

Original Article

Psychological Distress, Coping Strategies and Social Support in Parents of Children with Leukemia

Muzamil Tariq¹, Dildar Muhammad², Sardar Ali³, Shahla Arshad⁴, Amir Sultan^{5*}, Muhammad Nadim⁶, Iffat Aisha⁷, Sahib Jahan⁸

¹Lecturer, College of Nursing Balochistan, Quetta, Pakistan.

²Associate Professor, Institute of Nursing Sciences, Khyber Medical University, Peshawar, Pakistan.

³Assistant Professor, Institute of Nursing Sciences, Khyber Medical University, Peshawar, Pakistan.

⁴Lecturer, Institute of Nursing Sciences, Khyber Medical University, Peshawar, Pakistan.

⁵Associate Professor, Department of Nursing, Times Institute, Multan, Pakistan.

⁶Registered Nurse, Oncology Chemobay Department, Ministry of Health, Kuwait.

⁷Nursing Lecturer, Government College of Nursing, Mardan, Pakistan.

⁸Principal, Shahid College of Nursing, Shabqadar, Charsadda, Pakistan.

*Corresponding Author: Amir Sultan, Associate Professor; Email: amirsultan204@gmail.com

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ABSTRACT

Background: Leukemia poses significant distress for affected children and their families, necessitating extensive parental involvement in care. Parents must manage multiple clinic visits, medication administration, and provide emotional support during treatment, impacting their psychological well-being.

Objective: To assess the levels of psychological distress, coping strategies, and social support among parents of children with leukemia.

Methods: This analytical cross-sectional study was conducted at Bolan Medical Complex and Cinar Cancer Hospital in Quetta, Baluchistan. A total of 341 parents participated, with data collected via three standardized questionnaires: the Coping Health Inventory for Parents (CHIP), Kessler Psychological Distress Scale (K10), and Multidimensional Scale of Perceived Social Support. Ethical approval was granted by the Khyber Medical University Peshawar.

Results: Among the participants, 36.1% were aged 25-35 years; 61.9% were male. Educational levels were 73.9% secondary and 23.8% primary. Psychological distress was reported as moderate by 86%, while 76% utilized fair coping strategies, and 95% experienced medium social support. There was no significant correlation between psychological distress and coping strategies; however, a negative association was noted between social support and psychological distress.

Conclusion: The study reveals substantial psychological distress among parents, with prevalent fair coping strategies and medium social support. Enhanced social support is negatively associated with psychological distress, highlighting the need for targeted support interventions.

Keywords: Coping Strategies, Leukemia, Parents, Psychological Distress, Social Support.

INTRODUCTION

Childhood cancer, commonly diagnosed between the ages of 0 and 14, represents a significant global health challenge and is a leading cause of death among children worldwide. In 2021, approximately 10,500 children in this age group were diagnosed with cancer in the United States, with 1,190 succumbing to the disease (4). The global burden of cancer is disproportionately distributed, with about 80% of childhood cancer cases occurring in low- and middle-income countries where healthcare resources are limited (1). Cancer remains the leading cause of death globally and the second highest in the United States, where the expected number of new cancer cases was 1,735,350, leading to 609,640 deaths in 2018 (3). In Pakistan, a country facing similar healthcare challenges, cancer ranks as a major cause of morbidity and mortality among children. In 2017, pediatric cancers constituted 10% of all cancers, with leukemia being notably prevalent, accounting for 46.5% of these cases (13).

The diagnosis of pediatric cancer places immense psychological and emotional strains on families, especially parents who are integral to the care and support of the affected child. Studies have indicated a high prevalence of psychological distress among parents; for instance, significant levels of anxiety were reported by 67.6% of Jordanian parents of children with cancer, and a staggering 84% of

caregivers in America experienced severe anxiety (17). The responsibility borne by parents includes accompanying their child to numerous medical appointments, administering medication, and providing emotional support during painful procedures. Such duties can profoundly affect parents' quality of life and mental health, with many experiencing stress, anxiety, and depression (18). This study aims to evaluate the prevalence of psychological distress (PD) among parents of children undergoing cancer treatment and to explore the associated stresses and coping mechanisms. It also seeks to ascertain the effectiveness of these coping strategies in mitigating psychological distress. Despite the critical nature of these issues, there is a lack of comprehensive data on the levels of distress experienced by parents in Pakistan and the efficacy of their coping mechanisms, highlighting a significant gap in the existing research. This study, therefore, not only aims to fill this research gap by documenting these experiences but also seeks to contribute to the development of targeted interventions that can support parents during this challenging period.

METHODS

An analytical cross-sectional study was conducted at Bolan Medical Complex and Cinar Cancer Hospital in Quetta, Baluchistan, from June to December 2023. These tertiary care hospitals serve a large population and are critical providers of specialized care in the region. The study focused on the psychological distress, coping strategies, and perceived social support among parents of children with leukemia, both newly diagnosed and relapsed, who were receiving treatment at these facilities.

The sample size was determined using the Raosoft sample size calculator. Assuming a confidence level of 95%, a margin of error of 5%, and an anticipated population proportion of 50%, the required sample size was calculated to be 341 participants. Consecutive sampling was employed to recruit participants who met the inclusion criteria. Eligible participants were parents of children aged 1 to 12 years undergoing treatment for leukemia for at least six months. Exclusion criteria included parents under 18 years of age, those with critical illnesses such as chronic kidney disease, cancer, or coronary heart disease, and those unwilling to participate voluntarily in the study.

Data collection involved three standardized questionnaires. The Coping Health Inventory for Parents (CHIP), a 45-item tool with a Cronbach's alpha of 0.93, was used to evaluate the coping strategies of the parents. Coping effectiveness was categorized as poor (score less than 50%), fair (score between 50 to 75%), and good (score more than 75%) (19). The Kessler Psychological Distress Scale (K10), a 10-item scale with a Cronbach's alpha of 0.83, assessed the level of psychological distress, categorized into low (score less than 50%), moderate (score between 50 to 75%), and severe (score more than 75%) (20). Lastly, the Multidimensional Scale of Perceived Social Support, a 12-item scale with a Cronbach's alpha of 0.84, was used to assess the level of social support perceived by the parents, rated as low, medium, or high based on similar scoring thresholds (21).

Prior to data collection, approvals were obtained from the hospital directors of the concerned hospitals and the study was endorsed by the Advanced Studies and Research Board and the Ethical Review Committee of Khyber Medical University. The aims and objectives of the study were clearly explained to the potential participants, and informed consent was obtained, ensuring compliance with the Declaration of Helsinki to protect participants' rights. Data confidentiality was maintained using a password-protected file. Statistical analysis was performed using SPSS version 24. Frequencies and percentages were calculated for all variables to describe the sample characteristics. The association between psychological distress and socio-demographic profiles was examined using the Pearson r correlation test, while relationships between psychological distress, coping strategies, and social support were analyzed using the Chi-square test. This comprehensive methodology ensured robust data collection and analysis, facilitating a detailed understanding of the impacts of pediatric leukemia on parents.

RESULTS

The study aimed to evaluate the psychological distress and coping strategies among parents of children with cancer in Baluchistan. It included 341 participants, predominantly between the ages of 25 and 35 years (36.1%), followed by the 36 to 45 year age group (30.8%) and those under 25 (27.9%). The cohort consisted mainly of males (61.9%), and a significant majority had attained secondary education (73.9%), while 23.8% had completed primary education. The family structure of the participants was fairly divided, with 58.1% from nuclear families and 41.9% residing in joint family arrangements. Participants from rural areas constituted 68.3% of the sample, contrasting with 31.7% from urban settings.

The assessment of psychological distress was conducted using the Kessler Psychological Distress Scale, which inquired about symptoms experienced in the past four weeks such as tiredness, nervousness, and feelings of hopelessness. The results indicated that a large majority of parents (86%) experienced moderate levels of psychological distress, with 11% suffering severe distress and a small fraction (3%) reporting mild distress.

Regarding coping strategies, these were evaluated through the Coping Health Inventory for Parents (CHIP), which revealed that 76% of the participants utilized fair coping strategies, 15% resorted to poor strategies, and only 9% demonstrated good coping strategies.

Social support was measured using the Multidimensional Scale of Perceived Social Support. Notably, 95% of the respondents reported medium levels of social support during their child's illness, whereas only 5% perceived their social support as low. Surprisingly, none reported high levels of social support.

The analysis of the association between socio-demographic factors and psychological distress showed no significant correlations with gender ($P=0.599$), education ($P=0.872$), type of family ($P=0.740$), place of residence ($P=0.722$), or age ($P=0.718$). However, an association between coping strategies and type of family structure was identified, indicating significant differences; those from nuclear families tended to have better coping strategies compared to those from joint families ($P=0.041$).

Furthermore, no significant associations were found between socio-demographic factors and social support. Gender, education, family type, residence, and age did not significantly influence the level of social support received ($P>0.5$ for all).

In the correlation analysis using the Pearson r correlation test, psychological distress did not correlate with coping strategies, but a weak negative correlation was noted between psychological distress and social support, suggesting that higher social support might be associated with lower psychological distress. Similarly, there was no significant correlation between social support and coping strategies. These findings underscore the complexity of the psychological and social dynamics faced by parents of children with cancer.

Table 1: Socio-demographic profile of the Participants, n=341

	Frequency	Percent
Age of the Participants		
Less than 25 Years	95	27.9
25 - 35 Years	123	36.1
36 - 45 Years	105	30.8
More than 45 Years	18	5.3
Total	341	100.0
Gender of the participants		
Male	211	61.9
Female	130	38.1
Total	341	100.0
Education Status of the Participants		
Primary or less	47	13.8
Secondary	252	73.9
Master and Above	42	12.3
Total	341	100.0
Type of family of the Participants		
Nuclear Family	198	58.1
Joint Family	143	41.9
Total	341	100.0
Residence of the Participants		
Rural	233	68.3
Urban	108	31.7
Total	341	100.0

Figure 1: Level of Psychological Distress

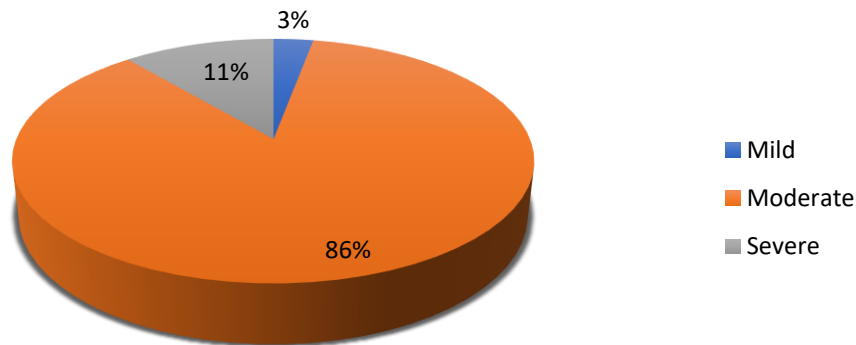


Figure 1: Pie-Chart depicting psychological distress among the parents of children with leukemia

Figure 2: Level of Coping Strategies

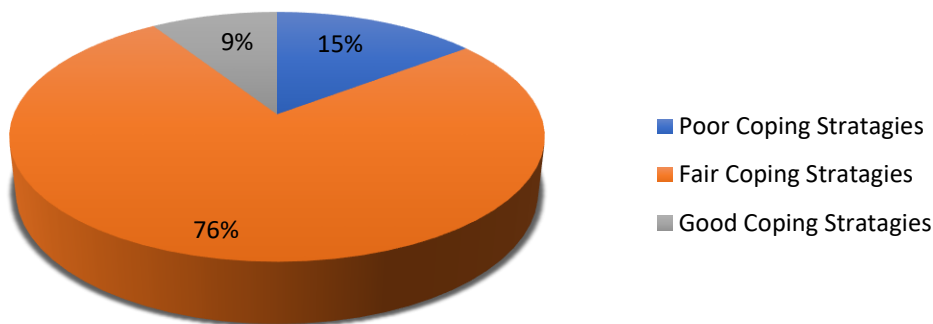


Figure 2: Pie-Chart depicting coping strategies of the parents of children with leukemia

Figure 3: level of Social Support

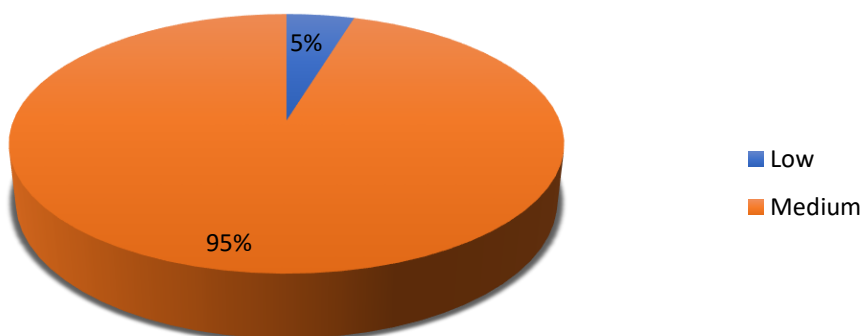


Figure 3: Pie-Chart depicting level of social support among the parents of children with leukemia

Table 2: Association of psychological distress & socio-demographic of the participants

	Mild	Moderate	Severe	Total	P-Value
Gender					
Male	7	183	21	211	P=0.599
Female	3	110	17	130	
Education					
Primary	2	39	6	47	P=0.872
Secondary	7	216	29	252	
Master and Above	1	38	3	42	
Type of family					
Nuclear Family	7	169	22	198	P=0.740
Joint Family	3	124	16	143	
Residence					
Rural	8	199	26	233	P=0.722
Urban	2	94	12	108	
Age					
Less than 25 Years	4	78	13	95	P=0.718
25 - 35 Years	2	107	14	123	
35 - 45 Years	4	91	10	105	
More than 45 Years	0	17	1	18	

Table 3: Association among coping strategies and socio-demographic of the participants

	Poor Coping Strategies	Fair Coping Strategies	Good Coping Strategies	Total	P-Value
Gender					
Male	31	162	18	211	P=0.900
Female	19	98	13	130	
Education					
Primary	7	38	2	47	P=0.114
Secondary	32	196	24	252	
Master and Above	11	26	5	42	
Type of family					
Nuclear Family	21	157	20	198	P=0.041
Joint Family	29	103	11	143	
Residence					
Rural	36	179	18	233	P=0.396
Urban	14	81	13	108	
Age					
Less than 25 Years	14	71	10	95	P=0.956
25 - 35 Years	19	92	12	123	
35 - 45 Years	14	84	7	105	
More than 45 Years	3	13	2	18	

Table 4: Association among social support and socio-demographic profile of the participants, n=341

	Low	Medium	Total	P-Value
Gender				
Male	11	200	211	P=0.562
Female	5	125	130	
Education				
Primary	3	44	47	P=0.669
Secondary	12	240	252	
Master and Above	1	41	42	
Type of family				
Nuclear Family	8	190	198	P=0.503
Joint Family	8	135	143	
Residence				
Rural	11	222	233	P=0.970
Urban	5	103	108	
Age				
Less than 25 Years	4	91	95	P=0.581
25 - 35 Years	5	118	123	
35 - 45 Years	7	98	105	
More than 45 Years	0	18	18	

Table 5: correlation among psychological distress, coping strategy and social support

	Psychological Distress	Social Support	Coping Strategy
Psychological Distress	-	-.105	.046
Social Support		-	.026
Coping Strategy			-

DISCUSSION

The study aimed to examine psychological distress, coping strategies, and social support in parents of children with leukemia in Baluchistan and to evaluate the interrelationships among these variables. The findings revealed that a substantial proportion of parents experienced moderate to severe psychological distress and predominantly fair coping strategies, while most reported only medium levels of social support.

In the context of psychological distress, the study identified that 86% of the parents experienced moderate levels of distress, consistent with previous research by Isbel et al., which found that a significant number of parents of children with leukemia experience psychological distress (22). This was further supported by Schepers et al., who observed that parents of pediatric cancer patients exhibited higher levels of despair compared to parents of healthy children (23). The emotional burden during the initial treatment phase, characterized by its unpredictability and the need for rapid adjustment to a child's hospitalization, significantly contributes to this distress (24). This aligns with broader literature indicating that caring for children with serious illnesses universally imposes significant psychological stress on parents (25).

Regarding social support, 95% of participants reported medium levels of support, which highlights a gap in the availability or effectiveness of support systems for these parents. Prior studies have indicated that enhanced social support can significantly improve parents' ability to manage stress and contribute positively to their quality of life (26, 27). The moderate level of support observed in this study suggests potential areas for improvement in community and healthcare support structures for these families. The coping strategies employed by parents were primarily categorized as fair, with a predominance of emotion-focused rather than problem-focused approaches. This predominance aligns with findings from previous research suggesting that emotion-focused coping is often more utilized in situations perceived as uncontrollable, such as a child's severe illness (28). Coping through avoidance

and emotional distancing was common, reflecting a natural response to overwhelming stress and aligning with other studies indicating a reliance on avoidance and denial in such situations (29).

The study also found a negative correlation between psychological distress and social support, which supports the hypothesis that better social support can mitigate the impact of stress. This finding is supported by research suggesting that active coping strategies, such as seeking and using patient information, are associated with lower psychological distress (30, 31). Furthermore, the role of religiosity and religious coping in managing psychological distress was highlighted, with variations in the effectiveness based on the nature of religious coping employed (32).

However, the study had several limitations. The predominance of male participants may have influenced the findings, as caregiving roles and emotional expressions can vary significantly between genders. Additionally, the study focused primarily on socio-demographic variables without considering other potential influencers of psychological distress such as personality traits or previous mental health history. The use of standardized questionnaires, while facilitating structured data collection, required significant time from participants, potentially influencing their responses or willingness to fully engage.

In conclusion, the study underscores the profound impact of pediatric leukemia on parents' psychological health and highlights the critical role of coping strategies and social support. These findings suggest a need for targeted interventions to enhance coping mechanisms and support systems for parents facing the challenge of managing a child's severe illness. Enhanced understanding and support from healthcare providers, as well as broader community engagement, are essential to mitigate the psychological burden on these families.

CONCLUSION

The study elucidates the profound challenges faced by parents of children with leukemia, encompassing existential, physical, psychological, and social dimensions. Parents endure significant upheaval following diagnosis, dedicating immense energy to managing their child's treatment, and often struggle with emotional and psychological readjustment post-treatment. The findings highlight that effective coping strategies and robust social support systems are crucial in alleviating the psychological distress experienced by these parents. It is imperative that healthcare providers recognize the ongoing psychological impact and implement supportive measures that not only address immediate treatment needs but also assist parents in managing long-term emotional and psychological challenges associated with their child's illness.

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