Original Article

Determining, Ranking and Comparing Treatment Stressors in Children and Adolescents with Cancer in Tehran

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Abstract

Background: Studies show that cancer treatment procedures could increase stress in children and adolescents diagnosed with cancer. This study was conducted to determine the frequency of stressors in children and adolescents with cancer, and to compare it in boys and girls.

Methods: Relevant information was collected via a structured interview with 70 children and their mothers. Subjects were divided into four age groups of 0-3; 4-7; 8-12; 13-18. Stressors in physical, social and psychological aspects were determined and ranked. The main question asked was: "During the period of your disease, what has caused you the most suffering?" Whilst interviewing the mothers, this question was altered to:" During the period of your child's disease, what caused him/her to suffer the most?" The answers were reflected back to the respondents, and were categorized in a validated check list after their confirmation.

Results: The most stressing items in the 0 to 3 age group were found to be worry, pain due to treatment procedures, and separation from their immediate family. In 4 to 7 age group, they were procedural pain, worry and fatigue. For the 8 to 12 age group, pain, separation from family and worry were the most stressing items. For the 13 to 18 age group, the main stressors were worry, pain, and parting from friends and losing them. Analysis by "Mann-Whitney U test" showed no significant differences in stressors between girls and boys.

Conclusion: Our findings revealed that worry and procedural pain are the most common stressors in children treated for malignancy. Caregivers need to be aware of this fact and should take appropriate steps to relieve these stressors.

Keywords: Child; Adolescence; Cancer; Psychology

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Introduction

It is a known fact that cancer in childhood is a stressful, traumatic and painful experience that unfortunately some children have to confront [1]. A research published in 1997 shows that the problems cancerous children and their parents face after cancer diagnoses are much more compared with the problems that ordinary children and parents experience. However, this difference in the amount of problems decreases one year after diagnosis along with establishing the treatment procedure [2]. Other researches show that for children with cancer, the treatment procedures and experiences in that period are more traumatic and painful than cancer itself [3].

Hence, to categorize the problems of children with cancer, 3 aspects may be considered: problems due to medical and diagnosis procedures, treatment procedures, and adapting with the disease [4].

In Ensker et al. research, six categories regarding influencing factors on the children's life situation were found: (1) medical treatment and side effects; (2) isolation and being left behind; (3) togetherness and support; (4) being in the center; (5) feelings and reactions; and (6) quality of care. About half of the variables on the list of problems were mentioned in 1 or more of the 10 interviews [5].

Table 1. Ranking of Stressors in 4 Group Ages by Fridman Test

Category	0 to 3 years		4 to 7 years		8 to 12 years		13 to 18 years	
	ranking	precedence	ranking	precedence	ranking	precedence	ranking	precedence
Pain due to treatment procedures	22.15	2nd	21.98	1st	22.15	1st	19.44	2nd
Nausea	15.09	5th	14.02	7th	16.80	5th	15.75	8th
Fatigue	17.65	4th	17.58	3rd	14.70	8th	12.06	12th
Vertigo	10.50	16th	10.54	17th	10.00	19th	11.00	14th
Mouth sores	11.21	12th	11.60	14th	10.35	17th	9.19	17th
Lack of appetite	14.82	6th	14.96	6th	13.75	9th	17.19	4th
Drowsiness	10.94	14th	10.80	16th	10.30	18th	9.19	17th
Pain from disease such backache	13.12	9th	12.98	8th	10.60	16th	11.94	13th
Getting separated from friends and losing them	11.88	11th	12.20	11th	17.75	4th	19.13	3rd
Getting separated from family	18.47	3rd	17.28	4th	19.53	2nd	15.88	7th
Falling behind from education	10.50	16th	10.54	17th	12.40	11th	15.63	9th
Casted out by peers	10.91	15th	10.80	16th	11.05	13th	14.38	10th
Fight with other patients	10.50	16th	12.26	10th	10.35	17th	8.81	18th
Worry	22.82	1st	21.28	2nd	18.48	3rd	20.25	1st
Worry about death	10.50	16th	11.30	15th	10.00	19th	9.75	16th
Suffering from changed appearance	13.82	7th	15.30	5th	14.83	7th	16.75	6th
Feeling of alienation	10.50	16th	10.54	17th	10.35	17th	10.75	15th
Being the center of attention	10.50	16th	10.54	17th	10.73	14th	11.94	13th
Guilt feeling	10.50	16th	10.54	17th	12.68	10th	16.88	5th
Losing trust in others	11.06	13th	11.78	12th	10.00	19th	9.75	16th
Hopelessness	10.50	16th	10.54	17th	11.98	12th	9.75	16th
Worrying about financial items	10.50	16th	10.54	17th	10.00	19th	13.19	11th
Distress due to alteration of life	10.50	16th	10.54	17th	10.70	15th	8.81	18th
Lack of entertainment and boredom	12.76	10th	12.80	9th	14.85	6th	8.81	18th
Limitations caused by the disease	13.29	8th	11.76	13th	10.70	15th	8.81	18th

Based on the Colins et al. study, the most common symptoms were: lack of energy, pain, drowsiness, nausea, cough and lack of appetite, as well as psychological symptoms such as sadness, nervousness, worry and irritability [6].

Kuppenheimer and Brown found that before starting the treatment procedures, during and after it, children experience and demonstrate severe phobia and anxiety [7].

Stegenga and Ward-Smith conducted a research and found that children experience problems mainly in six themes: (1) the stunning loss of normalcy, (2) gaining information, (3) the importance of friends and their reactions, (4) getting used to cancer, (5) giving back, and (6) family support [8].

In another research, losing hair and missing leisure activities were identified as the most prevalent aspects of distress. Worry about not getting well, nausea, pain from procedures and treatments, and worry about missing school were rated as the overall worst aspects by most adolescents. Conclusively, 12% reached the cut-off score for potential clinical anxiety, and 21% for potential clinical depression [9].

Regarding fatigue during illness and treatment, several different researches have been conducted and confirmed that this subject is one of the most customary problems of children with cancer. Although complaining about fatigue has increased during recent years, unfortunately the exact process of fatigue generation is not known [10].

A number of studies suggest that youth diagnosed with cancer are at increased risk for a variety of psychosocial adjustment problems including poor self-esteem, poor self-satisfaction, less ambitious ideals, death anxiety, depression, poor social skills, school reintegration problems, and school phobia [11].

A recent research in Iran shows that 29.9% of adolescences with cancer suffer from depression, with no significant differences between girls and boys [12].

One of the most interesting researches about problems and complaints of children with cancer have been conducted by Hedstrom et al. in 2003. In this research, data were gathered through interviews with 50 children, 65 parents, and 118 nurses. Data were analyzed by content analysis. The most frequently mentioned aspects of distress referred to the physical dimension: pain resulting from diagnostic procedures and treatments, nausea, and fatigue. The most frequently mentioned physical aspect of distress for children 0 to 3, 4 to 7, and 8 to 12 years of age, was pain resulting from diagnostic procedures and treatments; and for children ≥13 years of age, it was nausea. The most frequently mentioned aspects of distress referred to the emotional aspects which were categorized as confinement, feeling of alienation, and worry before medical procedures. The most frequently mentioned emotional aspect of distress for 0 to 3 year-old children was confinement; for 4 to 7 year-olds it was feeling of alienation; it was worry about death for 8 to 12 year-old children; and changed appearance for ≥13 years of age children. For children 0 to 3, 4 to 7, and ≥13 years of age, aspects of distress of a physical character were mentioned most frequently. For children 8 to 12 years of age, aspects of distress of an emotional character were mentioned most frequently [6].

In this study, the aim was to obtain accurate data on the problems children with cancer face in Iran; and to find the exact answer to the question of "what has caused the child with cancer the most amount of suffering during the disease period".

Materials and Methods

In this research, we have studied stressors in children and adolescents with cancer who referred to Mofid Hospital, Shohada Hospital, and Markaze Teby Kodakan during July 2010 to April 2011.

The chosen samples were either available or volunteer subjects.

The main technique for data collection was direct interview. During our study, 70 children and adolescents were interviewed, and subdivided into four age groups: 17 subjects in the 0 to 3 age group, 25 in the 4 to 7age group, 20 subjects in the 8 to 12 age group, and 8 subjects in the 13 to 18 age group.

The interview in each age group was designed according to their condition. For example, for the 0 to 3 age group, the interview was conducted with their parents. In each interview, after verbalizing the problems by the patient or her/his parents, the researcher summarized and reflected the data back to the subject to ensure that the concept had been understood and conveyed properly. The resulting data were thereafter entered into a checklist.

The checklist used in this study was designed by the researcher based on available literature and the other similar researches. In the first step, this checklist was re-examined during a pilot study and was partially changed, mainly by adding some new items. In the second step, the content-validity of the checklist was checked and confirmed by 2 specialists who are faculty members of Shahid Beheshti University. This modified checklist was used in the main body of the study without any further changes.

Moreover, Additional data including age, sex, etc. were collected and recorded.

The analysis was carried out in two parts: In the first part the ranking of stressors were determined

Table 2. Mann-Whitney U Test Results Regarding Differences in Physical Stressors between Cancerous Boys and Girls under Age 18

Gender	Number	Ranking Average	Ranking Sum
girl	34	34.53	1174.00
Boy	36	36.42	1311.00
Total	70		
Asymp Sig 2 Tailed: 0.05	Z: -0.390	Wilcoxon W: 1174.00	Mann-Whitney U test: 579.00

Table 3. Mann-Whitney U Test Results Regarding Differences in Social Stressors between Cancerous Boys and Girls under Age 18

Gender	Number	Ranking Average	Ranking Sum
girl	34	34,44	1171,00
Boy	36	36,55	1314,00
Total	70		
Asymp Sig 2 Tailed: 0.05	Z: -0.434	Wilcoxon W: 1171.00	Mann-Whitney U test: 576.00

Table 4. Mann-Whitney U Test Results Regarding Differences in Psychological Stressors between Cancerous Boys and Girls under Age 18

Gender	Number	Ranking Average	Ranking Sum
girl	34	36,78	1250,50
Boy	36	34,29	1234,50
Total	70		
Asymp Sig 2 Tailed: 0.05	Z: -0.516	Wilcoxon W: 1234.500	Mann-Whitney U test: 568.500

according to "Fridman test". The results of the first part are shown in table 1.

In the second part, "Mann-Whitney U test" was employed to investigate whether there are any significant differences between girls and boys. The "Mann-Whitney U test" was conducted based on the frequency of each stressor for the patients according to their answers. The results of this part are shown in Tables 2, 3 and 4.

Results

In this study, it was found that the most frequently mentioned stressors for 0 to 3 year -old children were 'hospital fear', 'pain due to treatment procedures', ' being separated from family', 'fatigue' and ' nausea'. For 4 to 7 year- old children, they were 'pain due to treatment procedures', 'worry', 'fatigue', ' getting separated from family' and 'suffering from changed appearance'. For 8 to 12 year-olds, they were 'pain due to treatment procedures', 'getting separated from family', 'worry', ' being separated from friends and losing them' , and ' nausea'. For 13 to 18 year-old children, they were 'worry', 'pain due to treatment procedures', 'being separated from friends and losing them', ' lack of appetite' and 'sense of guilt'.

After "Mann-Whitney U test", it was observed that there are no significant differences in stressors between girls and boys in the three aspects of physical, social, and psychological.

Discussion

Comparison of results between this test and similar tests conducted by other researchers leads to interesting results.

First, in the study conducted by Hedstrom et al. it was found that psychological factors play a more significant role than physical factors in 8 to 12 year-old children [6]. However, this study shows that the first concern is the pain resulted from the treatment procedure in this age group; hence physical factors are of prime importance. Some points were mentioned regarding this difference beforehand such as treatment systems in which children are cured, and the amount of importance each of these systems give to the child's pain experience.

The second issue encompasses the age group of 13 to 18 which fall in the adolescent category. According to the report on the adolescents in

Hedstrom et al.'s research, physical problems especially nausea were the prominent concern in this group followed by appearance changes. It was previously mentioned that in Hedstrom interview with nurses it was demonstrated that they had expected psychological factors to be more important for the adolescents based on the argument that since the members of this age group are aware of their disease, they must be more distressed by it. However, eventually what had been observed was different from what the nurses expected [6]. Nevertheless, this study revealed that worry and fear from hospital, pain due to treatment procedure, separation from friends and losing them, loss of appetite, and sense of guilt for causing trouble for their parents, were the first five stressors in this age group. This question may be raised that what has caused the difference?

The first point to be kept in mind is the small number of subjects in this age group. The amount of interviews in this group was the least compared to others, and was limited to eight interviews. Keeping this in mind, it seems that interpretations of results needed more caution.

Yet even in this small number of subjects, it was observed that the subjects were mainly uncomfortable with answering questions in the presence of their parents and accompanying relatives, while revealing more worry and discomfort when alone. This issue is important since it seems that the adolescents subject to the interview have a slight familiarity with management techniques for stress and negative agitation, hence finding concealment from others especially their parents to be the only way out. Also, it should be kept in mind that one of main five stressors of this group is the sense of guilt due to causing difficulty for others; a factor which could justify the concealment of their worry and concern.

Another important issue to be taken into account is the loss of appetite. The significance of this factor is highlighted since it does not exist in the five main factors of any other age groups. It should be noted that the change of appetite during the adolescence is seen in healthy young people too, which may be related to their level of worry. Solid judgment regarding this argument requires a more thorough investigation.

According to the results extracted from "Mann-Whitney U test" conducted on two different age groups of boys and girls and in three aspects, it was observed that no major distinction of stressors exists between the two groups. This comparison was made since previous studies claimed that girls are psychologically more vulnerable than boys [13]. This was not a result confirmed by the current study. It is noteworthy to mention some points in this regard. The first point is the number of girls and boys who participated in this research. If the number of boys and girls increases, then the results would change. The second point is the importance of the item of pain due to treatment procedures. In the 0 to 3 age group, this item is the most important compared to the other groups. The importance of this item may affect the other items and decrease their importance for patients during the interview. The third point is the concept of 'more vulnerable'. If another study had been conducted using the longitudinal method, then the study findings would have shown that the effect of stress could follow in girls more than boys in the long run. However, as this aspect was neglected in this study, we cannot draw any certain conclusions in this regard.

About the finding of this study, we refer to the discovery of an Iranian research published in 2011. It shows that 29.9 % of adolescents with cancer suffered from depression, and no significant differences were found between girls and boys [14]. Based on this result, we could state that Sanderberg et al. finding may not be inferable in Iran.

Conclusion

The findings of this study revealed that worry and procedural pain are the most common stressors in children treated for malignancy. Caregivers should be aware of this fact and take appropriate steps to relieve these stressors. The significant importance of "pain" as a stressor in children and adolescents with cancer, which was shown in this research, in comparison with similar researches in western countries, may be due to less importance the medical staffs give to the patient's pain experience in Tehran. It seems that by changing the view of the medical staff and improvement of facilities, changes in this area might be achievable.

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Conflicts of Interest

The authors have no conflicts of interest.

Authors' Contribution

Narges Azizi designed the study, gathered and analyzed the data and wrote the paper. Ladan Mansour and Karineh Tahmassian contributed to study design and analysis. Farideh Mousavi contributed to data collection.

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