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Participation in Daily Life Activities among Children with Cancer

Ahmad Mohammadi*, Afsoon Hassani Mehraban*♦, Shahla Ansari Damavandi, Mehdi Alizadeh Zarei*, Malek Amini***

**Department of Occupational Therapy, Iran University of Medical Sciences, Tehran, Iran*
***Department of Pediatric Oncology, Ali Asghar Hospital, Iran University of Medical Sciences, Tehran, Iran*

Abstract

Background: Participation in daily life activities is an essential aspect of health, which can facilitate a child's development. Children with cancer are at risk of functional limitations and participation restrictions. The present study aims to investigate participation of children with cancer in daily life activities compared to healthy peers.

Methods: This was a comparative cross-sectional study. In the first phase, we assessed the test-retest reliability of the Iranian Children Participation Assessment Scale in 30 children (6-12 years of age) diagnosed with cancer and their parents (child and parent versions). The second phase of the study included a comparison of daily life activities as measured by the Iranian Children Participation Assessment Scale between the children with cancer (diagnosed at least 4 months prior and currently receiving active treatment) and their age- and gender-matched healthy peers.

Results: The child version had excellent reliability according to Cronbach's alpha in diversity of activities (0.97), intensity of participation (0.95), with whom they participated (0.95), and enjoyment of daily activities (0.94). The parent version had excellent reliability (Cronbach's alpha) as follows: 0.99 for diversity, 0.97 for intensity, 0.97 for with whom, 0.98 for enjoyment, and 0.98 for parents' satisfaction. The coefficients of agreement were 0.77 (total scores of diversity), 0.63 (intensity), 0.60 (with whom), and 0.91 (enjoyment). The child version indicated that children with cancer had significantly lower scores in daily life activities items of diversity (P=0.000), intensity (P=0.000), with whom (P=0.000), and enjoyment (P=0.000) compared to healthy children. Based on the total scores in the parent version, children with cancer showed significantly lower scores in diversity (P=0.001), intensity (P=0.000), with whom (P=0.001), enjoyment (P=0.002), and satisfaction (P=0.000) compared to the healthy group.

Conclusion: The findings of the present study show that cancer diagnosis and treatment can restrict children's participation in daily life activities. Early planning and intervention to facilitate participation in these activities can minimize negative consequences and may mitigate or prevent adverse long-term functional effects of childhood cancer.

♦**Corresponding Author:**
Afsoon Hassani Mehraban, PhD
Department of Occupational Therapy, Iran University of Medical Sciences, Tehran, Iran
Tel: +98 9123905660
Email: afsoonmehraban@hotmail.com; a.mehraban@iums.ac.ir

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Introduction

Participation in the activities of daily life in childhood is necessary for the health of all children, regardless of their health status or ability level.[1] According to the International Classification of Functioning, Disability and Health, the World Health Organization defines participation as involvement in a life situation.[2] This involvement in purposeful activities enables a child to gain confidence, develop skills, and create a sense of competence. Participation in daily life activities is needed for physical, mental, and emotional health.[3] According to the International Society of Pediatric Oncology (2015), approximately 25000 cancer cases are diagnosed each year with estimates that suggest 90000 annual deaths due to cancer in children.[4] Cancer is the third-leading cause of death after heart problems and accidents, in Iran. However, childhood cancers (in those under 15 years of age) are rare (less than 1%of cancer diagnoses).[5] The childhood cancer incidence rate is estimated by the World Health Organization to be approximately 100 per million children. The incidence rate of childhood cancer in Iran is 48 to 112 per million among girls and 51 to 144 per million among boys in different provinces. The most common childhood cancers are leukemia, lymphoma, and tumors of the central nervous system.[6]

Developments over the past few decades in pediatric oncology have improved the survival rate in children less than 14 years of age. The five-year survival rate of these children reached 80%-85% in 2010 compared to 25%-30% during the 1970s.[7-9]

A childhood cancer diagnosis means living with disruptions to daily roles and routines.[10] The process of diagnosis, hospitalization, and cancer treatment can cause distress for the child and family that lead to physical, psychological, and social problems.[11-15] The new protocols of chemotherapy for leukemia are long and usually last 2.5-3.5 years.[16] This condition has its effects even after recovery and treatment throughout one's life. According to statistics, 60% of these children will experience chronic health problems later. These problems will become severe in 27%.[4] Functional and social limitations are reported in 69% of survivors. These restrictions can influence a child's ability to participate in everyday activities, which are necessary for their self-care, play, and school.[17]

Studies in this field have mostly investigated quality of life in survivors of childhood cancer. There are few studies that address daily life activities during treatment. We have taken into consideration the importance of activity in a child's daily life and their role in treatment planning and prevention of subsequent problems. The current study aims to investigate participation of children with cancer in daily life activities during active treatment and its comparison with healthy peers.

Materials and Methods

We conducted this comparative cross-sectional study in two phases. The first phase aimed to determine test-retest reliability of the Iranian Children Participation Assessment Scale (ICPAS). This test was designed in Persian to evaluate participation in daily life activities by 6-12 year-olds Iranian children. In this phase, children with cancer and their parents completed the ICPAS form over a two-week interval to examine the reliability of the tool. The second phase of the study included a comparison of daily life activities in children with cancer and their healthy peers.

Participants in this study included 30 children between the ages of 6-12 years who were diagnosed at least four months earlier and undergoing chemotherapy. We included 30 healthy children, whose age and gender matched the children with cancer. Parents in both groups of children were studied. This study was conducted from January, 2015 to June, 2016. Parent participants provided written consent for themselves and their children. Table 1 lists the characteristics of the children and parents that participated in this study.

We have used the ICPAS form to collect data in three sections: demographic information, medical records, and participation in activities of

Table 1. Demographics and participants' characteristics.

	Cancer child N=30	Healthy child N=30	Parent of cancer child N=30	Parent of healthy child N=30
Gender (female: male)	16:14	16:14	28:2	29:1
Mean age ±SD (years)	8.93±1.85	8.93±1.85	37.86±3.73	36.96±4.29
Cancer type				
Leukemia	21			
Central nervous system tumors	5			
Non-Hodgkin lymphoma	3			
Rhabdomyosarcoma	1			
Mean time since diagnosis ±SD (months)	10.20±2.91			
Mean time since treatment ±SD (months)	8.46±2.90			
Treatment type				
Chemotherapy	30			
Surgery	7			
Radiotherapy	4			
Educational level of parents				
High school			9	8
B.Sc.			13	15
M.Sc.			6	7
Ph.D.			2	0

daily life. The form consists of 8 areas: activities of daily living (ADL), instrumental ADL (IADL), play, leisure, social participation, education, work, and sleep/rest. There are 71 items in the child and parent versions. The child version measures diversity of activities, intensity of participation, with whom they participated, and enjoyment of daily activities. The parent version measures these criteria in addition to parental satisfaction regarding how the activities are undertaken by the child. A previous study has determined Cronbach's alpha coefficients of 0.84 for the child version and 0.94 for the parent version, with test-retest reliability of 0.92 for the child version and 0.95 for the parent version.[18]

Statistical analysis

Data analysis was performed using SPSS 18 software. Demographic data and medical records were examined using descriptive statistics (mean, standard deviation). Data related to reliability was examined by the intra class correlation coefficient (Cronbach's alpha for the parent and child forms), Spearman's correlation coefficient (agreement of parent and child), and a comparison of daily life activities by the independent t-test [95% confidence interval (CI)].

Table 2. Test-retest reliability of the Iranian Children Participation Assessment Scale (ICPAS)-child version.

	Diversity of activities	Intensity of participation	With whom participated	Enjoyment of daily activities
ADL	0.94	0.94	0.93	0.94
IADL	0.97	0.97	0.96	0.96
Play	0.95	0.94	0.93	0.94
Leisure	0.97	0.96	0.94	0.97
Social	0.97	0.96	0.94	0.96
Education	1.00	0.90	1.00	0.99
Work	0.94	0.99	0.88	0.90
Sleep	0.95	0.94	0.91	0.89
Total	0.97	0.95	0.95	0.94

ADL: Activities of daily living; IADL: Instrumental activities of daily living

Table 3. Test-retest reliability of the Iranian Children Participation Assessment Scale (ICPAS)-parent version.

	Diversity of activities	Intensity of participation	With whom participated	Enjoyment of daily activities	Parents' satisfaction
ADL	0.99	0.98	0.98	0.97	0.99
IADL	0.98	0.98	0.88	0.98	0.99
Play	0.97	0.98	0.97	0.97	0.97
Leisure	0.99	0.93	0.97	0.98	0.99
Social	0.98	0.96	0.98	0.97	0.98
Education	1.00	0.97	0.89	0.96	0.99
Work	1.00	0.99	0.96	0.97	0.98
Sleep	1.00	0.99	0.93	0.96	0.96
Total	0.99	0.97	0.97	0.98	0.98

ADL: Activities of daily living; IADL: Instrumental activities of daily living

Results

A total of 60 children (30 healthy and 30 with cancer) and one parent for each child participated in this study. There were 32 (53.3%) female and 28 (46.7%) male children. Among parents, 57 mothers (95%) and 3 fathers (5%) participated in the study (Table 1).

Reliability of the Iranian Children Participation Assessment Scale (ICPAS)

A total of 30 children with cancer (16 girls and 14 boys) 8.93±1.85 years of age with one parent each (28 mothers and 2 fathers) who were 37.86±3.73 years of age participated in the reliability phase. Cronbach's alpha for the total scores were: diversity of activities (0.97), intensity of participation (0.95), with whom they participated (0.95), and enjoyment of daily activities (0.94), which suggested excellent reliability of the child version. Table 2 shows the analysis of reliability for all areas of participation in the child version.

The parent version had Cronbach's alpha for the total scores as follows: diversity of activities (0.99), intensity of participation (0.97), with whom they participated (0.97), enjoyment of daily activities (0.98), and parents' satisfaction (0.98), which suggested excellent reliability of the parent version. Table 3 shows the analysis of reliability for all areas of participation in the parent version.

Table 4 shows the agreement between the parent and child versions. The coefficients of agreement for total scores were: diversity of activities (0.77), intensity of participation (0.63), with whom they participated (0.60), and enjoyment of daily activities (0.91). Table 4 shows that areas of diversity at sleep (0.20), intensity at leisure (0.39), with whom they participated at sleep (0.37) and enjoyment at sleep (0.35) were not significant and showed poor agreement.

Comparison

In the comparison phase, we compared the daily life activities of 30 children with cancer

Table 4. Agreement between child and parent versions (Inter-Class Correlation)

	Diversity of activities	Intensity of participation	With whom participated	Enjoyment of daily activities
ADL	0.89	0.87	0.51	0.58
IADL	0.69	0.71	0.58	0.74
Play	0.65	0.62	0.59	0.56
Leisure	0.48	0.39 (P=0.10)	0.54	0.45
Social	0.75	0.64	0.82	0.70
Education	1.00	0.99	1.00	0.99
Work	1.00	0.98	0.96	0.87
Sleep	0.20 (P=0.42)	0.54	0.37 (P=0.12)	0.35 (P=0.15)
Total	0.77	0.63	0.60	0.91

ADL: Activities of daily living; IADL: Instrumental activities of daily living

Table 5. Participation in daily life activities-child version.

	Group	Mean	S.D.	*P*-value	95% CI	
					Lower	Upper
ADL diversity	Healthy	9.96	0.49	0.000	0.63	1.62
	Cancer	8.83	1.26			
ADL intensity	Healthy	56.40	3.86	0.000	5.34	10.92
	Cancer	48.26	6.54			
IADL diversity	Healthy	8.33	1.82	0.000	1.08	3.18
	Cancer	6.20	2.21			
IADL intensity	Healthy	42.43	9.60	0.000	10.21	20.11
	Cancer	27.26	9.54			
IADL enjoyment	Healthy	28.23	8.25	0.023	0.72	9.41
	Cancer	23.16	8.55			
Play diversity	Healthy	8.93	2.04	0.000	1.09	3.36
	Cancer	6.70	2.33			
Play intensity	Healthy	35.96	11.28	0.000	7.5	19.79
	Cancer	22.30	12.41			
Play with whom	Healthy	26.06	7.48	0.000	7.97	14.68
	Cancer	14.73	5.31			
Play enjoyment	Healthy	39.93	9.45	0.000	6.66	19.93
	Cancer	28.13	10.40			
Leisure diversity	Healthy	10.00	2.71	0.000	1.88	4.65
	Cancer	6.73	2.63			
Leisure intensity	Healthy	37.13	12.74	0.000	9.09	20.10
	Cancer	22.53	8.02			
Leisure with whom	Healthy	20.53	6.08	0.000	3.52	9.73
	Cancer	13.90	5.93			
Leisure enjoyment	Healthy	43.10	11.80	0.000	10.33	21.90
	Cancer	26.96	10.59			
Social diversity	Healthy	6.26	2.49	0.001	0.94	3.52
	Cancer	4.03	2.49			
Social intensity	Healthy	18.66	1.031	0.003	2.53	11.93
	Cancer	11.13	7.68			
Social with whom	Healthy	15.20	6.48	0.001	2.70	9.36
	Cancer	9.16	6.38			
Social enjoyment	Healthy	26.73	10.61	0.000	7.60	15.13
	Cancer	16.86	9.73			
Education diversity	Healthy	0.83	0.95	0.011	0.13	0.99
	Cancer	0.26	0.63			
Education intensity	Healthy	3.90	4.58	0.001	1.51	5.08
	Cancer	0.60	1.59			
Education with whom	Healthy	2.10	2.83	0.002	0.71	2.88
	Cancer	0.30	0.70			
Education enjoyment	Healthy	3.76	4.66	0.003	1.04	4.81
	Cancer	0.83	2.08			
Work diversity	Healthy	0.96	0.31	0.000	0.31	0.75
	Cancer	0.43	0.50			
Work intensity	Healthy	5.46	1.96	0.000	2.20	4.66
	Cancer	2.03	2.73			
Work with whom	Healthy	1.66	0.99	0.000	0.56	1.50
	Cancer	0.63	0.80			
Work enjoyment	Healthy	3.43	1.47	0.000	1.23	2.89
	Cancer	1.36	1.73			
Sleep intensity	Healthy	17.33	1.47	0.047	0.029	2.50
	Cancer	16.06	3.05			
Total diversity	Healthy	6.03	0.86	0.000	1.01	2.04

Table 5. Participation in daily life activities-child version.

	Group	Mean	S.D.	*P*-value	95% CI	
					Lower	Upper
	Cancer	4.50	1.10			
Total intensity	Healthy	27.16	4.31	0.000	6.11	10.58
	Cancer	1.81	4.33			
Total with whom	Healthy	11.92	2.20	0.000	2.79	5.00
	Cancer	8.02	2.07			
Total enjoyment	Healthy	23.42	3.79	0.000	4.02	8.47
	Cancer	17.17	4.77			

ADL: Activities of daily living; IADL: Instrumental activities of daily living

(16 girls and 14 boys) to 30 peers in terms of age and gender along with 28 mothers and 2 fathers in the cancer group, and 29 mothers and 1 father in the healthy group. Table 5 compares the mean scores of the children from both groups. Children in the cancer group had significantly lower mean scores compared to children in the healthy group in diversity of activities, intensity of participation, with whom they participated, and enjoyment of daily activities.

We observed no significant differences in specific areas of with whom they participated at ADL, enjoyment of activity in ADL, with whom they participated at IADL, diversity at sleep, with whom they participated at sleep, and enjoyment at sleep between children with cancer and healthy children. A significant difference existed in the means of both groups in other areas. The children with cancer had a higher mean value in the with whom they participated at sleep are compared to the healthy group, however the healthy children had higher mean values in other areas.

A comparison of the scores from the parent version showed significantly lower total scores from the five criteria of diversity of activities, intensity of participation, with whom they participated, enjoyment of daily activities, and parents' satisfaction in the children with cancer compared to healthy children (Table 6). There were no significant differences in the specific areas of with whom they participated in activity at ADL, enjoyment of activity in ADL, satisfaction at ADL activities, enjoyment in activity at IADL, with whom they participated at work, diversity at sleep, intensity at sleep, enjoyment at sleep, and satisfaction at sleep. However significant differences existed in the means of both groups in other areas. These results approximated the findings of the child version. Children with cancer had higher scores in with whom they participated at ADL, diversity at sleep, intensity at sleep, with whom they participated at sleep, enjoyment at sleep, and satisfaction at sleep compared to the healthy group. The mean scores of the healthy group were higher in other areas.

Discussion

In the current study, we have compared participation in daily life activities between children with cancer and healthy children. As previously mentioned, most studies in this field are related to the quality of life of child survivors of pediatric cancer. As expected, cancer diagnosis and its treatment process can influence daily activities of a child and their quality of life.[19-25] In the current study, the participation pattern of children with cancer in daily life activities was significantly lower compared to healthy children in all criteria: diversity of activities, intensity of participation, with whom they participated, enjoyment of daily activities, and parent satisfaction in both the child and parent versions. Studies related to quality of life in children with cancer supported these results. Kyung et al. studied quality of life, ADL, and stress in parents of children with brain tumors. They reported deficiencies in performing activities of daily life in these children compared to healthy children. The areas of physical health, emotional functioning, social functioning, school, and total score of quality of life were also lower than in the control group.[26] Miralles et al. analyzed the functional needs of adolescents with cancer in

Table 6. Participation in daily life activities-parent version.

	Group	Mean	S.D.	*P*-value	95% CI	
					Lower	Upper
ADL diversity	Healthy	9.40	1.30	0.031	0.07	1.45
	Cancer	8.63	1.37			
ADL intensity	Healthy	53.53	7.47	0.002	2.35	9.78
	Cancer	47.46	6.89			
IADL diversity	Healthy	7.33	2.13	0.016	0.26	2.53
	Cancer	5.93	2.24			
IADL intensity	Healthy	35.10	9.82	0.001	4.12	14.1
	Cancer	26.96	9.54			
IADL with whom	Healthy	12.93	5.84	0.015	0.69	6.30
	Cancer	9.43	4.98			
IADL satisfaction	Healthy	24.53	8.06	0.004	2.15	10.91
	Cancer	18.00	8.86			
Play diversity	Healthy	8.33	3.09	0.003	0.79	3.67
	Cancer	6.10	2.42			
Play intensity	Healthy	30.50	11.33	0.002	4.14	17.05
	Cancer	19.90	13.53			
Play with whom	Healthy	21.56	11.05	0.001	3.49	12.64
	Cancer	13.50	5.87			
Play enjoyment	Healthy	35.66	14.43	0.002	3.97	16.82
	Cancer	25.26	10.04			
Play satisfaction	Healthy	30.30	11.80	0.000	5.36	15.49
	Cancer	19.86	7.27			
Leisure diversity	Healthy	8.70	3.66	0.009	0.59	3.94
	Cancer	6.43	2.73			
Leisure intensity	Healthy	31.03	12.84	0.001	4.38	16.21
	Cancer	20.73	9.85			
Leisure with whom	Healthy	18.26	8.21	0.007	1.49	8.90
	Cancer	13.06	5.88			
Leisure enjoyment	Healthy	36.20	15.67	0.004	3.64	17.75
	Cancer	25.50	11.26			
Leisure satisfaction	Healthy	31.53	14.11	0.000	5.49	18.04
	Cancer	19.76	9.77			
Social diversity	Healthy	5.76	2.99	0.003	0.75	3.57
	Cancer	3.60	2.42			
Social intensity	Healthy	14.96	8.21	0.002	0.72	9.07
	Cancer	10.06	7.94			
Social with whom	Healthy	12.50	7.33	0.015	0.88	7.98
	Cancer	8.06	6.36			
Social enjoyment	Healthy	23.73	13.42	0.005	2.80	14.92
	Cancer	14.86	9.72			
Social satisfaction	Healthy	20.60	11.26	0.001	4.08	14.18
	Cancer	11.46	7.99			
Education diversity	Healthy	0.93	1.1	0.023	0.081	1.05
	Cancer	0.36	0.71			
Education intensity	Healthy	3.93	4.29	0.001	1.50	4.83
	Cancer	0.76	1.52			
Education with whom	Healthy	1.96	3.46	0.043	0.044	2.75
	Cancer	0.56	1.16			
Education enjoyment	Healthy	3.83	5.02	0.016	0.52	4.61
	Cancer	1.26	2.46			
Education satisfaction	Healthy	3.53	4.36	0.008	0.69	4.23
	Cancer	1.06	2.11			

Table 6. Participation in daily life activities-parent version.

	Group	Mean	S.D.	*P*-value	95% CI	
					Lower	Upper
Work diversity	Healthy	0.8	0.48	0.006	0.11	0.62
	Cancer	0.43	0.50			
Work intensity	Healthy	4.50	2.80	0.001	1.12	3.94
	Cancer	1.96	2.64			
Work enjoyment	Healthy	2.70	1.95	0.004	0.47	2.32
	Cancer	1.30	1.62			
Work satisfaction	Healthy	2.63	1.84	0.002	0.57	2.29
	Cancer	1.20	1.47			
Sleep with whom	Healthy	3.13	1.50	0.024	-1.74	-0.12
	Cancer	4.06	1.61			
Total diversity	Healthy	5.45	1.40	0.001	0.50	1.85
	Cancer	4.27	1.17			
Total intensity	Healthy	23.42	4.97	0.000	3.16	8.12
	Cancer	17.78	4.62			
Total with whom	Healthy	10.26	3.50	0.001	1.15	4.25
	Cancer	7.55	2.36			
Total enjoyment	Healthy	21.02	6.72	0.002	1.78	7.89
	Cancer	16.18	4.95			
Total satisfaction	Healthy	19.35	5.55	0.000	3.05	8.20
	Cancer	13.72	4.32			

ADL: Activities of daily living; IADL: Instrumental activities of daily living

performing meaningful activities in hospital sectors. They mentioned educational and recreational needs, interaction with personnel, and hospitalization environment facilities as priorities. Changes in these cases could lead to performance exclusion, and affect health and quality of life.[4] Demers et al. investigated daily life activities of children with brain tumor histories and reported that these children had lower performance levels in daily life activities compared to healthy children. The performance levels of these children had a positive correlation with health-related quality of life.[27] Ness et al. also reported more functional limitations in self-care and engaged in life routines (housework), school, and the workplace in childhood cancer survivors compared to their healthy siblings.[28]

Specific investigation of the ADL areas showed no significant difference in the with whom they participated and enjoyment criteria in the child form and in the enjoyment, with whom they participated, and satisfaction criteria in the parent form. In the IADL area, no significant difference existed in the criterion "with whom" in the child form and criterion of "enjoyment" in the parent form. Though diversity and intensity in IADL and ADL were reported to be lower in children with cancer compared to the healthy group, it seemed that children with cancer enjoyed daily activities just as their healthy peers did, and accepted help from others in performing them. Although there was no significant difference observed between both groups in the with whom they participated at ADL (parent form) criterion, the mean of the cancer group was higher than the healthy group. Batra et al. also reported that quality of life and play activities of children with cancer as lower than those of their healthy peers. In this study, self-care and pain had the greatest influence. A follow-up with these children after four months after treatment stopped showed no significant improvement in quality of life for them.[29]

Except for the criterion intensity, we observed no significant difference in the sleep/rest areas in children with cancer compared to the healthy group. Considering these results, this area had the least changes in daily life activities. It seemed that, despite the greater need for sleep and rest in these children, probably because of limitations in

daily activities and physical performance these criteria did not show many changes. In the with whom they participated at sleep (child form) criterion, despite the lack of significant difference, the cancer group had a higher mean score than the healthy group. This difference was probably due to the special conditions of these children. Parents preferred to be with them during sleep and rest, and had more supervision over them. Orseyet al. investigated the sleep patterns of children with cancer and their relationship with physical activities. They observed reduced quality and quantity of sleep in these children. Sleeping patterns in these children had a direct relationship to their physical activities.[30] In support of these findings, we observed no significant differences in all criteria related to sleep/rest (except for "with whom") in the parent version. However, the mean score for all sleep/rest area criteria in the parent form of the children with cancer was higher compared to parents of the healthy group.

In the with whom they participated at work (parent form) criterion there was no significant difference observed between the two groups. Considering that children with cancer generally have limited or no school activities and homework, parents probably attempted to compensate for education of their children with more intervention and help. Sunget al. studied quality of life in children with acute lymphoblastic leukemia and reported lower total quality of life in these children compared to the society's norm. Physical, emotional, social, and school functions of these children were reported to be two standard deviations below the society's norm.[16] Studies by Kyung et al. also supported a deficiency in performing daily life activities and significant reduction in school performance in children with brain tumors.[26]

Limitations of this research include the small sample size and lack of follow-up for the results during different phases of treatment and recovery. The use of more functional tools in assessing participation in daily life activities can provide better, more accurate results. Although school activities in children with cancer become limited or, in some cases cease, investigation of participation in educational areas and school can be useful.

Conclusion

Participation in daily life activities is necessary for development of physical, emotional, psychological, and social skills and to promote quality of life, whether in normal, sick, or disabled children. Findings of the current research have shown that diagnosis and treatment, as well as multiple and prolonged hospitalizations influence participation in daily activities by these children. Considering the significance of these activities, understanding the pattern of participation can help medical, rehabilitation, and other experts for treatment planning and follow-up, and prevention of secondary problems after recovery and treatment cessation.

Conflict of Interest

No conflict of interest is declared.

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