Original Study

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Evaluation of Psychological Well-Being Among Care Providers of Oral Cancer Patients In A Tertiary Care Setting: A Cross-Sectional Analysis

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Abstract

Background:

Oral cancer remains a major global health concern, particularly in south Asian countries, where it contributes significantly to cancer-related morbidity and mortality. In Pakistan, it is recognized as the second most prevalent malignancy, with an age-standardized incidence rate of 21.9 per 100,000, considerably higher than rates reported in neighboring regions. Family members who assume care giving responsibilities for patients with oral cancer face numerous emotional, physical, and financial challenges. These prolonged demands often lead to psychological distress and diminished well-being.

Objective:

the objective of this study is to evaluate the prevalence of anxiety, depression, and perceived stress among family caregivers of oral cancer patients in tertiary care hospital in Karachi.

Methodology:

A descriptive cross-sectional study was conducted at a private tertiary care hospital in Karachi over a six-month period (June–November 2024). Adult informal caregivers of histologically confirmed oral cancer patients were enrolled through purposive sampling. Data were collected using two standardized tools: the 12-item zarit burden interview (zbi) and the depression, anxiety, and stress scale–21 (dass-21). Statistical analyses were performed to evaluate the frequency and severity of mental health outcomes.

Results:

High levels of psychological strain were identified among care providers, with 82.9% reporting difficulty maintaining positive emotions, 57.9% experiencing physical symptoms of stress, and 61.2% showing low self-worth.

Conclusion:

Care providing for oral cancer patients imposes a substantial emotional burden. Interventions focused on caregiver education, psychological counseling, and structured support services are essential to enhance mental well-being and overall caregiving quality.

Keywords: oral cancer, caregiver burden, anxiety, depression, perceived stress, psychosocial support.

Introduction:

Cancer continues to be a major contributor to global morbidity and mortality, ranking as the leading cause of death in many developed countries and the second leading cause in developing nations (1). Among all malignancies, head and neck cancers (hncs) constitute a significant proportion, representing the sixth most common cancer group worldwide (2). Within this group, oral cavity cancer is the predominant subtype, accounting for the majority of hnc cases (3). It is estimated that globally, oral cancer accounts for more than 630,000 new cases and over 350,000 deaths annually, reflecting its substantial impact on public health (4). In South Asia, particularly in Pakistan, India, Bangladesh, and Sri lanka, the prevalence of oral cancer is alarmingly high, largely due to region specific risk factors such as the consumption of smokeless tobacco, betel nut (areca nut), and betel quid (5). According to national cancer registries, oral cancer ranks as the second most common malignancy in Pakistan, with an increasing trend among both men and women (6). Despite advances in early detection, radiotherapy, and chemotherapeutic regimens, survival outcomes remain poor, especially in patients presenting at advanced stages. The chronic and debilitating course of the disease affects not only the patients

themselves but also imposes a considerable burden on those who care for them (7). Patients with oral cancer often experience disfigurement, impaired speech and swallowing, and chronic pain symptoms that significantly diminish their quality of life (8). The management of such patients, particularly in advanced or terminal stages, requires prolonged and complex care. In many low- and middle-income countries, including Pakistan, the majority of care giving responsibilities falls on family members rather than trained healthcare professionals (9). These family caregivers (fcs), typically spouses, children, or siblings, provide crucial support in daily care, emotional reassurance, and financial decision-making (10).

However, the care giving role is associated with considerable psychological and emotional strain. Caregivers frequently experience anxiety, depression, sleep disturbances, and feelings of helplessness as they navigate the emotional and physical challenges of supporting a loved one with cancer (11). The continuous stress of care giving, combined with anticipatory grief and uncertainty about the patient's prognosis, can lead to burnout and deterioration in mental health (12). Studies conducted in oncology and palliative care settings have shown that 30–50% of caregivers report clinically significant levels of anxiety or depression (13). Additionally, some caregivers experience symptoms similar to post-traumatic stress disorder (ptsd), as well as persistent sadness and loss of social engagement (14).

In Pakistan, where formal psychosocial support systems for caregivers are limited, the mental health burden of family members caring for oral cancer patients remains under-recognized (15). Cultural and social expectations often dictate that family members provide full-time care without professional assistance, further exacerbating their stress levels. Moreover, societal stigma associated with both cancer and mental health issues prevents caregivers from seeking psychological support (16). This neglect not only affects caregivers' well-being but may also indirectly compromise the quality of care provided to the patient (17).

Recognizing caregiver distress as an integral aspect of comprehensive cancer management is therefore crucial. By identifying the emotional and psychological challenges faced by caregivers, healthcare professionals can develop structured interventions to improve coping strategies and enhance resilience among this vulnerable group (18,19).

The rationale of this study is to evaluate the mental health status of family caregivers of oral cancer patients in tertiary care hospitals in Karachi. Evaluating their levels of anxiety, depression, and perceived stress will provide essential insight into the psychosocial toll of caregiving in a high-burden region. Understanding these psychological dimensions is critical for the development of evidence-based interventions that strengthen emotional resilience, reduce caregiver burnout, and improve patient care outcomes. The objective of this study is to evaluate the levels of anxiety, depression, and perceived stress among family caregivers of oral cancer patients receiving treatment in tertiary care hospitals of Karachi, and to identify the psychosocial factors influencing these mental health outcomes. Findings from this study will support healthcare professionals and policymakers in designing targeted mental health programs, counseling services, and caregiver education initiatives aimed at enhancing overall family well-being and quality of life.

Methodology and data collection:

A descriptive cross-sectional study was conducted over a six-month period at a private tertiary care hospital in Karachi, Pakistan, from June 2024 to November 2024. The study aimed to assess the mental health status of family caregivers of terminally ill oral cancer patients. A total of 152 caregivers were included in the study using a convenience sampling technique**.** Participants were recruited from the oncology ward where patients were receiving palliative or active oncological treatment. Care givers older than 18 years and family

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members providing unpaid care and are the prime members were included in the study while visitors were not involved in care giving, care givers not willing to participate in the study, only hospital accompanying members of the family and temporary care givers were excluded from the study.

prior to data collection, ethical approval was obtained from the hospital's institutional review board (irb), and formal permission was secured from the head of the oncology department. All participants were informed about the study's purpose, procedures, and confidentiality protocols. Written informed consent was obtained from each caregiver before participation. Participants were also assured of their right to withdraw from the study at any stage without any consequence to themselves or their patient's care. The data were collected using a pretested, self-structured, closed-ended questionnaire which consists of four parts which consist of socio-demographics of the family caregivers, patient's clinical details, a 12-item standardized validated zarit burden interview (zbi) questionnaire and depression, anxiety and stress scale – 21 (dass-21).
After obtaining consent, questionnaires were distributed directly to participants during their hospital visits or while accompanying patients in the oncology ward. Assistance was provided to those who faced difficulties in reading or understanding the questionnaire. The anonymity of participants was maintained throughout the process to ensure confidentiality and unbiased responses.

Statistical analysis:
Data were checked for completeness and consistency before analysis. The responses were coded and entered into statistical package for the social sciences (spss) version 26.0 for analysis. Descriptive statistics such as mean, standard deviation, frequencies, and percentages were calculated for demographic and clinical variables. Inferential statistics, including chi-square tests and correlation analyses, were applied to determine associations between caregiver characteristics, burden, and psychological distress. A p-value ≤ 0.05 was considered statistically significant.

Results:
A total of 152 family caregivers participated in this study. Most caregivers **(**50.7%**)** were between 33 and 40 years of age, followed by 30.9% aged 26–32 years, and 18.4% aged 18–25 years**.** A clear gender imbalance was observed, as 67.8% of caregivers were female, compared to 32.2% male, indicating that caregiving responsibilities were primarily assumed by women.

In terms of education, the majority of participants were educated beyond secondary school. About 37.5**%** held postgraduate qualifications**,** 23.7% were graduates**,** 16.4% had completed secondary education, and 15.8% had primary education, while only 6.6**%** reported no formal schooling. Educational background may influence caregivers' ability to understand disease processes and cope with caregiving demands.

The economic profile revealed that 61% of caregivers had a monthly household income below pkr 50,000, reflecting a low-income population. Another 25.7% earned between pkr 50,000 and 100,000, and 14% reported incomes above pkr 100,000**.**

Regarding the duration of care**,** 53.9**%** had been caregivers for less than one year, while 46.1% had provided care for over one year**.** Most patients were in advanced disease stages, with 42.8% at stage iii and 50.7% at stage iv**,** while only 3.3% each were at stage I or II.

Additionally, 79.6**%** of patients were receiving palliative care. Despite the complexity of care, only 37.5% of caregivers had received formal training. Emotional or family support was reported by 63.2%**,** while 36.8% lacked such support, underscoring a need for structured psychosocial assistance for caregivers.

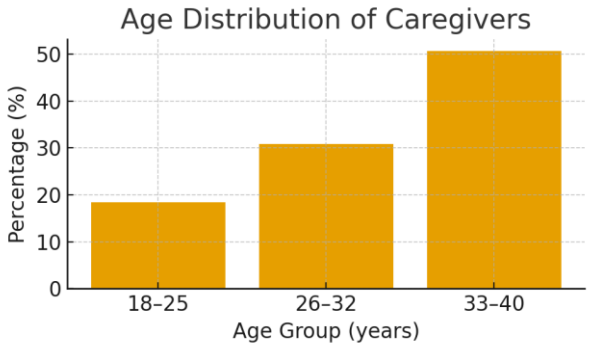

Figure 1: age distribution of caregivers. Most were aged 33–40 years.

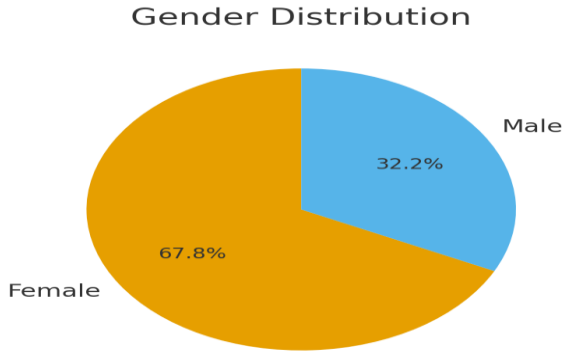

Figure 2: gender distribution showing predominance of female caregivers.

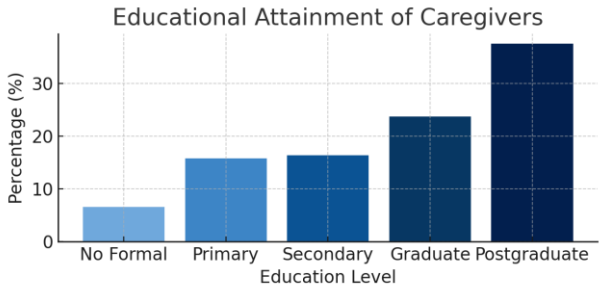

Figure 3: educational levels of caregivers. Majority had graduate or postgraduate education.

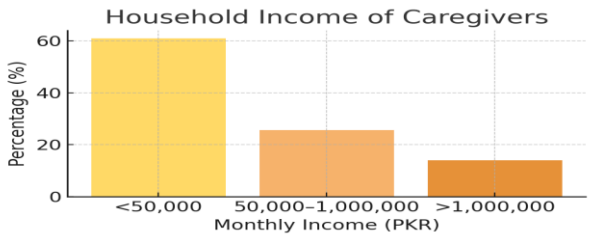

Figure 4: household income distribution highlights majority from low-income households.

Table 1-demographic information		
Demographics		**N (%)**
Age	18-25	28 (18.4)
	26-32	47 (30.9)
	33-40	77 (50.7)
Gender	Female	103 (67.8)
	Male	49 (32.2)
Education	No formal education	10 (6.6)
	Primary	24 (15.8)
	Secondary	25 (16.4)
	Graduate	36 (23.7)
	Postgraduate	57 (37.5)
Income	<50k	92 (61)
	>50k-<1000000	39 (25.7)
	>1000000	21 (14.0)
Care giving duration (how many months)	<1year	82 (53.9)
	>1 year	70 (46.1)
Stage of illness	Stage 1	5 (3.3)
	Stage 2	5 (3.3)
	Stage 3	65 (42.8)
	Stage 4	77 (50.7)
Palliative care	No	31 (20.4)
	Yes	121 (79.6)
Any training received by the primary care giver	No	95 (62.5)
	Yes	57 (37.5)
Any support given to care giver (emotional or financial)	No	56 (36.8)
	Yes	96 (63.2)

Table 2: *Zarit* burden questionnaire responses

Zarit burden Interview (zbi) questionnaire		**N**	**(%)**
I spend so much time caring for my relative that I have little time for myself.	Always	10	6.6
	Very frequently	76	50.0
	Rarely	10	6.6
	Sometimes	56	36.8
I feel stressed trying to balance caregiving with my work or family duties.	always	30	19.7
	Never	5	3.3
	Very frequently	82	53.9
	Rarely	5	3.3
I often feel angry or irritated when I am around my relative.	Always	20	13.2
	Very frequently	82	53.9
	Rarely	14	9.2
	Sometimes	36	23.7
	Always	20	13.2
Caring for my relative negatively affects my relationships with family or friends.	Nearly always	41	27.0
	Very frequently	44	28.9
	Rarely	5	3.3
	Sometimes	62	40.8
I feel emotionally strained when spending time with my relative.	Nearly always	32	21.1
	Very frequently	75	49.3
	Rarely	8	5.3
	Sometimes	37	24.3
My health has declined because of my care giving responsibilities.	Always	38	25.0
	Very frequently	73	48.0
	Rarely	9	5.9
	Sometimes	32	21.1
I feel that I have lost some of my personal privacy due to care giving.	Always	31	20.4
	Very frequently	70	46.1
	Rarely	10	6.6
	Sometimes	41	27.0

The findings from the zarit burden interview (zbi) indicate that caregivers experience a substantial burden across emotional, physical, and social domains. Half of the respondents (50%) reported that they quite frequently did not have enough time for themselves due to caregiving responsibilities, and 53.9% experienced frequent stress while trying to balance caregiving with other responsibilities such as work or family duties. Emotional strain was prominent, with 53.9% of caregivers reporting frequent feelings of anger when around their relative, and over half (55.9%) felt that caregiving had a negative impact on their relationships with family and friends. Additionally, 49.3% reported feeling strained in the presence of the person they were caring for.

Physical health was also affected, with 48% of respondents stating that their health had suffered due to caregiving, and 46.1% reported a lack of privacy, which may further contribute to emotional fatigue. A majority (56.6%) noted that their social life had been negatively impacted. In terms of confidence and preparedness, 52.6% frequently felt uncertain about what to do in caregiving situations, while 42.1% felt they could do a better job, and 24.3% believed they should be doing more.

Signs of emotional exhaustion and psychological distress were widespread. A large majority (82.9%) often felt they were unable to experience positive emotions, and over 50% reported frequent difficulty relaxing and winding down. Physical symptoms associated with stress were also common 57.9% reported awareness of dryness in the mouth. Feelings of low self-worth were noted by 61.2% of caregivers, and 52.6% admitted to often feel agitated. Anxiety-related concerns were also prevalent, with 57.9% worried about situations where they might panic or embarrass themselves. Notably, 51.3% of respondents reported that they almost always found it difficult to relax. These results collectively highlight the intense emotional and psychological burden faced by caregivers.

Discussion:

Caring for patients with terminal illnesses such as advanced oral cancer presents a multidimensional challenge that profoundly impacts the caregiver's physical, emotional, and psychological well-being (20). Family caregivers often face persistent stress, anxiety, depression, and a decline in their overall quality of life as they manage complex medical routines, emotional distress, and financial strain. These findings are consistent with prior research indicating that caregiving for terminally ill individuals places an enduring psychological and physical burden on caregivers (21).

The concept of caregiving burden encompasses both objective and subjective components. The objective burden reflects tangible disruptions—such as financial hardship, time constraints, and changes in social roles—while the subjective burden relates to emotional exhaustion, psychological distress, and feelings of helplessness. In this study, caregivers frequently reported overlapping experiences of both forms, demonstrating how long-term caregiving responsibilities can negatively influence their health and social well-being (22).

Although socio-demographic variables such as age, gender, education, and income did not exhibit a statistically significant relationship with anxiety or depression levels, patterns observed suggest that female caregivers tend to experience higher levels of emotional distress, aligning with previous research highlighting gender disparities in psychological vulnerability among caregivers. These findings align with local and regional data from South Asia, where women are often the primary caregivers within family structures, bearing the dual responsibilities of caregiving and household management (23).

Notably, the prevalence of anxiety and depression among caregivers of oral cancer patients in this study was comparable to international literature, where rates range from 38% to 73%. Studies from Pakistan and neighboring countries similarly report elevated psychological morbidity among caregivers, exacerbated by limited access to counseling, social support systems, and palliative care services (24).

Given the increasing incidence of oral cancer in Pakistan, addressing the mental health of caregivers is an urgent public health priority (25). This study underscores the need for structured psychosocial interventions such as counseling services, caregiver education, and community-based support programs to mitigate psychological distress and improve caregiver resilience. Ultimately, recognizing and supporting caregivers not only improves their quality of life but also enhances patient care outcomes, fostering a more compassionate and sustainable healthcare framework.

Conclusion:

Caring for individuals with oral cancer places a considerable physical, emotional, and psychological strain on family caregivers. The findings of this study highlight that caregiving extends far beyond physical assistance, involving the navigation of continuous emotional challenges, financial pressures, and social limitations. To mitigate these burdens, there is a critical need for structured caregiver education programs that enhance understanding of the disease and improve caregiving skills. Additionally, implementing hospital-based psychological counseling and peer-support systems can provide essential emotional relief and promote mental resilience among caregivers. Recognizing the caregiver as an integral part of the treatment team is vital for improving both patient outcomes and caregiver well-being. Future research should focus on developing sustainable, long-term strategies and community-based interventions aimed at empowering caregivers and strengthening the overall framework of cancer care delivery.

References:

1. Ghosh s, sinha r, khandelwal d, sharma n, zodpey s. Understanding the psychosocial impact of oral cancer on family caregivers and their coping mechanisms: a qualitative study in rural wardha, central india. *Indian j palliat care*. 2019;25(3):421–7. Doi:10.4103/ijpc.ijpc_9_19.

2. Belapurkar p, acharya s, shukla s, kumar s, khurana k, acharya n. Prevalence of anxiety, depression, and perceived stress among family caregivers of patients diagnosed with oral cancer in a tertiary care hospital in central india: a cross-sectional study. *Cureus*. 2023;15(10):e47100. Doi:10.7759/cureus.47100.

3. Zahid n, zahid w, khalid w, azam si, ikram m, hassan a, et al. Resilience and its associated factors in head and neck cancer patients in pakistan: an analytical cross-sectional study. *Bmc cancer*. 2021;21(1):888. Doi:10.1186/s12885-021-08624-8.

4. Ejaz b, maqbool a, malik n, khawar a, hassan n, muazzam a. Grief among cancer patients: predictor of burden of care and mental health among their caregivers. *Palarch's j archaeol egypt/egyptol*. 2021;18(17):68–80.

5. Kim b, kim j, ahn hy, park s, hwang ic, park sj. Exploring the role of practical and emotional death preparation in reducing

emotional distress among family caregivers of terminally ill cancer patients: a multicenter cross-sectional study. *Cancers (basel)*. 2023;17(8):1380. Doi:10.3390/cancers17081380.

6. Chan lm, ng scj. Prevalence and correlates of caregiver anxiety in family caregivers of patients with advanced cancer: a cross-sectional study in a palliative care unit in hong kong. *East asian arch psychiatry*. 2022;32(2):27–33. Doi:10.12809/eaap2171.

7. Ahmad as, doss jg, ismail sm, kiong sc, jelon ma, thangavalu l, et al. Quality of life vs. Supportive care needs for oral cancer caregivers: are they related? *Curr oncol*. 2023;30(2):1733–44. Doi:10.3390/curroncol30020134.

8. Qadir tf, haqqani s, khalid a, huma z, medhin g. Frequency and correlates of symptoms of anxiety and depression among young caregivers of cancer patients: a pilot study. *Bmc res notes*. 2018;11:631. Doi:10.1186/s13104-018-3747-7.

9. Zyada f, sheta m, el degwi h, saad r. Anxiety, depression, and strain among caregivers of terminally ill patients. *Egypt j psychiatr*. 2013;34(2):77–84. Doi:10.7123/01.ejp.0000419667.93575.14.

10. Irshad s, batool i, nazim h. Relationship between caregiver burden and psychological well-being among caregivers of cancer patients: mediating role of resilience. *Bull bus econ*. 2024;13(2):763–6. Doi:10.61506/01.00391.

11. Sharma bp, haque mi, hossain mb, sarker rj, abedin es, shahinuzzaman m, et al. Depression and anxiety status among informal caregivers of patients with cancer treated at selected tertiary hospitals in nepal. *J taibah univ med sci*. 2024;19(3):482–91. Doi:10.1016/j.jtumed.2024.03.007.

12. Samal s, panda n, rath j, pani sr, panda b. Mental health status of caregivers of cancer patients attending a tertiary care hospital in bhubaneswar, odisha [version 1; peer review: awaiting peer review]. *F1000research*. 2024;13:1403. Doi:10.12688/f1000research.157319.1.

13. Valeberg bt, grov ek. Symptoms in the cancer patient—of importance for their caregivers' quality of life and mental health? *Eur j oncol nurs*. 2013;17(1):46–51. Doi:10.1016/j.ejon.2012.01.009.

14. Khan mf, hayhoe rp, kabir r. Exploring the risk factors for oral cancer in pakistan: a systematic literature review. *Dent j (basel)*. 2024;12(2):25. Doi:10.3390/dj12020025.

15. Zhang sz, xie l, shang zj. Burden of oral cancer on the 10 most populous countries from 1990 to 2019: estimates from the global burden of disease study 2019. *Int j environ res public health*. 2022;19(2):875. Doi:10.3390/ijerph19020875.

16. Longacre ml, ridge ja, burtness ba, galloway tj, fang cy. Psychological functioning of caregivers for head and neck cancer patients. *Oral oncol*. 2011;48(1):18–25. Doi:10.1016/j.oraloncology.2011.11.012.

17. Tang y, hua y, huang x, cao y, sun x. Psychological burden of patients with head and neck cancer undergoing radiotherapy and their family caregivers: a cross-sectional survey. *J multidiscip healthc*. 2023;16:927–35. Doi:10.2147/jmdh.s398064.

18. Karimi moghaddam z, rostami m, zeraatchi a, et al. Caregiving burden, depression, and anxiety among family caregivers of patients with cancer: an investigation of patient and caregiver factors. *Front psychol*. 2023;14:1059605. Doi:10.3389/fpsyg.2023.1059605.

19. Lee y, lin py, chien cy, fang fm. Depression, anxiety, quality of life, and predictors of depressive disorders in caregivers of patients with head and neck cancer: a six-month follow-up study. *Psychooncology*. 2017;26(2):149–60. Doi:10.1002/pon.4109.

20. Shanfield morris s, sannes t. Pre-loss grief and preparedness for death among caregivers of terminally ill cancer patients: a systematic review. *Soc sci med*. 2021;276:113865. Doi:10.1016/j.socscimed.2021.113865.
21. Palos gr, mendoza tr, liao kp, et al. Caregiver symptom burden: the risk of caring for an underserved patient with advanced cancer. *Cancer*. 2011;117(5):1070–9. Doi:10.1002/cncr.25695.
22. Heidari gorji ma, haghshenas m, kasaeeyan a, et al. Quality of life and depression in caregivers of patients with breast cancer. *Bmc res notes*. 2012;5:310. Doi:10.1186/1756-0500-5-310.
23. Balfe m, foxwell sc, et al. Understanding the challenges and needs of informal caregivers to individuals with head and neck cancer: a basis for developing internet-based support. *Eur j oncol nurs*. 2023;64:102347. Doi:10.1016/j.ejon.2023.102347.
24. Ghaffar hma, ujala m, nadeem ms, mahmood h, rahim sa, abbas m. Investigation of depression in cancer patients' caregivers in combined military hospital, rawalpindi. *Pak j public health*. 2021;10(3):154–9. Doi:10.32413/pjph.v10i3.624.
25. Shah sgs, shah sls, hameed a, khalil zur, masood a, shah fj. Evaluating the impact of site of oral cancer on the quality of life of patients. *Pak j health sci*. 2025;6(1):102–6. Doi:10.54393/pjhs.v6i1.2274.

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Dr. Mohsin Khan: Conception and design of work, drafting
Dr. Faizan Abdul Hussain Lakhdeer: Supervised the research and provided critical evaluation for intellectual context
Dr. Ayesha: Data collection & final draft support
Dr. Leena Siddiqui: Data collection