ORIGINAL ARTICLE

Assessment of Post-Traumatic Stress Disorder and Role of Spirituality Amongst Caregivers of Pediatric Cancer Patients in Pakistan

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ABSTRACT

Objective: This study examined the levels of Post-Traumatic Stress Disorder (PTSD) in pediatric cancer caregivers and the impact of spirituality on PTSD in Pakistan.

Study Design: Cross-sectional study.

Place and Duration of Study: The study was carried out at the Department of Oncology, Shaukat Khanum Memorial Cancer Hospital & Research Centre, Peshawar, Northwest General Hospital & Research Centre, Peshawar in Khyber Pakhtunkhwa (KPK), Pakistan Institute of Medical Sciences, Islamabad and Quaid-e-Azam International Hospital in Islamabad, Pakistan from January 2023 to March 2023.

Methods: The study comprised 153 Caregivers of pediatric cancer patients aged One month –12 Years using convenience sampling. The PTSD Checklist-Civilian Version (PCL-C) and Caregiver's Spirituality Scale (CSS-10) were used to collect data.

Results: Results of the study found that 81 caregivers (52.94%) had high PTSD, and 96 (62.74%) had high spirituality. Females reported higher PTSD and spirituality than guys. Graduates have more PTSD and spirituality than illiterates and matriculate. PTSD and spirituality had a negative Pearson's Correlation Coefficient.

Conclusion: The study emphasizes spirituality as a caregiver's mental health protector. Healthcare practitioners caring for pediatric cancer patients can use the findings to lessen PTSD symptoms by targeting caregivers' spiritual needs. Convenience sampling and self-report measurements decrease generalizability. Future study is needed to investigate the association between PTSD and spirituality in caregivers of pediatric cancer patients.

Keywords*: Caregivers, PTSD, Spirituality.*

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Introduction

Traumatic situations most often cause Post Traumatic Stress Disorder (PTSD). PTSD is prevalent, with a lifetime frequency of 3.9% in the general population and 5.6% among trauma survivors. PTSD disorder burdens individuals, families, and society.[1] Cancer is the most significant cause of mortality for children and adolescents globally, with an estimated 300,000 new cases diagnosed each year.[2] The entire family may experience symptoms of anxiety, melancholy, or posttraumatic stress as a result of a child's acute sickness, especially if they need to be hospitalized. Specific stresses associated with cancer have been identified by researchers, including those linked to daily/role functioning, communication, and caregiving, as well as feelings of terror and helplessness during diagnosis and treatment.[3] Mothers experience more stress than fathers do

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when dealing with their parent's cancer. Pediatric cancer is still a life-changing diagnosis with significant prognostic uncertainty and high caregiving demands for children and their parents, who usually provide intense care. Parents of children with chronic severe illnesses have received increasing attention recently for having psychopathological symptoms. Caregivers of critically ill patients sometimes struggle to adjust to new activities and roles while suffering from sadness, anxiety, and PTSD.[4] Cancer exerts a significant impact on the patients and their loved ones' lives. Caregivers are stressed when patients can't manage their symptoms. Caregivers' stress results in both psychological and physical consequences. Caregivers' PTSD intrusive symptoms may result in persistent worry and a lack of parental presence, manifested by being overprotective of their children and failing to recognize and recognize their children's symptoms. The level of caregivers' trauma exposure and PTSD is connected with a poor perception of their children's impacts and behavior, as well as more inconsistent and risky parenting conduct.[5]

Cancer patients often rely on family members as caregivers because they help with the numerous demands that develop throughout treatment. Family caregivers like parents, spouses, siblings, friends, and neighbors provide long-term, in-home care for loved ones without pay. Many caregivers lose touch with family and friends due to daily disruptions. The caregiver's performance also impacts the patient's cancer coping style, including depression management. Unfortunately, unpleasant feelings, including worry, depression, and post-traumatic stress, can affect patients and caregivers. When patients cannot manage their symptoms, caregivers experience stress, despair, worry, fear, loneliness, psychosomatic signs, marital troubles, and physical symptoms like tiredness, anorexia, indigestion, constipation, severe sleeping disorders, and pain.[6] Caregiver burden describes several levels of distress brought on by a mismatch between care demands and resources. Psychological distress is the most investigated aspect of caregiver quality of life. Carer burden is associated with specific carer characteristics. These characteristics encompass the presence of depression and anxiety disorder, lower levels of quality of life, diminished self-efficacy, and reduced utilization of support resources.[6]

Spirituality and religion are particularly relevant for combat trauma for several reasons.[7] These include "beliefs, values, behaviors, and experiences related to ultimate meaning, often involving deities and dogma formulated by faith groups or institutions over time." Previous research found that religion/spirituality was connected with more well-being, self-compassion, and a sense of personal accomplishment, as well as reduced depression, anxiety, and burnout. Spirituality evolves as individuals seek direction, significance, truth, power, harmony, equilibrium, devotion, belief, and purpose.[8] When making decisions about their children's wellbeing, carers must consider the impact of their actions on the environment. Spirituality was a significant resource for overcoming difficulties in caregiving. Spirituality aids in overcoming adversity.[9] Spirituality has been linked to care-related factors, including the time spent on cancer caregiving. It is widely acknowledged that spirituality helps family carers cope with stressful life challenges.[10]

Caregiver burden was associated with depression and anxiety disorder, poorer quality of life scores, lower self-efficacy, and reduced support utilization. It was also found that caregiver burden was consistently associated with depression among cancer caregivers. In the literature on cancer caregiving,[11] studies have revealed an inverse relationship between caregiver burden and spirituality. Two perspectives might be taken into consideration while examining the connection between posttraumatic growth and spirituality. A person's spirituality can be seen as a resource that helps them deal with adversity or as a means by which they might grow spiritually due to a traumatic experience.[11] We intend to study spirituality as a personal strength. There have been reports of posttraumatic growth in parents of children with pediatric cancer in recent years. Still, very few of these studies have focused on the connection between spirituality and posttraumatic growth, even though spirituality can be taken into account when designing interventions. Patients who received less

spiritual care than expected reported higher levels of depressive symptoms and a lack of significance and tranquillity.[12]

The two primary objectives of the study wereto assess the frequency and intensity of post-traumatic stress disorder (PTSD) in carers of pediatric cancer patients in KPK and Punjab, Pakistan, by employing the PTSD Checklist-Civilian Version. Also, to Examine the correlation between carers' levels of spirituality, as assessed by the Caregiver's Spirituality Scale, and the effects of PTSD while investigating the potential safeguarding influence of spirituality.

Since cancer is a chronic disease hurting life, it causes physiological and psychological problems and affects patients and their families. Based on the mentioned literature review, PTSD is an emergent issue frequently reported by caregivers of children with pediatric cancer. Caretakers of children with cancer and their levels of post-traumatic stress disorder (PTSD) and the effects of spirituality on this population in Pakistan have received very little attention in the current literature. Nevertheless, a thorough evaluation is required to determine the present level of understanding in this particular field.

Methods

Study Design

The study used a cross-sectional study design to evaluate the levels of PTSD in carers of pediatric cancer patients, as well as the associated consequences of spirituality in the context of Pakistan. The method of "Purposive Convenience Sampling" was employed. The caregivers of pediatric cancer patients age 0 to 12 years were intentionally selected since they are directly related to the study's primary objective. Although leading cancer hospitals in KPK and Punjab are easily accessible, the purposeful feature of participant selection guarantees that only those who match the requirements for studying the influence of PTSD and spirituality are included.

The data was gathered from the Oncology Department of Shaukat Khanum Memorial Cancer Hospital & Research Centre, Peshawar, Northwest General Hospital & Research Centre, Peshawar in Khyber Pakhtunkhwa (KPK), Pakistan Institute of Medical Sciences, Islamabad and Quaid-e-Azam International Hospital in Islamabad, Pakistan from January 2023 to March 2023. The ethical approval was obtained from the IRB/ERB Committee of HITEC-IMS, bearing letter no. HITEC-IRB-24-2023 held on 1st December 2020.

Calculations for determining the appropriate sample size were conducted using the "Raosoft" and "Openapi" web tools to ensure the reliability of the results. The calculations considered a confidence level of 95%, a margin of error of 5%, and an assumed response distribution rate of 50%, which was found to be 140. To account for probable non-responses and offer a more comprehensive representation of caregivers' experiences in Oncology wards, the study aimed for a larger sample size (n=153) despite the initial guideline of a sample size of 140. Participants gave informed, verbal consent before data collection. Data collectors explained each questionnaire item and recorded the data. The questionnaire asked about the caregivers' relationship to the patient and their age, gender, education level, occupation, and monthly income. Caregiver PTSD was detected using the PTSD Checklist-Civilian Version (PCL-C). A standardized self-report rating scale for PTSD, known as the PTSD Checklist-Civilian Version (PCL-C), consists of 17 questions corresponding to the most significant PTSD symptoms. It takes five to ten minutes to complete the questionnaire. Indicating mild to moderately severe PTSD symptoms are scores of 17 to 29, moderate to moderately high PTSD symptoms are scores of 30 to 44, and severe PTSD symptoms are scores of 45 to 85.[13] The level of spirituality was assessed using the Caregiver's Spirituality Scale (CSS-10). The 10-item Caregiver's Spirituality Scale (CSS-10) evaluates a caregiver's spirituality by considering their belief in God and their potential for spiritual growth on a 4-point (0 to 3) Likert scale. It took 5 to 10 minutes to complete. The mean of each variable was used as a reference to generate cut points, which define high and low degrees of spirituality. A score of 33 or higher indicates a high level of spirituality, while a score of 33 or lower indicates a low level of spirituality.

Data Analysis

The data were analyzed using SPSS version 28. The described statistics were used to analyze the demographic characteristics. Mean values of PTSD

were utilized to evaluate the severity of PTSD symptoms and cutoff criteria were employed to categorize study participants as having either Low PTSD, Moderate PTSD, or High PTSD. Participants were divided into high-spirituality and low-spirituality groups based on their level of Spirituality, which was evaluated using a cutoff criterion. We used Pearson's Correlation Coefficient to examine how PTSD and Spirituality are connected.

Results

The data in (Table 1) indicates that out of a total sample size of 153 people, 63 are male and 90 are female, which makes up 41.17% and 58.82%, respectively. Table 1 presents the sociodemographic and demographic characteristics of the population.

Statistics in Table 2 show that there were 153 people in the group, with 26 men and 55 women making up 41.26% and 61.11%, respectively. Overall, the data reveals that there is a distinct gender gap in terms of PTSD and spirituality, with females reporting higher levels of PTSD and spirituality than males. Graduates reported higher PTSD and spirituality levels than illiterate and matric participants.

Significant differences were observed within the studied sample when conducting independent t-tests for various factors, such as Gender, Age, Education, Relationship with Patients (RWP), Post Traumatic Stress Disorder (PTSD), and Spirituality. The variables of gender, age, education level, RWP, PTSD scores, and spirituality scores all demonstrate statistically significant variations, as evidenced by *p*-values of 0.001. (See Table 3). The means and

Table 1: Demographics of caregivers

Variables	n	Percentage %
Age Range		
18-29	43	28.10 %
30-39	49	32.02 %
40-50	35	22.87 %
≥ 50	26	16.99 %
Gender		
Male	63	41.17 %
Female	90	58.82 %
Education		
Illiterate	33	21.6 %
Matric	75	49.0 %
Graduate	45	29.4 %
Relationship with Patient		
Parents	122	79.7 %
Siblings	6	3.9 %
Uncle or Aunt	25	16.3 %

Table 2: Frequencies of caregivers with levels of PTSD and spirituality

S.no	Total	n=153	Male (n=63)	Female (n=90)	v	Matric (n=75)	Graduate (n=45)
1	High PTSD[1]	81 (52.94%)	26 (41.26%)	55 (61.11%)	21(63.63%)	30 (40%)	30 (66.66%)
2	Moderate PTSD	51 (33.33%)	22 (34.92%)	29 (32.22%)	7 (21.21%)	32 (42.66%)	12 (26.66%)
3	Low PTSD	21 (13.70%)	15 (23.80%)	6 (6.66%)	5 (15.15%)	13 (17.33%)	3 (6.66%)
4	High Spirituality	96 (62.74%)	43 (68.25%)	64 (71.11%)	19 (57.57%)	54 (72%)	29 (64.44%)
5	Low Spirituality	57 (37.25%)	20 (31.74%)	26 (28.88%)	9 (27.27%)	21 (28%)	16 (35.55%)

standard deviations offer valuable insights into each factor's central tendency and dispersion within the sample, allowing for a comprehensive understanding of the data.

Table 3: Independent t-test results of various factors

Variables	Mean	Standard Deviation	*P*-Value
Gender	1.59	.494	0.001
Age	36.78	10.406	0.001
Education	2.09	.710	0.001
RWP	1.37	.750	0.001
PTSD	46.8562	15.61899	0.001
Spirituality	38.0261	3.49237	0.001

The Pearson correlation coefficient of (r=0.059) reveals a weak positive relationship between PTSD and Spirituality. (Table 4). Assuming a weak positive correlation, it follows that when one variable grows, the other also tends to increase. Several other research that have looked into the connection between PTSD and spirituality have come to similar conclusions.

Table 4: Pearson correlation between Post Traumatic Stress Disorder (PTSD) and spirituality

Variables	Mean	Std. Deviation	Pearson Correlation Coefficient (*r*)
PTSD	46.8562	15.61899	0.059
Spirituality	38.0261	3.49237	

[1]*Post Traumatic Stress Disorder (PTSD)*

Discussion

The present study aimed to examine the frequency of Post-Traumatic Stress Disorder (PTSD) and the impacts of spirituality on caregivers of pediatric cancer patients. A meta-analysis of 17 research discovered a moderate positive correlation (r = 0.52) between PTSD and religious or spiritual practices.[14] Furthermore, Peters and Colleagues observed a substantial correlation between PTSD and spiritual practices, including prayer and meditation (r = 0.41).[15] Because spiritual beliefs and practices can give one's life meaning and purpose, they may mitigate the negative impacts of trauma, which may explain the correlation between PTSD and spirituality.

The findings elucidate significant patterns in the correlation between post-traumatic stress disorder (PTSD) and spirituality. The observed gender disparity aligns with recent studies that have reported a higher prevalence of post-traumatic stress disorder (PTSD) among women, as well as a greater inclination towards spirituality in women.[16] Furthermore, it is worth noting that there exists a correlation between higher education and elevated levels of post-traumatic stress disorder (PTSD) and spirituality. This correlation is supported by previous research studies that have demonstrated a higher prevalence of trauma exposure among educated individuals within specific populations.[17] Additionally, connections have been established between education and engagement in spiritual practices, as evidenced by the findings.[18] Significantly, it is noteworthy to highlight the existence of a positive correlation between post-traumatic stress disorder (PTSD) and spirituality, which aligns with the accumulating body of evidence indicating that individuals with PTSD frequently exhibit heightened levels of spirituality and engage in religious coping strategies.[19,20]

The findings above enhance comprehension of the intricate role of spirituality in the context of trauma. Previous research has shown that females cope with stress through social support seeking, while males use problem-solving strategies.[21] This finding is consistent with previous studies showing a positive relationship between education and mental health

outcomes.[22] The findings of our study align with prior research, indicating that an elevated level of spirituality does not seem to mitigate the likelihood of experiencing symptoms associated with post-traumatic stress disorder (PTSD).[23] Bahramian et al. (2023) observed that female pediatric cancer caregivers had more distress and anxiety than male caregivers.[24] According to (2023), female caregivers of children with cancer had higher stress, anxiety, and depression than male caregivers.[25] The current study's result that education level affected PTSD and spirituality supports prior studies that found a beneficial association between education and mental health outcomes. Chi et al. (2018) discovered that cancer caregivers with more excellent education had better mental health.[26] The findings of our study align with prior research, which has consistently demonstrated that the career burden is linked to depression among individuals providing care for cancer patients.[27] In the realm of cancer caregiving literature, previous investigations have revealed a notable correlation between career burden and spirituality, with findings consistently indicating an inverse relationship. In conclusion, this study's findings on PTSD and spirituality in pediatric cancer caregivers support earlier research.[28] The study highlights the necessity of addressing pediatric cancer caregivers' mental health needs and the possible advantages of spiritual assistance. These findings can inform future studies on PTSD treatments and spirituality in this vulnerable demographic.

Conclusion

This study affects healthcare providers and policymakers. Healthcare professionals should prioritize mental health for pediatric cancer caregivers due to the high prevalence of PTSD symptoms. Spiritual assistance for pediatric cancer patients and caregivers may improve psychological well-being. Policymakers should fund counseling and other mental health treatments for pediatric cancer caregivers. These findings can inform future studies on PTSD treatments and spiritual well-being in vulnerable populations.

Research Limitations and Future Research Directions

Future research needs to address some of the study's limitations. Longitudinal studies could investigate changes in PTSD symptoms and spirituality over time among caregivers of pediatric cancer patients. Finally, future studies could explore the effectiveness of interventions such as counseling, spiritual support, or other forms of therapy for reducing PTSD symptoms and promoting spiritual well-being among caregivers of pediatric cancer patients. Further research should be conducted to explore the potential gender-based differences in mental health and to identify potential interventions to address any disparities that may exist.

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Authors Contribution

NB: Study designing, data collection, data analysis, results and interpretation, manuscript writing and proof reading
QA: Idea conception, study designing, data collection, manuscript writing and proof reading
NK: Data collection
HN: Data collection
MIK: Study designing Data collection
AKA: Data collection, data analysis, results and interpretation