

## **Development and Validation of a Psychological Assessment Scale for Adolescents with Leukemia**

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### **Abstract**



*The study aimed to develop and validate a scale that records biopsychosocial problems in adolescents with leukemia. First, 30 adolescents with leukemia were individually interviewed to produce an item pool of twenty-eight divergent problems. Repeated items were excluded, and the final 25-item list of distinct problems was pilot tested among 25 adolescents with leukemia as a 4-point self-report measure of the Psychological Symptom Scale. A sample of 250 adolescents received the final 25-item list, the Cancer Pain Rating Scale (Ikram & Rafiq, 2021), and a demographic information sheet containing age, stage of leukemia, and history of the pre-and post-chemotherapy sessions were recorded. Further to validate the items Principle Component Analysis was administered through which 19 items with four factors were identified: biological, emotional, social, and psychological. Results revealed high concurrent and internal validity of the measure. The results have been debated regarding the implications of mental health symptoms for adolescent counseling services and suggest further research.*

**Keywords:** Development, Validation, Psychological Symptoms, Adolescents, Leukemia, Counselling

### **Introduction**

Adolescent age is known to bring about changes of emotional and physical nature, and diagnosis of life-threatening illness like cancer during this time can affect psychological development during that age. There is limited research into how children and adolescents feel and perceive their lives while experiencing this illness. As how this illness affects their current living and how they assume and plan their future. Earlier studies confirmed that children and adolescents with cancer tend to be at risk of number of health problems predominantly psychological in nature. Anxiety, physical, low self-esteem, inefficiency, depressive symptoms, inability to cope, family, school, or social problems. Therefore, research studies have shown that there is no preferred or effective coping strategy and that there are a variety of coping strategies that differ according to individual characteristics and specific situations. The painful experience of cancer changes adolescents' perceptions of the world, causing them to see minimal problems than before. Appropriate application of family coping strategies also contributes to feelings of well-being, contentment, hope, well-being, closeness with family, improved quality of life, improved prospects for the future, as well as emotional growth. is also maximized (Wechsler et al., 2013).

Adolescent cancer patients are a challenge for health professionals because they are at a sensitive developmental age and have severe illnesses. Therefore, health professionals should consider factors that influence adolescents' life satisfaction, hopes, and psychological well-being, as well as factors that reinforce reported problems. Indeed, general life quality during cancer treatment is a vital aspect and can offer help to patients' recovery and healing, but research studies have focused primarily on adolescent cancer survival (Reinfjell et al., 2017).

A small body of literature revealed adjustment problems in adolescents during cancer treatment which are primarily psychological in nature. In some studies, it was revealed that overall there were no significantly higher levels of depression or anxiety in cancer patients, in comparison

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with longitudinal or age-matched controls, only 17-30% of patients showed symptoms of anxiety or depression (Pai et al., 2006; Patenaude & Kupst, 2005; Saevarsdottir et al., 2010)

Abrams et al. (2007) reported that there is an insignificant difference when healthy adolescents were compared with control and cancerous adolescents on depression and anxiety, although the majority of cancer patients in both groups had depression and anxiety. The scores for leukemia cancer were found to be rising. Treatment of leukemia cancer is highly intensive, causing significant damage to the intellectual development of adolescents and leukemia itself, and the treatment causes a negative psychological impact (Eiser, 1979).

Emotional and social support is also very important for young people with cancer to lead a positive life. Adolescents with cancer lack emotional and social support, resulting in a poor quality of life, difficulty coping with anxiety and depression, impaired emotional communication, and family were observed to become inadequately supported and terrified. Pain is a psychological challenge in adolescents with leukemia cancer. Additionally, research studies have shown that being diagnosed with cancer makes patients, mostly adolescents, dependent on caregivers, leading to sadness, depression, helplessness, and anxiety. Adolescents may be reluctant to engage in or participate in social activities, and even absenteeism is reported by schools because of depression (Twycross et al., 2015).

A retrospective study was conducted by Shabbir and his colleagues to investigate the prevalence of leukemia types in over 400 patients admitted to cancer hospitals in Khyber Pakhtunkhwa, Pakistan. Acute lymphocytic leukemia (ALL) was found to be 49.5% (n=198) and acute myeloid leukemia (AML) was more common than 31.25% (n=125). The study also looked at gender differences and found that it was more common in men than women and that the majority of patients were under the age of 20 (Shabbir et al., 2019). This comprehensive study shows that although the statistics are relative, even in Pakistan ALL is more common and leukemia patients are under the age of 20, but the situation is more or less the same around the world.

A descriptive study found that adolescents diagnosed with leukemia had physical and social problems related to the disease and treatment. As a result, they had fears and concerns about treatment side effects and prognosis. Fear and anxiety about death increase, especially during the relapse period. The nature of adolescents' friends and family relationships is altered, and their future life plans are disrupted after illness (Cavusoglu, 2000). Given the changes that adolescents experience in the psychosocial domain during the transition from childhood to adolescence, the cancer experience at this life stage may vary in terms of symptom presentation and relative distress. It was evident through statistical analysis of 2021 that adolescents with cancer have severe and persistent anxiety symptoms and may have difficulty communicating symptoms due to disease severity and language impairment. (Mahakwe et al., 2021).

Numerous studies have shown that adolescent cancer patients experience psychological problems (e.g., anxiety, depression, low self-esteem, disruptive thought patterns), physical problems (pain, weakness, shortness of breath, etc.), and school-related problems. Problems (e.g., school difficulties), non-attendance, school interruptions) compared to healthy adolescents (Ruland et al., 2009). Other psychosocial issues commonly reported in cancer patients were cognitive problems, concerns about recurrence and side effects, and physical appearance after treatment (Tremolada et al., 2020). Primarily, this study reported that self-esteem and academic difficulties were significantly higher in adolescents with cancer than in healthy adolescents (Akca et al., 2018; Tremolada et al., 2017; Zanato et al., 2017)

Adolescence is an essential developmental period for every individual in terms of psychological and social growth. Cancer in adolescence not only complicates physical health but also creates barriers to mental and social health. During development, adolescents face challenges consisting of body image issues, decisions about future goals (education, career, etc.), identity development, and intimate relationships. Physical and cognitive vulnerabilities associated with the cancer experience or side effects of existing treatments can impair adolescents' ability to cope with these developmental challenges, ultimately leading to the development of mental health problems. may maximize the risk of developing psychological problems. There are limited assessment tools available for clinicians and researchers on the psychological health of adolescent cancer survivors, so the main purpose of this research is to develop and validate an assessment tool that can systematically measure the mental health symptoms of adolescents with cancer. For that purpose, certain

observations were made regarding psychological symptoms (e.g., tantrums, helplessness, low self-esteem, sleep problems, etc).

Through this development in research, we hope to suggest assessments and interventions for adolescents suffering from cancer and identify areas that need further investigation. However, range of are based on western findings, In order to fill this gap in Pakistani cultural context how psychological symptoms among adolescents with leukemia cancer are manifested is studied in current research. By considering the dearth of research on leukemia patients in Pakistan it is necessary and fundamental to investigate this area. Therefore, this current study aims at exploring and determining the psychometric properties of the Psychological Symptoms Assessment Scale (PSAS).

This research realistically studied the following objectives.

- Develop a Psychological Symptoms Assessment Scale (PSAS) to assess the psychological symptoms of Adolescents with leukemia cancer.
- Determine psychometric properties of the Psychological Symptoms Assessment Scale for leukemia patients (PSAS).

### Method

In order to make a measuring scale questionnaire, an item generation process was done. For that, a phenomenological approach was used to gather information from the patients regarding the psychological symptoms, through interviewing process over the period of 3 months, and some observations were also made which include temper tantrums, helplessness, low self-esteem, sleep problems, and so on. For this purpose, 30 patients between the age range of 10-16 years were selected from the department of oncology, and government set-up hospitals through purposive sampling. Participants were asked open-ended questions to elicit the psychological symptoms in Urdu. The interview was conducted on an individual basis. Further probing was also done for better clarity about their symptoms. Post interviewing obtained data on open-ended questions, was gathered by using content analysis. A list of 28 items was given to 10 field experts which include 3 clinical psychologists, 3 consultant doctors from the Department of oncology, 2 nurses working full-time in the department of oncology, and 02 caretakers (parents) of patients) with better knowledge about the research question of the proposed study. A finalized 25-item list was formulated after the experts' evaluation, and recurring and unclear items were removed (Psychological Symptoms Assessment Scale (PSAS).

In order to find out the practicability and sensitivity of items (reliability), a pilot study was conducted. The scale was initially administered to 25 patients (15 boys and 10 girls). No problems were reported during self-administration. It took ten to fifteen minutes to complete the assessment.

### Participants

The sample comprised 250 patients suffering from leukemia cancer from the oncology department of government hospitals, ages ranging from 10 to 16 years ( $M= 11.36$ ,  $SD=1.58$ ). The sample of patients was divided into main strata according to their cancer stage ( $M=1.88$ ,  $SD=.34$ ). Further, the subdivision was made on the basis of gender i.e., 165 (66.0%) were boys and 85 (34.0%) were girls and 244 (97.6%) of the total leukemia patients were gone through chemotherapy and only 6 (2.4%) were not, respectively.

### Measures

#### Demographic Performa

The demographic Performa included information pertaining to age, cancer stage, and gender, pre-post chemotherapy.

#### Psychological Symptoms Assessment Scale (PSAS)

The newly developed PSAS was used for measuring the psychological symptoms of adolescents with leukemia cancer. PSAS was comprised of 19 symptoms as expressed by cancer patients with four factors. The items of PSAS used a 3-point rating scale ranging from 0 = "not at all" to 3 = "extremely common". The lowest score on PSAS is 19 for all items and the highest score could be 57. The higher score would indicate a higher number of psychological problems among adolescents with cancer.

#### Cancer Pain Assessment Scale (CPAS)

This indigenous scale was developed by (Ikram & Rafiq, 2021) to measure the cancer pain of adolescents with leukemia cancer. In a research study, it was used to establish the concurrent validity of PSAS. CPAs intended to measure the intensity and nature of cancer pain. It has 23 items that

describe psychosomatic symptoms and physiological effects of pain. The scale is comprised of 4-point Likert items from 0-3 rating.

**Procedure**

After formal permission was granted, the authorities of the oncology department were briefed about the significance of the study and also its implication. Purposive sampling technique was used to collect data from oncology ward in governmental hospitals. Baseline information of participants related to their gender, stage of the disease, and pre-post chemotherapy was acquired through demographic information sheet e items of age, .. The purpose, relevance, and applicability of the current study were explained to the authorities, and further permission was taken to participate in the project. After taking approval from management, participants were approached and their guardians explained the importance of the study. Participation was on volunteer basis and formal written assent from their parents was taken.. Almost 15-20 minutes were spent on each participant in the process of filling out the questionnaires.

**Results**

In order to examine demographic differences of leukemia patients on the Psychological Symptoms Assessment Scale (PSAS) means, standard deviations, and frequency (percentages) were carried out as presented in Tables 1 and 2. Exploratory factor analysis (EFA) was applied for the final structure of PSAS is presented in Table 3 with a Scree plot in Figure 1. The psychometric properties of PSAS were yielded through construct validity and concurrent validity as presented in Table 4.

As shown in Tables 1 and 2, the means, standard deviations, and frequency (percentages) of demographic variables including age, gender, and chemotherapy, and cancer stage of leukemia patients on the Psychological Symptoms Assessment Scale (PSAS). The results showed that the mean age of participants is 11.36 (*SD*=1.58) and the mean stage of leukemia patients is 1.88 (*SD*=.34). Out of 250 participants 165 (66.0%) were boys and 85 (34.0%) were girls. Further, 244 (97.6%) of the total leukemia patients were gone through chemotherapy and only 6 (2.4%) were not, respectively.

**Table 1**

*Means, Standard Deviations of Age and Cancer Stage of Leukemia patients on Psychological Symptoms Assessment Scale (PSAS, N=250)*

Variable	<i>M</i>	<i>SD</i>
Age	11.36	1.58
Cancer Stage	1.88	.34

**Table 2**

*Frequency and Percentages of Demographic Variables of Leukemia patients on Psychological Symptoms Scale (PSS, N=250)*

Variable	<i>f</i> %
Gender	
Boys	165 (66.0%)
Girls	85 (34.0%)
Chemotherapy	
Yes	244 (97.6%)
No	6 (2.4%)

*Note. f = Frequency; % = Percentage*

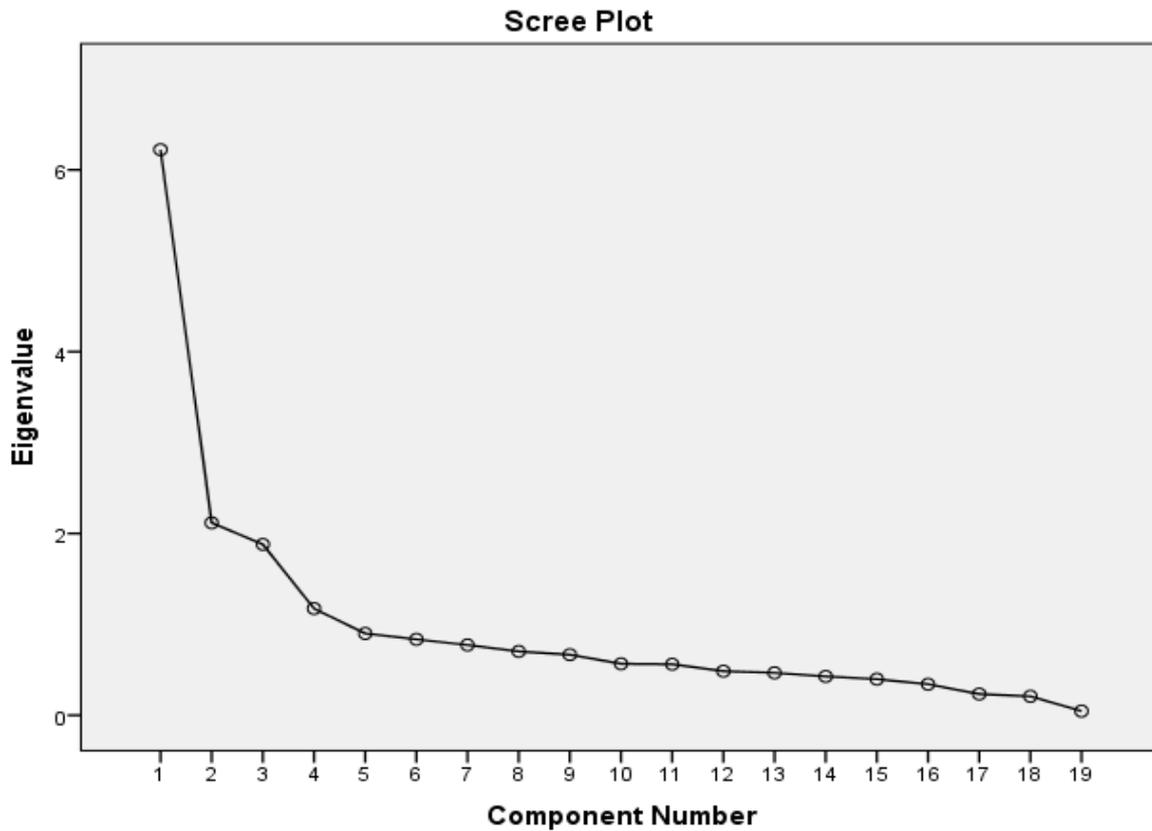
**Exploratory Factor Analysis (EFA)**

Finalization of items for PSAS was made through, item-total correlation analysis; out of 25, only 19 items with significant correlation were included (see Table 2). The items with .40 and above factor loading were retained and considered in the final factor structure. The value of Kaiser-Meyer-Olkin's measure of sampling adequacy (KMO).84 suggests that the data is suitable for the factor analysis and Bartlett's Test of Sphericity was significant ( $\chi^2 (171) = 2303.74 p < .001$ ).

For the extraction of the factors, factor analysis with 1 and 4-factor solutions was tried but the best fit solution with minimum dubious items was with 4 factors. Total 59.97% variance was explained by three factors. Further, every factor has a minimum of 3 items and a maximum of 6 items and according to Guildford (1952), for sufficient reliability minimum of three items in a factor is acceptable.

**Figure 1**

*Scree Plot Showing Extraction of Factors of Psychological Symptoms Assessment Scale (PSAS)*



A scree plot was obtained which described the number of factors that can be extracted by noticing the slope of the curve. In Figure 1, the slope of the curve suggested that 4 factors can be extracted. The Kaiser-Guttman's retention criterion of Eigen Values (Kaiser, 1974) was followed for extraction of factors.

**Table 3**

*Factor Structure and Eigen Values of 19 items of Psychological Symptoms Assessment Scale with Varimax Rotation (N=250)*

Sr. No	Item No	Factor I	Factor II	Factor III	Factor IV
1	1	<b>.83</b>	.08	.13	.08
2	2	<b>.79</b>	.14	.11	.17
3	3	<b>.72</b>	.18	.11	.26
4	4	<b>.68</b>	.26	.14	.18
5	7	<b>.58</b>	.11	.05	.12
6	5	<b>.57</b>	.44	.15	-.07
7	13	.09	<b>.72</b>	.40	.16
8	12	.06	<b>.72</b>	.41	.10
9	9	.24	<b>.64</b>	.05	.30
10	8	.31	<b>.56</b>	-.03	.03
11	6	.43	<b>.56</b>	.14	-.09
12	10	.14	.23	<b>.91</b>	.05
13	11	.13	.24	<b>.90</b>	.00
14	14	.24	.03	<b>.73</b>	.28
15	16	.06	-.00	.01	<b>.74</b>
16	15	.05	-.10	.14	<b>.73</b>
17	17	.25	.06	.07	<b>.66</b>
18	18	.09	.25	.04	<b>.63</b>
19	19	.13	.18	.06	<b>.58</b>
Eigen Values		6.22	2.12	1.88	1.17
% Variance		32.75	11.14	9.89	6.18
Cumulative %		32.75	43.89	53.78	59.97

*Note.* Items with above .40 loadings are boldfaced in the resultant factors.

The items with .40 or above loading or above factor loadings were retained in their respective factors and less than .40 were excluded.

By considering the common themes and appropriateness of every item, each factor was assigned a specific label by a researcher (Table 4).

**Table 4**

*Items of Four Factors*

Behavioral	Emotional	Social	Psychological
1. Avoid talking to people	1. Feeling exhausted/bored	1. Avoid talking to friends	1. Disturbed/restless sleep
2. Isolation	2. Getting angry	2. Avoid talking to loved ones	2. Poor self-image
3. Being sad	3. Giving up/ quitting on things of no interest	3. Weeping more than usual.	3. Aches and pains
4. Irritable	4. Difficult to complete even small tasks.		4. Lethargy
5. Over-reacting on a day to day stuff.	5. Lack of interest in almost everything		5. Feeling embarrassed persistently

**Construct Validity**

A robust positive correlation on 4-factors was obtained on PSAS. Further, Cronbach’s Alpha value ranges from .72 to .88 indicating high internal consistency (see Table 5).

**Concurrent Validity**

The concurrent validity of PSAS was established with CPAS. The results revealed a significant positive correlation between a total of PSAS and CPAS ( $r = .68, p < .01$ ), which showed adolescents with leukemia cancer who have psychological symptoms experienced cancer pain as measured by CPAS. As adolescents with leukemia cancer have more cancer pain tends to be connected to more psychological challenges (see Table 5).

**Table 5**

*Summary of Intercorrelations, Means, Standard Deviations, and Cronbach Alphas of PSAS, Subscales, and CPAS (N=250)*

Factor	1	2	3	4	5	CPAS_T
1. Behavioral	—	.58**	.38**	.36**	.84**	.63**
2. Emotional		—	.50**	.30**	.83**	.58**
3. Social			—	.25**	.68**	.39**
4. Psychological				—	.59**	.36**
5. PSAS Total					—	.68**
<i>M</i>	11.92	9.10	6.08	12.15	39.25	26.15
<i>SD</i>	3.91	3.34	2.44	2.40	9.13	7.19
$\alpha$	.84	.77	.88	.72	.88	.86

*Note.* CPAS T = Total of Cancer Pain Assessment Scale, PSAS = Psychological Symptoms Assessment Scale.

\*\* $p < .01$ .

As shown in Table 5, the intercorrelations, means, standard deviations, and Cronbach Alpha values of PSS, its subscales, and CPAS. Both scales have satisfactory reliability. The results showed a significant correlation between subscales of PSS and CPAS total, such as behavioural ( $r = .63, p < .01$ ), emotional ( $r = .58, p < .01$ ), social ( $r = .39, p < .01$ ), and psychological ( $r = .36, p < .01$ ). The overall results showed a significant correlation between a total of PSS and CPAS ( $r = .68, p < .01$ ).

**Discussion**

Regardless of the maximum survival rates, cancer is affecting the physical, psychological, and social health of adolescent patients and their families. Simultaneously, it is challenging for health professionals to maintain the physical health along with the psycho-social health of patients (Bessell, 2001). This current study aimed to explore gaps in the literature relating to the inferences at the psycho-social level of acute and chronic adolescent patients. Therefore, a scale was aimed to develop and validate the assessment of psychological symptoms among adolescents with leukemia.

Assessing severity of psychological symptoms in adolescents is critical, as adolescents undergoing cancer treatment experience and perhaps only seek assistance, when their psychological symptoms become severe (Gibson et al., 2010; Woodgate, 2003). It is identified that self-reporting symptoms were reassuring for adolescents, as they feel more in control while reporting symptoms and helped and allowed them to see how symptoms modified eventually (Woodgate, 2003). There were

studies based on qualitative literature only (Tremolada et al., 2020; Gibson et al., 2010); therefore, it is important to identify feasible and clinically useful symptoms assessing. The current research targeted on the expression of the psychological symptoms experienced by adolescents with leukemia cancer. The data collected on a 19-item scale comprised four important factors i.e., behavior, emotional, social, and psychological through EFA, which is considered the best statistical method to reduce data in scale development (Korlen et al., 2018). On the other hand, available scales only assess the biopsychosocial manifestations which are associated with mental health challenges, but studies have also pointed out that such bio-psycho-social experiences vary from culture to culture (Gopalkrishan, 2018). Therefore, this study is the first of its kind which focused to establish and validate a culturally sensitive and relevant assessment scale to gauge the psychological symptoms experienced by adolescents with leukemia. Among the various manifestations, this study particularly explored four significant and key indicators of psychological symptoms, such as behavioral, emotional, social, and psychological problems.

The results indicated that symptoms (behavioral & emotional), including attention, depression, withdrawal, and anxiety problems have also reported among adolescents with Acute Lymphoblastic Leukemia (Moore, 2007; Sharan et al., 1999, Twycross et al., 2015). Mainly, adolescents with chronic diseases have more behavioral problems than normal and adolescents with less threatening diseases (Boekaerts & Roer, 1999). The elevated behavioral and emotional symptoms primarily are associated with a higher level of internalizing issues, specifically somatic complaints, depression, social withdrawal, and severe anxiety, as researchers reported somatic complaints in survivors of childhood cancer (Moore, 2007).

The results indicated that behavioral, emotional, social, and psychological symptoms are elevated due to side effects of treatment and prognosis, and may even increase concerns about death (Cavusoglu, 2000), also many sufferers experience continual symptoms of anxiety that perhaps affect their language and communication (Mahakwe et al., 2021). Adolescents begin to form many of the behavior styles that will eventually put influence their adult lives, mainly putting hurdles on the formation of new relationships, complicating their independence, put delays their education, and career (Schultz et al., 2007; Zebrack & Chesler, 2001). Thus the current study indicates that psychological symptoms stimulate worry in adolescents that consequently causes palpitations, tension, and weakness (Ikram & Rafiq, 2021).

Reportedly, in Pakistan, the intensity and prevalence of under-treatment of leukemia are at an distressing point, due to a lack of scales for measuring psychological symptoms, insufficient training of clinicians, lack of proper treatments and medications, socioeconomic factors, and other hurdles that hinder the effectual assessment and management of psychological symptoms of cancer patients, specifically adolescents and children (Ikram & Rafiq, 2021; Majeed et al., 2019), also the healthcare personnel, perhaps have an inappropriate attitude towards the adolescents with leukemia cancer, hindering them to express their pain and psychological symptoms. Therefore, the painful experience of having cancer can alter adolescents' insight of viewing problems, so proper use of family coping strategies certainly enhances emotional growth as well as feelings of well-being, satisfy them with life, give them hope, make them feel happier, and closer towards family (Wechsler et al., 2013).

### **Limitations**

The data used in the current study is perhaps not evenly representative due to gender differences, and separate research studies are needed to deal with this issue. Furthermore, comparatively the sample size was insufficient, as the data was conducted during the COVID-19 pandemic might have exacerbate symptoms. The study represents the bio-psycho-social manifestations associated with clinical population of adolescents suffering from leukemia cancer.

### **Conclusion**

The current study concluded that the psychological symptoms in leukemia patients are significant in effective management. There has always been a dire need to bring awareness around society related to behavioral, emotional, social, and psychological factors that are strongly associated with mental health problems in cancer patients. This study is unique and the only of its kind to serve as a foundation for developing distinct clinical and counselling strategies in Pakistan along with interventions to minimize such symptoms related to biopsychosocial problems in cancer patients.

### **Recommendations**

- This scale must be extended to the adult population.
- It is recommended to make this scale a part of pre-assessment at oncology departments for better understanding of problems and interventions.

### **Conflict of Interest**

No internal or external funding was received while conducting this study; also, authors declare no conflict of interest.

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