ISSN: 1607-8322, e-ISSN: 2220-5799 **Anaesthesia, Pain & Intensive Care**

Vol 25(4); August 2021 DOI: 10.35975/apic.v25i4.1573

ORIGINAL RESEARCH **PAIN MANAGEMENT**

Development and validation of a 'Cancer Pain Assessment Scale' in leukemia patients

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Abstract

Background & objectives: Studies have shown that in cancer patients one of the most frequently reported and feared symptoms is unpredictable and uncontrollable pain that drives the individual to desperation and distress. Leukemia patients are not immune to pains of variable severity. So, it is crucial and extremely important to develop a tool that can document the pain experience of adolescents with leukemia for better pain management.

The current study was aimed to develop a scale – 'Cancer Pain Assessment Scale' (CPAS) for the assessment of pain experienced by leukemia patients.

Methodology: Initially a semi-structured interview was conducted taking the sample of thirty patients out of whom 19 were males and 11 females. The subjects were then interviewed individually and an item pool of different pain statements explained by them was generated. After the exclusion of repeated and dubious items, the final list of 30 items was handed over to 10 experts for empirical validation. Twenty-five items out of thirty were found appropriate by the experts, and after computing the content validity index (CVI), 23 items were finalized in the final CPAS. To find reliability, a pilot study was done by administering the newly developed scale (CPAS) on 125 cancer patients with prior permission.

Results: By using Principle Component Factor Analysis through Varimax Rotation the results extracted three factors solution of the scale namely physical symptoms, physiological symptoms, and psychosomatic symptoms. The outcomes of the pilot study suggested that the scale items were easy to understand and user-friendly.

Conclusion: The scale has satisfactory internal consistency and concurrent validity. Moreover, the study highlighted the physical and psychosomatic aspects of pain, the finding of which would help the clinicians to design pain management strategies accordingly as per our cultural understanding.

Key words: Pain; Pain, cancer; Psychological effect; Psychosomatic; Leukemia; Depression; Anxiety; Adolescence

Citation: Ikram S, Rafiq M. Development and validation of a Cancer Pain Assessment Scale in leukemia patients. Anaesth. pain intensive care 2021;25(4):436–442. **DOI:** 10.35975/apic.v25i4.1573

Received: March 26, 2021, **Reviewed:** May 19, 2021, **Accepted:** May 19, 2021

1. Introduction

Cancer is considered one of the non-communicable diseases in which the cells start dividing abnormally and without any control and affect the surrounding tissues. The incidence of pediatric cancer in children is increasing day by day, and it is estimated that about11,000 new cancer cases are being reported in children under the age of 20 y every year, out of which about 70% are related to leukemia or cancer of the blood.[1] According to the Punjab Cancer Registry

report, leukemia is the predominant cancer in children and it has become the most prevalent cancer in Punjab. The worldwide ratio of leukemia patients is 1–4.75 per 100,000 population but in Pakistan, it constitutes about 17.9%.

Pain is considered to be the most prevalent symptom experienced by cancer patients that leads to desperation and distress.[2] Prior studies indicated that the prevalence of pain is 50% in cancer patients that led to 75% in advanced age due to which many cancer survivors end up with long-term physical and psychological disabilities.[3] It is indicated through the study that pain in cancer patients varies to emotional, spiritual, mental, relational, and physical that induce fear of death.[4] Thus, pain is not only due to biological factors but a psychological and physical aspect also played a significant role in cancer patients that is crucial to monitor to understand the painful experiences.[5]

One of the types of cancer patients that experienced severe pain is related to Leukemia. It is related to bone pain in which the bone marrow expands due to the accumulation of white blood cells that induces acute and dull pain. The studies indicated the 21-59% of children who suffered from acute leukemia experience bone and joint pain, malaise, night sweats, fatigue, pain due to failure of bone marrow, palpitations, weakness, nausea, and bleeding that harms their physical as well as mental health.[6] According to the Mayo clinic of leukemia (2018), body aches pains, pale, pain due to bleeding or non-stop bleeding, and pain due to tiny spots all over the body are few physical indicators that induce pain because of Leukemia. Apart from the physical pain, the cancer patient also experiences emotional or psychological pain. The emotional pain started after the diagnosis of leukemia, by which the patient as well as the family experience painful and stressful feelings of fear regarding stressful and violent treatments or medical procedures. Apart, the emotional pain is also linked with tension regarding arranging money for the treatment that include lengthy hospitalizations[1] and several therapies especially chemotherapy which is considered to be stressful and pain induces period for cancer patients.[7] These affected individuals have difficulties in dealing with the pain that led to decreased quality of life, increased risk of psychological burden due to tension and anxiety and cancer-related distress about their recovery.[8]

It is indicated that emotional and social support played a positive role in the life of cancer patients. There is a lack of emotional and social support in cancer patients and their families that led to the inability to cope with anxiety and pain resulted in low quality of life. Inability to emotionally express, inadequate family relationships and fears of pain led to psychological complications in leukemia cancer patients. The study also indicated that diagnosis of cancer led the patience to depend on caregivers that resulted in helplessness, sadness, depression, anxiety, and hopelessness. Interrupted and unpredictable school attendance in children and adolescents, coupled with outcomes such as hair loss and drastic weight change, may leave adolescents reluctant to engage in age-expected socialization.[9]

Apart from the several factors regarding the pain in cancer patients, cancer pain management is considered a major element of successful cancer survivorship. The exact indication of pain experienced by the cancer patients led to the repeated painful medical procedures, such as bone marrow aspirations, lumbar punctures, and venipuncture. Apart from this, social support one of the most important contributors to adaption to the life of cancer patients. Perceived social support can be more important, it can be emotionally instrumental, informative and appraisal. It allows the patients how they can accept and cope with the problem in a social situation.[3] Emotional focus coping is associated with stress that is embranchment fear, anxiety, depression, and other problems. Additionally, the pain experience is related to many psychosocial/spiritual factors.[2] So it is crucial to document the pain experiences of adolescents with leukemia for the proper management of the disease. To effectively manage the pain, the nature and location of pain must be acknowledged assessed, and determined. For instance, patient A is exhibiting emotional distress and suicidal ideation whereas patient B is suffering from extreme physical symptoms including swelling, bleeding, burning, etc. Therefore, it is crucial to develop a scale through which one can quantitatively assess the severity of pain and devise an effective mode of pain management for the patient, i.e., psychological or physical.

2. Methodology

The Cancer Pain Assessment Scale (CPAS) was developed in three stages. Stage 1 describes the gathering and collating procedure of aspects (psychological, physical, and emotional), intensity, and location of pain, followed by stage II of empirical validation and in stage III the psychometric properties
of the scale were established.

2.1. Phase I

2.1.1. Gathering problems

Initially, whilst gathering information from the patients regarding the level, aspects, and intensity of pain, via rigorous interviewing over 3 months, certain observations were made (tantrums, swelling, joint pain sleep problems, etc.), Furthermore upon securing the consent of the hospital management and 30 patients. A list of 50 expressions of pain was assembled. Items that were dubious, vague or overlapping were merged or modified keeping close to their original connotations. Items that were expressed in idiosyncratic or slang words were also excluded. Thus a comprehensive list of 30 items was organized.

2.2. Phase II

2.2.1. Empirical Validation through Experts

To gather empirical validation of the final list of pain experiences, 10 experienced individuals (3 clinical psychologists, 3 oncologists, 2 nurses working in the oncology department, 2 parents of leukemia patients) were approached and informed about the premise of the study.

All experts had a minimum of 3 years of experience with cancer patients. They were asked to rate each of the 30 problems on a 3-point rating scale ranging from 0 = "not at all" to 3 = "extremely common" for their frequency of occurrence of cancer patients. At the end of stage II, all the problems were listed in descending order of frequency of occurrence as rated by the experts. Twenty-five items out of thirty were found appropriate and more illustrating by the experts, and after computing the content validity index (CVI) 25 items were finalized to be kept in the final CPAS. Which is then used for further psychometric properties in stage III.

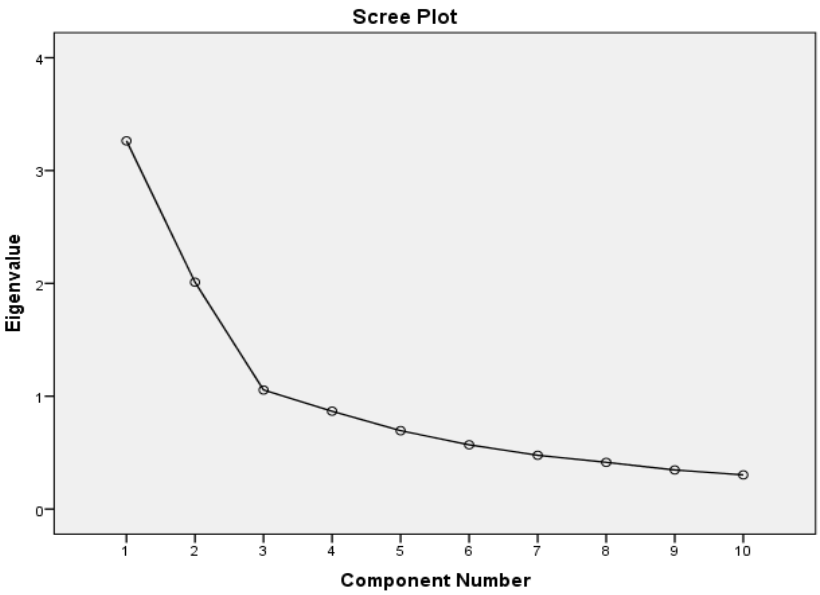

Figure 1: Scree plot suggests three factors can be extracted and was retained for further analysis.

2.2.2. Pilot study

Twenty-five items were piloted on 25 patients (15 boys and 10 girls) for readability and to test the layout. Two problems were excluded from the scale because their wording was not clear to some children. In this way, 23 items were retained for further psychometric phase.

2.3. Phase III

This phase was intended to determine the psychometric properties of the CPAS. The participants comprised 125 cancer patients ranged from 10 to 16 years. The sample was selected from the oncology department of government hospitals, through purposive sampling. The demographic questionnaire included the items of age, stage of the disease, gender, and pre/post-chemotherapy.

The newly developed scale was the indigenous scale that was developed by the researcher. The main purpose of the scale was to measure the intensity and nature of pain. The scale comprised 4 points Likert scale of 0–3 rating. The scale comprised 23 items that described the psychosomatic symptoms and physiological effects of pain. described the

Table 1: Factor structure and eigenvalues of 13 Items of CPAS with Varimax rotation. (N=125)

S. No.	Item No.	F1	F2	F3
1	C2	**.877**	.222	.077
2	C1	**.872**	.159	.136
3	C3	**.868**	.221	.154
4	C20	**.438**	.393	.252
5	C7	.106	**.741**	.086
6	C11	.270	**.665**	.136
7	C14	.352	**.644**	.141
8	C15	.269	**.618**	.127
9	C5	.-.005	**.556**	.220
10	C21	.126	.020	**.819**
11	C23	.103	.220	**.727**
12	C22	.102	.257	**.713**
13	C17	.287	.398	**.407**
Eigen value		2.873	2.64	2.09
% Variance		22.10	20.37	16.12
Cumulative %		22.10	42.47	58.59

Note: *Items with .30 or above loading are boldfaced*

psychosomatic symptoms and physiological effects of pain.

To validate the indigenous scale, McGill Pain Questionnaire was used to check the concurrent validity. The Cronbach alpha for McGill Pain Questionnaire was .69 and .72, respectively.

A total 0f 125 samples were targeted directly and questionnaires were filled from the participants who were willing to participate in the study voluntarily maintaining the confidentiality of their name and identity. Permission from the oncology department of government hospitals was taken. The participants who wanted to be a part of this research showed a willingness by responding positively and signed consent from their parents. In this way, the participants were approached and questionnaires were filled by them. Almost 15-20 min were spent filling the questionnaires.

3. Results

Item analysis was done by computing item-total correlation on 23 items of CPAS, 13 items showed significant item-total correlation. The items above .30

Table 2: Items of 3 factors

No.	Factor 1: Physical Symptoms (4 items)	Factor 2: Psychosomatic Symptoms	Factor 3: Psychological Symptoms
1.	Burning in the body	Feeling tenderness in the body.	Fear of pain.
2.	Swollen joints.	Feeling extreme weakness.	Feeling suffocated.
3.	Feeling pins and Needles in the body.	Feeling as if someone stabbing in the bones.	Worrisome thoughts.
4.	Splitting pain	Feeling irritable due to aches.	Feeling as though body is being cut into pieces.
5.		Feeling of being numb.	

loading were retained and considered in the final factor structure. Further sampling adequacy, Kaiser-Meyer-Olkin (KMO) was found to .876, and Bartlett's test of sphericity was found to be significant ($\chi 2$ (78,125) = 1208.22, $p < .001$). A scree plot was obtained which described the number of factors that can be extracted by noticing the slope of the curve. In

Table 3: Psychometric properties of the CPAS. (N= 125)

Factor	k	M(SD)	α
1. Physical	4	6.50(3.9)	.85
2. Psycho-somatic	5	8.66(2.07)	.70
3. Psycholo-gical	4	10.98(2.6)	.74

Note: n = no. of items. α = Cronbach's alpha.

the Figure 1, the slope of the curve suggested that 3 factors can be extracted. Factor structure and Eigen values of 13 items of CPAS with principal component analysis and Varimax Rotation are shown in Table 1. Table 1 shows the final factors that were extracted with .30 or above loading. For the extraction of the factors, factor analysis with 1 and 4-factor solution was tried but the best fit solution with minimum

dubious items was with 3 factors. Factor 1 and factor 3 has 4 items while factor 2 has 5 items.

3.1. Items of 3 factors

By considering the common themes and appropriateness of every item, each factor was assigned a specific label by a researcher (Table 2)

experience. i.e physiological, psychosomatic and psychological. For this, qualitative and quantitative research approach was used in collection and analysis of the data respectively. In the qualitative part, a phenomenological research design was used to explore the lived experiences of the patients related to

Table 4: Summary of inter-correlations, Means ± SD, and Cronbach alphas of CPAS, factors, McGill pain scale. (N=125)

Measure	1	2	3	4	5	6	7
1. Physiological pain	-	.554**	.428**	.677**	.588**	.233	546**
2. Psychosomatic pain		-	.519**	.826**	.615**	.253	.574**
3. Psychological pain		-	-	.717**	.368*	.385*	.717**
4. Total cancer pain			-	-	.677**	.357	.655**
5. Sensory				-	-	.539**	.970**
6. Affective					-	-	.728**
7. McGill*						-	-
Mean ± SD	*6.50 ± 3.97*	*8.66 ± 2.07*	*10.98 ± 2.66*	*26.14 ± 7.18*	*27.36 ± 3.33*	*9.36 ± 1.18*	*36.73 ± 4.10*
α	.85	.74	.70	.86	.71	.72	.75

Legend: **McGill – Total McGill pain assessment; **p < .05. Mean ± SD and α values of the seven item above in each column are highlighted by blue color*

The psychometric properties of CPAS were through descriptive analysis and based on mean, standard deviation, Cronbach's Alpha, values, and inter-factor correlation that demonstrated the relationship among factors of psychosocial issues associated with CPAS (Table 3).

Table 4 describes means, standard deviations, Cronbach alpha values, potential, and actual response range with skewness values. The results indicated that the value of Cronbach's Alpha ranged from .70 to .86 of factors; the CPAS and its factors have good internal consistency.

To establish the concurrent validity of the CPAS, Pearson Product correlation was conducted with McGill Pain Questionnaire and its factors have a significant positive correlation with the CPAS.

4. Discussion

The current study was aimed to develop a scale for the assessment of pain associated with leukemia patients. The study resulted in three factors of the pain in the form of brief items and exploratory studies are considered best to explore the lived experiences.[10] Different types of pain experienced by the patients vary in intensity and affect the daily routine of the patients differently. The nature of the pain also has a great impact on the life of the patient. The clinicians have started to notice the pain that the cancer patients experience to evaluate it, manage it effectively and give them a better life. Various studies have suggested that most of the patients continue to experience pain or are being affected by factors that are severe enough to impair their routine functions even though most of them receive some kind of treatment for their pain. As opposed to some other studies,[11-12] our study focused on the manifestations of the pain experienced by the cancer patients, in particular the leukemia patients. The data collected in the form of twenty-five items was reduced to three important factors, i.e physiological, psychosomatic, and psychological through the exploratory factor analysis which is considered the best way of data reduction in scale development.[13]

However, there are certain scales available to measure the physio-psychological manifestations associated with pain but studies have indicated that such physiological and psychological experiences vary among cultures.[14] So, the study was focused to develop a culturally relevant scale to measure the pain experienced by leukemia patients. Our study explored three important manifestations of the pain i.e. physical, psychosomatic, and psychological issues. Studies have shown that sufferers may become depressed or anxious, and may even want to end their lives due to the chronic nature of the disease. Pain disrupts their day-to-day activities and relations which become a focus of attention for both the clinical and medical practitioners to thoroughly understand and assess the nature of the pain to provide sound pain management to the patients. The literature suggests that many factors induce pain in cancer patients and a major barrier to pain control is the lack of proper pain assessment, which later on leads to under-treatment, especially in children or adolescent patients.[15] As the adolescence stage is considered to be a critical stage in which on one hand they are exploring the world by making new relations and the adaptations to the environment and on the other facing the challenges. Thus the under-treatment of cancer pain in adolescence leads to severe physical and psychological disabilities that impair their daily functioning.[16]

The results indicate that the physical factors are important, as the patients may suffer from irritation in some parts of the like turning the body into pieces. Neuropathic pain is usually caused by physical damage to the nerves or nerve endings. The patients describe physical pain as a burning sensation, shooting pain, tingling, or crawling under the skin, and sometimes it can be difficult for the patient to describe.[17] Physical pain in patients may also be associated with pain due to treatment, numbness, feeling exhausted, feeling weakness, fatigue, and other related symptoms.[18]

The psychosomatic factor is the second factor that comprises fever, palpitation, nausea, and related factors that cause pain in cancer patients. The leukemic children usually exhibit intense fear, bone pain, joint pain and have night sweating with severe bleeding. Thus, these factors induce pain in the cancer patients which is needed to be treated for their well-being. A study indicated that somatic symptoms are important forecasters of the commencement of pain.[16] It also seems that cancer affects the emotional health of the patients, and even their families and caregivers. The disease induces life-changing experiences including anxiety, tension, distress, worrying, and depression.[19] Thus the current study exhibits the psychological factors as the third factor, and includes "remain worrying all the time", palpitations, anxiety, and weakness due to tension and feeling exhausted.

In Pakistan, the frequency of under-treatment of cancer pain is at an alarming stage. This is due to the inadequate training of the clinicians, lack of availability of necessary medications, lack of tools for assessing the pain, lack of awareness about the nature of the pain, inadequate performance of the opioids, socioeconomic factors, and other barriers that inhibit the effective assessment and management of cancer pain management as mentioned by Majeed et. al., (2019)[20] the healthcare staff may also have inappropriate behavior with the patients, inhibiting them to express their pain.

Apart from this, in Pakistan people have different ways of expressing the pain that differs from the Western cultures. The patients usually belong to a joint or collective family system, where they express their pain by keeping in mind the values and customs. By considering the burden on the caregiver the patients may restrict themselves from expressing their suffering and bear the pain silently.[20] Thus, many patients revert to religious or spiritual methods of healing the pain and feel relaxed. They may use social coping by keeping attention from family for acceptance. To understand and address the factors that define pain intensity and its nature, followed by its management and evaluation of the efficacy of different management strategies, it is crucial to have a reliable and valid scale.

5. Limitations

The sample size has been small, due to the COVID-19 pandemic at the time of this research. Moreover, the data may not be equally representative due to gender differences, and separate studies are required to address this issue. The study represents the pain manifestations associated with adolescent leukemia patients only.

6. Conclusion

The study concluded that the pain-induced factors in leukemia patients are crucial to understanding effective pain management. There is a need to create awareness in society regarding the physiological, psychological, and psychosomatic factors that are associated with pain in cancer patients. The study could serve as a pioneer for developing different counseling and clinical strategies along with the planning of different interventions to minimize such manifestations associated with cancer pain.

7. Conflict of interest

No funding, internal or external, was involved in the conduct of this study, and the authors declare no conflict of interest.

8. Authors' contribution

SI: Concept, experiments, manuscript writing
MR: Literature search, manuscript writing, review

9. References

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