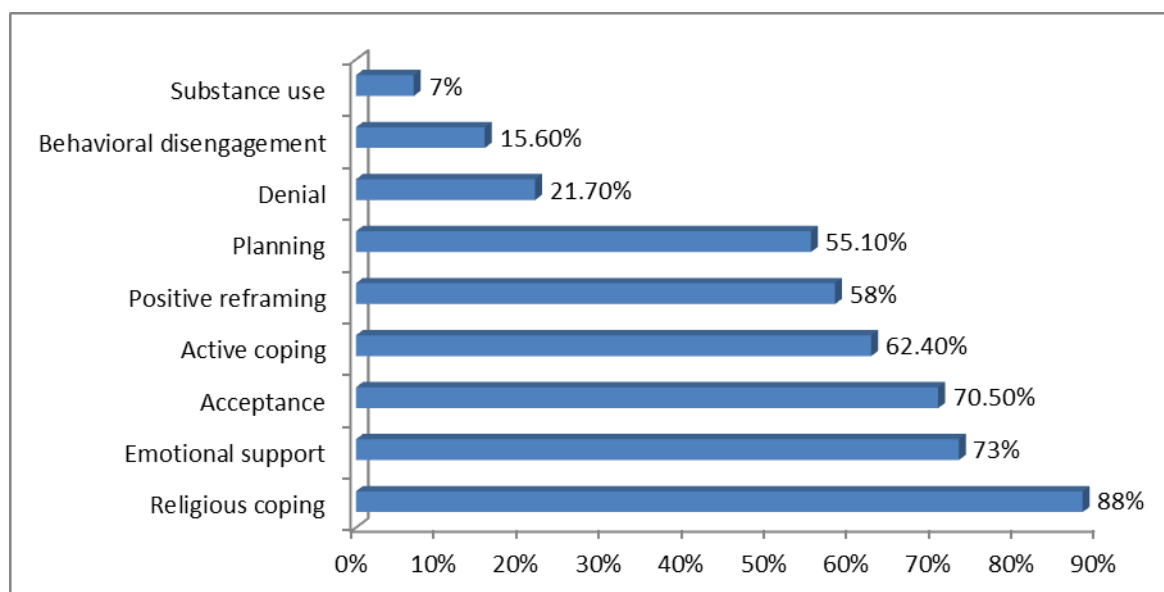
Duration of caregiving also influenced distress, with **69.5%** of those caring for more than 12 months experiencing significant distress compared to **45.0%** of those caring for  $\leq 12$  months ( $\chi^2 = 19.41$ ,  $p < 0.001$ ).

**Table II: Association of level of distress with demographics of the caregivers**

| Variable                   | Low/None n (%) | Moderate/Severe n (%) | $\chi^2$ (p-value) |
|----------------------------|----------------|-----------------------|--------------------|
| <b>Gender</b>              |                |                       |                    |
| Male (n = 167)             | 93 (55.7)      | 74 (44.3)             | 17.24 (<0.001)     |
| Female (n = 243)           | 86 (35.0)      | 157 (65.0)            |                    |
| <b>Income</b>              |                |                       |                    |
| <40,000 (n = 197)          | 61 (31.0)      | 136 (69.0)            | 21.88 (<0.001)     |
| $\geq 40,000$ (n = 213)    | 118 (55.4)     | 95 (44.6)             |                    |
| <b>Duration of Care</b>    |                |                       |                    |
| $\leq 12$ months (n = 220) | 121 (55.0)     | 99 (45.0)             | 19.41 (<0.001)     |
| >12 months (n = 190)       | 58 (30.5)      | 132 (69.5)            |                    |

\*\* $p < .01$

Coping responses were assessed using the *Brief COPE Inventory*. The most frequently reported strategies were **religious coping (88%)**, **seeking emotional support (73%)**, and **acceptance (70.5%)**. Other commonly used strategies included **active coping (62.4%)**, **positive reframing (58%)**, and **planning (55.1%)**. Maladaptive approaches such as **denial (21.7%)**, **behavioral disengagement (15.6%)**, and **substance use (7%)** were less common. Overall, caregivers relied more on positive and religious-based coping, with minimal reliance on negative strategies.

**Figure II: Frequency Distribution of Stress Coping Strategies among the Caregivers**

Logistic regression identified **female gender (AOR=1.9; 95% CI: 1.2–3.1; p=0.006)**, **low income (AOR=2.3; 95% CI: 1.4–3.7; p=0.001)**, and **>12 months caregiving (AOR=2.6; 95% CI: 1.5–4.2; p<0.001)** as independent predictors of moderate-to-severe psychological distress.

**Table III: Multivariable Logistic Regression Analysis of Factors Associated with Caregiver Burden**

| Predictor Variable       | Men                       |                              |         | Predictor Variable       | Women                     |                              |
|--------------------------|---------------------------|------------------------------|---------|--------------------------|---------------------------|------------------------------|
|                          | Adjusted Odds Ratio (AOR) | 95% Confidence Interval (CI) | p-value |                          | Adjusted Odds Ratio (AOR) | 95% Confidence Interval (CI) |
| Female gender            | 1.9                       | 1.2 – 3.1                    | 0.006   | Female gender            | 1.9                       | 1.2 – 3.1                    |
| Low income (<40,000 PKR) | 2.3                       | 1.4 – 3.7                    | 0.001   | Low income (<40,000 PKR) | 2.3                       | 1.4 – 3.7                    |
| Caregiving >12 months    | 2.6                       | 1.5 – 4.2                    | <0.001  | Caregiving >12 months    | 2.6                       | 1.5 – 4.2                    |

## IV.DISCUSSION

This study demonstrates that psychological distress is highly prevalent among caregivers of patients with chronic illnesses in Mirpur, AJK, with more than half of participants reporting high-to-severe levels of distress on the Kessler-10 scale. These findings confirm that caregiving is not only a supportive role but also a significant psychosocial challenge that directly impacts the well-being of family members. In health systems such as Pakistan's, where formal caregiving structures and social support services remain underdeveloped, the burden inevitably falls on families, making it essential to view caregivers as an at-risk population requiring systematic attention. Another study in India highlighted the role of caregivers in providing support to elderly highlighted the limited availability of social security system or any formal care support (Brinda et al., 2014). The gender disparity observed in this study is consistent with both local and global literature. Female caregivers were found to be nearly twice as likely as men to report moderate-to-severe distress. This is not unexpected, as women in South Asian societies often assume primary caregiving roles due to cultural expectations, limited decision-making power, and the simultaneous demands of household and childcare responsibilities (Brinda et al., 2014). A study in Southern Punjab similarly reported that female caregivers of patients with obsessive-compulsive disorder faced significantly higher levels of burden compared to men, reinforcing our findings (Ahmed et al., 2023). This compounded burden leaves them with little opportunity for self-care, increasing vulnerability to anxiety, depression, and exhaustion. Similar results

have been documented in both Pakistani and international studies, which consistently demonstrate that caregiving is associated with a greater psychological toll on women (Mekuriaw et al., 2023; Khan & Abbas, 2016). These findings emphasize the need for gender-sensitive policies that recognize the disproportionate strain placed on women and provide them with additional support mechanisms.

Socioeconomic factors also played a critical role in shaping caregiver well-being. Caregivers from households earning less than PKR 40,000 per month had more than twice the odds of experiencing distress compared to those from higher-income households. This finding reflects the dual challenge of financial strain and caregiving responsibilities. Chronic illnesses often demand long-term expenditures for treatment, medications, and hospital visits, which can drain already limited family resources (Kang et al., 2020). At the same time, caregiving reduces opportunities for stable employment and income generation, further intensifying the cycle of stress. These results resonate with studies from Ethiopia and other LMICs, where low socioeconomic status was a key predictor of caregiver burden<sup>29</sup>, and also align with Pakistani data indicating that financial strain is one of the most consistent determinants of caregiver stress (Khan & Abbas, 2016). Thus, financial insecurity is not only an economic challenge but also a significant psychological risk factor. Duration of caregiving emerged as another independent predictor of distress, with caregivers involved for more than 12 months reporting substantially higher odds of psychological strain compared to those with shorter caregiving durations. Chronic illnesses such as cancer, renal disease, and neurological disorders typically require prolonged and intensive care, often leading to emotional fatigue, burnout, and social isolation for caregivers. The longer the caregiving period, the more likely caregivers are to experience disruptions in personal routines, strained family relationships, and diminished coping resources. A study clearly indicated that caregivers' fatigue gets worsen with the duration of illness (Koyanagi et al., 2018). Evidence from South Asia and other LMICs mirrors this finding, suggesting that prolonged caregiving has cumulative negative effects on mental health (Jayathilaka et al., 2020), underscoring the need for structured respite care programs and long-term caregiver support systems.

Coping strategies used by caregivers revealed an important dimension of cultural adaptation. Religious coping was the most widely reported strategy, followed by emotional support and acceptance. In Muslim-majority and collectivist societies, reliance on faith practices such as prayer, recitation of the Holy Quran, and trust in divine will provides caregivers with a sense of meaning and resilience in the face of adversity. This explains the high prevalence of religious coping in the current study and parallels findings from other Islamic contexts (Ahmed et al., 2023). Adaptive strategies such as positive reframing, planning, and seeking emotional support were also reported frequently, indicating that many caregivers attempt constructive adjustments to their role despite the burden. However, maladaptive strategies, although less common, were still present in a notable minority. Denial, behavioral disengagement, and substance use reflect underlying emotional exhaustion and the absence of professional psychosocial support. Importantly, over-reliance on religious coping without complementary institutional or therapeutic interventions may restrict effective problem-solving in the long term, highlighting the importance of balancing cultural strengths with evidence-based mental health support. When compared with global evidence, the findings of this study reinforce the observation that caregiver distress tends to be higher in LMICs than in high-income countries (Jayathilaka et al., 2020). This disparity is largely attributable to weak healthcare infrastructure, limited formal support systems, and financial insecurity. For example, while distress levels among caregivers of malnourished children in Ethiopia were reported at 42.5% (Khan & Abbas, 2016), the prevalence in this study exceeded 56%, reflecting the compounded pressures of chronic illness caregiving in Pakistan. South Asian literature similarly indicates that socioeconomic vulnerability, limited access to healthcare and prolonged caregiving contribute to elevated psychological distress (Ahmed et al., 2023). At the same time, reliance on religious and family-based coping strategies underscores cultural resilience but also reveals gaps in institutional psychosocial support that are typically more available in high-income contexts.

This study's strengths include a relatively large sample size, high response rate, and the use of validated instruments such as the K10 and Brief COPE, which enhance the reliability of findings. The application of multivariate analysis further strengthens the evidence by identifying independent predictors of distress. However, several limitations must be acknowledged. The cross-sectional design restricts causal inference, meaning that while associations were identified, temporal relationships cannot be established. The single-institution setting may also limit generalizability to other regions of Pakistan, especially rural areas with different sociocultural and

healthcare dynamics. Self-reported measures could have introduced recall or social desirability bias, particularly regarding sensitive coping behaviors such as substance use. Additionally, caregivers of patients with multiple chronic illnesses were not analyzed separately, potentially masking unique patterns of burden in these groups. Despite these limitations, the implications of this study are significant. The findings highlight caregivers as an often-neglected yet vital component of chronic illness management. Their well-being directly influences patient outcomes, as distressed caregivers are less able to ensure adherence to treatment, provide emotional support, or manage the practical aspects of care effectively<sup>24</sup>. Policy-level interventions are urgently needed to support caregivers, especially women, low-income families, and those engaged in long-term caregiving. Interventions could include structured psychosocial support services, caregiver counseling programs, financial subsidies, and respite care initiatives. Importantly, given the high reliance on religious coping, faith-based and community-based approaches could serve as culturally appropriate entry points for mental health interventions, provided they are integrated with professional support systems. By recognizing and addressing caregiver needs, health systems in Pakistan can strengthen family-centered care and improve both caregiver and patient outcomes.

## V. CONCLUSION

This study reveals a high prevalence of psychological distress among caregivers of patients with chronic illnesses in semi-urban AJK, particularly women, low-income families, and long-term caregivers. Coping was largely religious and adaptive, though maladaptive strategies persisted in a minority. These findings highlight caregivers as “hidden patients” whose mental health directly affects patient care. Policy-makers should consider integrating routine caregiver screening, culturally sensitive counseling, financial relief, and community-based respite programs into chronic disease services. By addressing caregiver needs, Pakistan can move toward more equitable, family-centered healthcare.

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