Journal Homepage: - www.journalijar.com

INTERNATIONAL JOURNAL OF ADVANCED RESEARCH (IJAR)

Article DOI: 10.21474/IJAR01/20343
DOI URL: http://dx.doi.org/10.21474/IJAR01/20343

RESEARCH ARTICLE

QUALITY OF LIFE OF CHILDREN WITH LEUKAEMIA: A TERTIARY CARE INSTITUTE OF UTTARAKHAND

Sanjenbam Emon Chanu[1], Kamli Prakash[2], B.P Kalra[3] and Sanchita Pugazhendi[2]

1. Phd (Nursing) Scholar, Swami Rama Himalayan University, Dehradun.
2. Professor, Himalayan College of Nursing, Swami Rama Himalayan University, Dehradun.
3. Professor, Paediatric Department, Himalayan Institute of Medical Sciences, Swami Rama Himalayan University.

Manuscript Info

Manuscript History
Received: 28 November 2024
Final Accepted: 31 December 2024
Published: January 2025

Key words:-
Children, Parent, Leukaemia

Abstract

Background: Leukaemia is one of the most common childhood cancer among all the type of cancer. Having a child with cancer affect every parent's wellbeing both physically and mentally. It is very challenging for the parents to face it and it may disrupts even social life too. The objectives of the study was to assess quality of life of children with leukaemia.

Methods: Data were collected from ninety-eight parents of children who were diagnosed leukaemia and undergoing treatment at selected hospital of Dehradun,Uttarakhand. The Pediatric Quality of Life Inventory (PedsQL™) generic core 4.0 and (PedsQL™) cancer module scales were used to assess quality of life of children. The study identified the various items in each domain of HRQOL that were affected in children with ALL from parents 'perspective.

Results: Children with leukaemia had shown significantly lower HRQOL scores across all domains especially emotional and school functioning domain compared with other domains. Parents reported that children with ALL had problems with nausea, worry, treatment and procedural anxiety.

Conclusion: Based on the findings of the study, it was concluded that children with leukaemia experienced significantly poorer quality of life in various domains.

Introduction:-

Leukaemia is one of the most common childhood cancer and the incidence of it is increasing According to a recent National Cancer Registry Programme (NCRP) report in India, childhood cancers in the 0–14 age group accounted for 4.0% of all cancers.[1]Children with leukaemia undergo intensive treatment in terms of chemotherapy. Though there is an improvement in survival rates, children and their families are suffering in all the aspect of health which compromising directly or indirectly their quality of life. During treatment, children experience symptoms as side effects from chemotherapy which affects the health of the child. Quality of life encompasses multiple dimensions, including physical, mental, emotional, and social aspects, which reflect an individual's overall well-being. Since children may not be able to articulate their quality of life, it is essential to gather this information from their parents.Although studies primarily highlight physical challenges, they also reveal that children undergoing

Corresponding Author:- Sanjenbam Emon Chanu
Address:- Phd (Nursing) Scholar, Swami Rama Himalayan University, Dehradun.

leukaemia treatment may develop behavioural issues over time. The long and intensive nature of leukaemia treatment can affect a child's emotional and psychological well-being. Therefore, in the initial stages, a comprehensive assessment is essential to identify potential concerns, how the child adapt or adjust with the cancer during treatment which may affect in their overall quality of life. Caring children with difficult diagnosis or disease can cause stress within the family too.Therefore,study aimed to measure existing quality of life of children with leukaemia during chemotherapy.

Materials and Methods:-

The study was conducted in Paediatric Hematology Unit of Cancer Research Institute, Dehradun, Uttarakhand. Children aged 2-18 years diagnosed as leukaemia and treated with chemotherapy at this unit were enrolled in the study. Children and their parents were contacted for the data on the quality of life. Through interviewed in person, the data were collected from ninety-eight participants. Written informed consent was obtained from the parents regarding the willingness to participate in the study. Children who diagnosed and treated for ALL were included in the study. Children with pre-existing chronic medical illnesses and case ofrelapse were excluded from the study.The study toolsin the present studywerePedsQLGeneric Core 4.0 and PedsQL Cancer Module which is available in Hindi. A five point likert scale was used for the tool. A higher direction of dimensions score indicates lower problems and better quality of life. The participants evaluated how often a problem occurred in the past one month. The data were analysed through SPSS version 20.0 and presented under the following.

Results:-

Table 1:- Description of participants characteristics (n=98).

S.No	Variable	Frequency (f)	Percentage (%)
1	Informant		
	• Mother	81	82.7
	• Father	17	17.3
2	Age of informant in years		
	• 25-35	40	40.8
	• 36-45	48	49.0
	• 46-55	10	10.2
3	Type of family		
	• Nuclear	41	41.8
	• Joint	57	58.1
4	Income of the family (in Rs.)		
	• 10000 -20000	44	44.9
	• 20000-30000	28	28.6
	• 30000-40000	12	12.2
	• 41000-60000	14	14.3
5	Place of Residence		
	• Rural	64	65.3
	• Urban	34	34.7
6	Gender of Child		
	• Male	35	35.7
	• Female	63	64.3
7	Age of Child in years		
	• 2-4	09	9.2
	• 5-7	24	24.5
	• 8-12	38	38.8
	• 13-18	27	27.6
8	Diagnosis		
	• Acute lymphocytic leukaemia	83	84.7
	• Acute myloidleukaemia	15	15.3
9	History of Cancer in Family		
	• Yes	02	2.0

	• No	96	98.0

The table no.1 presents demographic and background characteristics of the informants (parents) and children with leukaemia, along with family-related factors. Majority of respondents providing information were mothers (82.7%), while fathers accounted for 17.3%. Most informants were between the age group of 36-45 years (49.0%), followed by 25-35 years (40.8%) and a smaller percentage in the 46-55 age group (10.2%). The majority of children belonged to joint families. The largest group of families had an income between ₹10,000-₹20,000 (44.9%). Most families were from rural areas (65.3%), whereas 34.7% resided in urban areas. Male child in the study constituted 35.7% of the children, while females made up 64.3%. The highest proportion of children were in the 8-12 years age group (38.8%), followed by 13-18 years (27.6%), 5-7 years (24.5%), and the least in the 2-4 years category (9.2%). The majority of children (84.7%) were diagnosed with Acute lymphoblastic Leukaemia (ALL), while 15.3% had Acute myeloid leukaemia (AML).Only 2.0% of the families had a history of cancer, while 98.0% reported no family history of the disease. The data indicates that most informants are mothers, children are predominantly from rural areas, and a significant proportion belong to low-income nuclear families. The majority of cases involve ALL, and only a small percentage have a family history of cancer.

Table 2:- Quality of life of children with Leukaemia based on Peds QL^{TM} 4.0 Generic Core as reported by parents n =98

Domains of Quality of Life	**Mean ± SD**
Physical Functioning	71.93±8.46
Emotional Functioning	62.44±11.91
Social Functioning	71.17± 10.78
School Functioning	64.32±10.79
Total Score	66.87±5.7

The table no. 2 presents mean scores and standard deviations (SD) for different domains of quality of life includingphysical functioning, emotional functioning, social functioning, and school functioning, along with an overall total score.Physical functioning has the highest mean score (71.93 ± 8.46), indicating relatively better quality of life as compared to other domains. Emotional functioning has the lowest mean score (62.44 ± 11.91), suggesting that emotional well-being is the most affected domain.Social functioning (71.17 ± 10.78) is close to physical functioning, implying that social interactions are relatively well maintained.School functioning (64.32 ± 10.79) shows moderate challenges in academic or school-related activities. The total Score (66.87 ± 5.7) represents the overall quality of life measure, summarizing all domains.

The above bar chart presents data on the quality of life of children as reported by their parents. It evaluates four key domains: emotional functioning, school functioning, social functioning, and physical functioning. Emotional Functioning has the lowest score, indicating that children may struggle the most in this aspect. School Functioning scores slightly higher but remains relatively low, suggesting that leukaemia affects children's academic participation and performance. Social Functioningis rated significantly higher, showing that children still maintain some level of social engagement despite their illness. Physical Functioning has the highest score, implying that parents perceive their children's physical well-being to be relatively better compared to other domains. Overall, the figure highlights that while children with leukaemia may experience significant emotional and school-related challenges, their social and physical well-being are comparatively better.

Table 3:- Quality of life of children with Leukaemia based on PedsQL$^{3.0}$ Cancer Module as reported by their parents **n =98**

Peds QL^{TM}3.0 Cancer Module Domains	**Mean ± SD**
Pain & Hurt	72.32.83±12.07
Nausea	61.98±9.70
Procedural Anxiety	61.03±12.12
Treatment Anxiety	60.20±11.06
Worry	61.88±11.38

Cognitive Problems	69.75±10.19
Perceived Physical Appearance	74.82±9.49
Communication	68.11±12.49
Total Score	66.26±4.30

The tableno 3.presents the quality of life scores for children with leukaemia, assessed using the PedsQL 3.0 Cancer Module. Among the different domains, perceived physical appearance" has the highest mean score (74.82 ± 9.49), suggesting that children generally have a positive perception of their physical appearance. This is followed closely by "Pain & Hurt" (72.32 ± 12.07) and "Cognitive Problems" (69.75 ± 10.19), indicating relatively better well-being in these aspects.On the other hand, "Treatment Anxiety" (60.20 ± 11.06) and "Procedural Anxiety" (61.03 ± 12.12) have lower scores, reflecting higher levels of distress related to medical procedures and treatments. The "Nausea" domain scores 61.98 ± 9.70, showing moderate impact.The total quality of life score across all domains is 66.26 ± 4.30, suggesting an overall moderate quality of life among children with leukaemia. The findings indicate that while children generally cope well in some areas, they experience notable challenges related to treatment procedures, anxiety, and nausea.

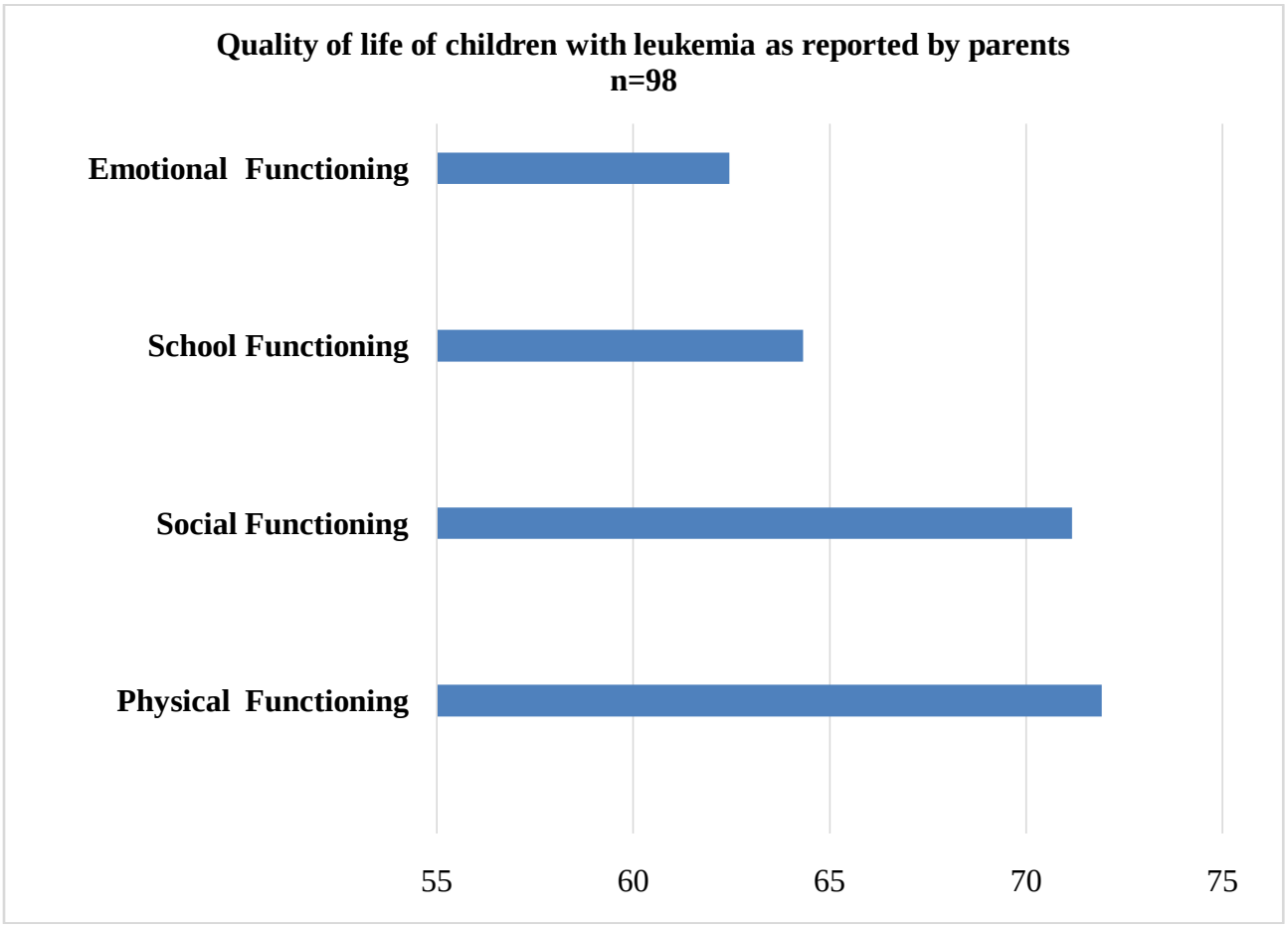

Fig No.1:- Bar Chart showingvarious domains of quality of life of children with leukaemia based on PedsQL Generic Core.

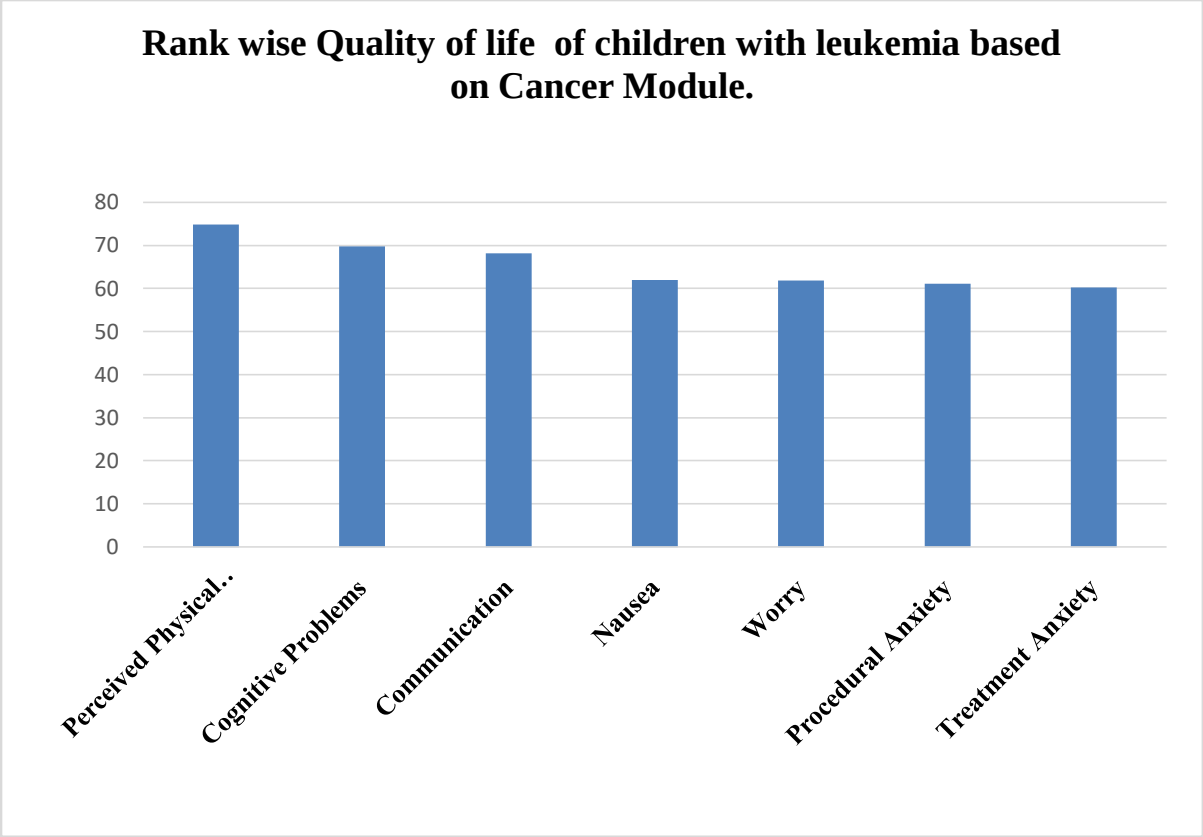

Fig No.2:- Bar Graph presents rank wise quality of life in various domain based on Cancer Module.

The above bar chart illustrates the rank-wise quality of life based on different domains of the Cancer module. A bar with a corresponding score, indicating the quality of life in that specific area, represents each domain.Perceived physical appearancehas the highest score (74.82), suggesting that children with cancer generally perceive their physical appearance more positively compared to other aspects.Cognitive problems (69.75) and communication (68.11) also have relatively high scores, indicating that these areas are less affected in comparison to others.Nausea (61.98), worry (61.88), procedural anxiety (61.03), and treatment anxiety (60.2) have the lowest scores, indicating that these aspects significantly impact children's well-being.The chart highlights that treatment-related anxiety, procedural anxiety, and nausea are among the most challenging issues for children with cancer, whereas perceived physical appearance and cognitive function are relatively better preserved.

Discussion:-

The current study provides data on quality of life of children with leukaemia. Based on the findings, Physical functioning has the highest mean score indicating relatively better domain in quality of life as compared to other domains like social, school and emotional. The lowest domain was emotional functioning with mean score (62.44 ± 11.91), suggesting that emotional well-being is the most affected domain. School functioning (64.32 ± 10.79) shows moderate challenges in academic or school-related activities. The total Score (66.87 ± 5.7) represents the overall quality of life measure, summarizing all domains. This study was supported by Raj M et.al 2017 reported Social functioning had highest score and emotional functioning was the lowest score.[2]Another similar findings by Courtney K Blackwellet al. (2019) found that children with chronic conditions tend to have lower emotional functioning compared to healthy peers, which aligns with the lower mean score[3]. Manjusha K et al. (2024) reported that Children with leukaemia found affected in physical health and psychosocial health, which was lower and found majority had behavioural problems[4]. The treatment of childhood leukaemia impacted the children and their families to a large extent showing high levels and severe impact of treatment-related side effects, and children with higher parent-reported toxicity .Children (5-7 years) reported lower HRQOL but 8 years and older otherwise reported their HRQOL at similar levels as the reference population. The parents' own HRQOL was negatively affected, especially the mental domains and especially in mothers, which may indicate a need for extra support[4] as reported by

Mogensen N. (2024)[5].Further study done by Liu D, Zhang Y (2024)reported that during the initial diagnosis of paediatric ALL, adequate attention should be paid to the aspects that may affect long-term clinical efficacy and quality of life, and suitable treatment plans should be implemented. Meanwhile, children's treatment compliance should be enhanced during therapy in order to increase their survival rate and quality of life with paediatric [6].

Findings of the present study on quality of life of children with leukaemia based on cancer module showed various domains were affected. Perceived physical appearance has the highest score (74.82), suggesting that children with cancer generally perceive their physical appearance more positively compared to other aspects. Cognitive problems (69.75) and communication (68.11) also have relatively high scores, indicating that these areas are less affected in comparison to others. The most affected domains were nausea (61.98), worry (61.88), procedural anxiety (61.03), and treatment anxiety (60.2) have the lowest scores, indicating that these domains significantly impact children's well-being. This findings is supported by Marhaeni W (2023) and mentioned in their study that children cancer with solid tumor had more problem in procedural anxiety, and also shorter duration of therapy had more problem in pain and hurt[7].similar finding reported by study by Arifah S (2025), which showed the lowest mean sub-scale QoL score was in procedural anxiety (72.25)[8].Another study by Saleh MS et.al. reported that the lowest mean score of quality of life was for the "procedure anxiety" (8.7 ± 23.9), followed by the "worry" domains (16.6 ± 28.5)[9]. Zareifar S (2011) evaluated health related quality of life of children of 6–18 years old patients diagnosed with acute leukaemia. They exhibited lower QOL, physical and cognitive functions in comparison with acute myelogenous leukaemia and they had more fatigue, pain and insomnia[10]**.**Parent proxy reports generally indicated worse fatigue, pain interference, and mobility. Patients aged ≤6 had more procedural anxiety than older patients and exhibited increased worry during their first year of treatment. The boys had increased cognitive problems than girls. Collectively, most patients had poor HRQOL.[11-14]

Conclusion:-

Collectively, we observed that most children with leukaemia had poor HRQOL with a lowest emotional and school functioning domain. Children also had procedural anxiety, treatment anxiety, worry and nausea found the most affect domain.

Funding

The research did not receive any specific grant from funding agencies

Reference:-

1. Kulothungan V., Sathishkumar K., Leburu S., et al. Burden of cancers in India–estimates of cancer crude incidence, YLLs, YLDs and DALYs for 2021 and 2025 based on National Cancer Registry Program. BMC Cancer. 2022;22:1–2. doi: 10.1186/s12885-022-09578-1. [DOI] [PMC free article] [PubMed] [Google Scholar][Ref list]
2. Raj M, Sudhakar A, Roy R, Champaneri B, Joy TM, Kumar RK. Health-related quality of life in Indian children: A community-based cross-sectional survey. Indian J Med Res. 2017;145(4):521-529. doi:10.4103/ijmr.IJMR_447_16
3. Blackwell CK, Elliott AJ, Ganiban J, et al. General Health and Life Satisfaction in Children With Chronic Illness. Pediatrics. 2019;143(6):e20182988. doi:10.1542/peds.2018-2988
4. Manjusha K, Rajesh Tv, AjithkumarVt, Krishnakumar P. Quality of Life and psychosocial problems of children with acute lymphoblastic leukemia 5 years after diagnosis–a cross sectional study. Int J Acad Med Pharm. 2024;6(1):1011-5.
5. Mogensen N. Impact of childhood leukemia and its treatment on Nordic children and families: the consent process, toxicity, and quality of life. Instförkvinnorsoch barns hälsa/Dept of Women's and Children's Health; 2024 Apr 24.
6. Liu D, Zhang YF. Analysis of factors affecting the clinical efficacy and quality of life in the treatment of pediatric acute lymphoblastic leukemia. Pakistan Journal of Medical Sciences. 2024 May;40(5):956.
7. Marhaeni W, Hidayah A, Sari RP, Margareth Y. Health-Related Quality of Life Assessment in Children with Cancer Using Pediatric Quality of Life InventoryTM in Ulin Hospital Banjarmasin. J. Adv. Med. Med. Res. [Internet]. 2023 Apr. 28 [cited 2025 Feb. 8];35(12):64-73. Available from: https://journaljammr.com/index.php/JAMMR/article/view/5036

8. Arifah S, Pookboonmee R, Patoomwan A, Kittidumrongsuk P, Andarsini M. Quality of life of children with acute lymphoblastic leukemia. PI [Internet]. 13Nov.2023 [cited 11Feb.2025];63(5):405-. Available from: https://paediatricaindonesiana.org/index.php/paediatrica-indonesiana/article/view/3234
9. Saleh, M.S., Mohammed, A.M., Bassiouni, D. et al. Evaluation of health-related quality of life and its domains in pediatric patients with cancer. J Egypt Natl CancInst **35**, 9 (2023). https://doi.org/10.1186/s43046-023-00168-1
10. Zareifar S, Farahmandfar MR, Cohan N, Modarresnia F, Haghpanah S. Evaluation of health related quality of life in 6-18 years old patients with acute leukemia during chemotherapy. Indian J Pediatr. 2012 Feb;79(2):177-82. doi: 10.1007/s12098-011-0483-0. Epub 2011 Jun 3. PMID: 21638073
11. Tager JB, Palou-Torres A, Bingen KM, et al. Health-related quality of life among pediatric patients with acute lymphoblastic leukemia: An exploratory cross-sectional study. Pediatr Blood Cancer. 2024;71(10):e31186. doi:10.1002/pbc.31186
12. Sudnawa, K. K., Yeepae, J., Photia, A., Rujkijyanont, P., Traivaree, C., &Monsereenusorn, C. (2024). Health-related quality of life and its determinant factors in Thai children with cancer: parents vs. children perspectives. BMC pediatrics, 24(1), 531. https://doi.org/10.1186/s12887-024-05010-8
13. LamyaAlnaim, AljoharaAlqub, Raghad BinSalleeh, Abdulrahman S. Alsultan, Sameh N. Awwad, Health-related quality of life among patients with childhood acute lymphoblastic leukemia in Saudi Arabia: A cross-sectional study, PediatricHematology Oncology Journal, Volume 8, Issue 1,2023,Pages 21-26,ISSN 2468-1245,https://doi.org/10.1016/j.phoj.2022.12.008.
14. Bakker, Anne et al **A systematic review of health-related quality of life in children and adolescents during treatment for cancer** EJC Paediatric Oncology, Volume 2, 100134.