

EFFECTS OF CHILDHOOD MALIGNANCY TREATMENT ON QUALITY OF LIFE: PRELIMINARY RESULTS OF THE QOLOP PROJECT

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Scope of the problem

Due to remarkable advances in the treatment of cancer in children and adolescents about 80% of patients reach long-term remissions today (Ries et al., 2007) as compared with less than 30% of childhood cancer survivors in 1960s. This population of children and young adults who were previously treated for childhood malignancy requires specialized care. Enhancing chances of survival of diseases that were previously considered as incurable is one of the greatest achievements of modern medicine. Expectations of both professional and lay public in the field of pediatric oncology shifted from the focus on quality palliative and symptomatic therapy to anticipation that the child will be cured and live to adult age. Therefore, *quality of life* comes into focus today. The new paradigm that defines success rate of contemporary oncological treatment of childhood malignancy is not to achieve only survival, but also *balance* between anti-cancer activity and toxicity, or late adverse effect of the therapy (Oeffinger, Robinson, 2007).

Two thirds of childhood cancer survivors suffer from at least one chronic health problem, approximately half of which are serious or even life-threatening conditions (Geenen et al., 2007, Oeffinger et al., 2006, Mladosičevičová, Kaiserová, Foltinová 2007). Only one third of survivors have no health problems. The most common health problems of patients who underwent childhood malignancy treatment are psychosocial and cognitive disorders that affect up to 40% childhood cancer survivors (Geenen et al., 2007). Understanding of these problems and adequate interventions can significantly enhance quality of life of patients.

Patients' awareness about the therapy and its possible long-term risks is usually poor (Oeffinger, Robinson, 2007, Kreitler, Ben Arush, 2004). However, many late effects can occur long after the therapy was finished (even after decades). The aim of

centers of comprehensive oncological care is therefore enhancement of awareness about the incidence of late effects of the therapy.

The “Qolop” Project (*Quality of Life Longitudinal Study of Oncology Pediatric Patients*)

The “qolop“ project is a prospective longitudinal quality of life study of oncology pediatric patients, commenced in Brno in autumn 2006 (www.qolop.eu). The research is conducted by the Pediatric Oncology Clinic at the Children’s Hospital, FN Brno, in collaboration with the Institute of Psychology of the Academy of Sciences of the Czech Republic (ASCR) and the Institute of Psychology at the Faculty of Arts, Masaryk University (FF MU).

The main purpose of the project is to identify the areas of reduced quality of life in children with cancer, including both the objective indicators (mobility, function of sense organs, social involvement), and the subjective well-being (emotional experience, life satisfaction). The identification has been based on the comparison between the children with cancer, the healthy population and the children with chronic non-cancerous disease. In the longitudinal perspective, the collected data will be used for the study of the treatment’s late effects and identification of significant antecedents of the quality of life in adulthood.

Children aged 8 – 18, two to five years in the remission period at the time of examination, enter the study on a continuous basis. In April 2008, when this study was in its preparatory stage, 73 cancer survivors, 263 clinically healthy elementary school children and 30 chronically diseased children were examined. For more details see the project’s website www.qolop.eu or a survey study designed by Blatný et al. (2007).

Goal of the study

For now, control sample of elementary school children is available only. Therefore only data from 37 cancer survivors falling into this age category can be analyzed. Considering the sample size, we decided to compare only significant life domains of cancer survivors and healthy children. Particularly, the study focused on conventional involvement, parent-child interactions, depressiveness and satisfaction with individual life domains.

Method

Sample

The sample consisted of 37 childhood cancer survivors aged 8 to 14 who had been in the remission for 2 to 5 years at the time of examination. Analyses were done for the entire sample and then separately for age category of 8 to 12 year (27 persons, 10 boys / 17 girls) and 13 to 14 years (10 persons, 6 boys / 4 girls). Out of 263 healthy children, pupils of elementary schools in Brno, a control group of children was created with adequate age and gender characteristics.

Methods

Degree of involvement in after-school activities was determined using a Conventional Involvement scale from SAHA questionnaire (Weissberg, 1991). Frequency of individual activities is ranked by children on a 5-point scale (“How many times a week?” 0x, 1x, 2-3x, 4-5x, 6-7x; scale range is 0-4), overall involvement in after-school and leisure activities is expressed by means of an average score.

Relationships between children and parents (parenting aspects) were determined by Parent-child interactions scale taken again from SAHA questionnaire that focuses on the following four parenting aspects: parental involvement, warmth, control and inconsistency of parenting. Children evaluated behavior of their parents on a 4-point scale (never – rarely – sometimes – often; 1-4). Degree of individual parenting aspects is again expressed by an average score.

Degree of depressiveness was measured by means of The Children’s Depression Inventory (CDI; Kovacs, 1992). The inventory consists of 27 items, each of them is divided to three options that should express seriousness of depressiveness symptoms (1-3). Children chose options that best corresponded with their feelings. Although the inventory has five sub-scales (Negative Mood, Interpersonal Problems, Ineffectiveness, Anhedonia, Negative Self-Esteem), we worked only with overall degree of depressiveness that is expressed by an average score.

Personal value of individual life domains and well-being in these domains were identified by the SQUALA method (Dragomirecká et al., 2006) that was modified to suit childhood age and extended to include items concerning life domains that could be affected by the consequences of the therapy (e.g. physical self-sufficiency). The questionnaire covers 30 life domains in total, both material (toys, home environment) and psychosocial (friendship, fairness). Children use a 5-point scale to define the importance of individual domains for them and then assess their satisfaction with these domains. This method is used above all to monitor changes of sources of well-being over time.

Differences between healthy and diseased children in the monitored characteristics were analyzed by nonparametric Mann-Whitney test.

Results

Descriptive statistics describing involvement in after-school activities, depressiveness degree and parenting aspects, and statistics identifying differences between the groups are demonstrated in Table 1. The results of test for modified SQUALA are described only verbally due to a large number of scales and relatively small number of significant differences.

		Group	All		8-12 years		13-14 years	
			m(SD)/median	U	m(SD)/median	U	m(SD)/median	U
Conventional Involvement		Onco	0.58(0.40)/0.50	1898.0	0.60(0.42)/0.50	893.5*	0.53(0.35)/0.50	182.5
		Contr	0.73(0.47)/0.67		0.80(0.48)/0.83		0.56(0.39)/0.50	
Depressiveness		Onco	1.30(0.21)/1.26	1902.0*	1.34(0.22)/1.30	1203.5	1.18(0.13)/1.19	67.0**
		Contr	1.44(0.30)/1.41		1.43(0.32)/1.37		1.46(0.27)/1.41	
Parenting	Involv.	Onco	3.02(0.54)/3.17	2356.0	3.06(0.50)/3.17	1236.0	2.92(0.66)/3.08	185.5
		Contr	2.87(0.64)/2.83		2.88(0.68)/2.83		2.84(0.54)/2.75	
	Warmth	Onco	3.62(0.38)/3.60	2226.5	3.67(0.36)/3.60	1150.5	3.51(0.43)/3.50	170.0
		Contr	3.39(0.62)/3.60		3.41(0.64)/3.60		3.33(0.59)/3.40	
	Control	Onco	2.84(0.60)/2.86	2517.0	2.81(0.62)/2.75	1226.0	2.93(0.54)/2.94	171.0
		Contr	2.90(0.66)/2.88		2.94(0.68)/3.00		2.76(0.59)/2.87	
	Incons.	Onco	2.14(0.71)/2.20	2243.0	2.14(0.78)/2.00	1209.0	2.16(0.49)/2.30	147.5
		Contr	2,33(0,68)/2,40		2,29(0,68)/2,40		2,42(0,69)/2,60	

* $P < 0.05$; ** $P < 0.01$

Table 1: Healthy children (Cotr) vs. children with cancer (Onco)

Childhood cancer survivors involve less in social activities (after-school, leisure time) than children from control group. This result was significant in 8 to 12 years age category. Childhood cancer survivors show significantly lower degree of depressiveness than children from control group – significant difference was found in 13 to 14 years age category. No significant differences were observed between cancer survivors and control group in self-perception of child-parent interaction.

As far as the importance of individual life domains is concerned, cancer survivors gave more weight to values “to have leisure time activities” (children aged 13 to 14) and “to be able to go to school” (children aged 8 to 12 years), and are more satisfied with their health and belief (8 to 12 years), ability to attend school (8 to 12 years) and their own appearance, as compared with children from control group.

Discussion

Lower involvement of childhood cancer survivors in social activities is no surprise, as it can be caused by (1) the effects of the therapy itself such as increased fatigability or higher sickness rate, (2) weakened social competencies due to a long-term isolation from peers and lack of contact with people under normal living conditions or, importantly, (3) increased protectiveness by parents who worry about their child’s health.

No significant differences between cancer survivors and control group were found in the children’s view on the quality of parent-child interaction. This result can be interpreted as the positive finding that parents of cancer survivors do not tend to consider their children as sick patients. The abovementioned protectiveness is probably limited to domains where increased control of behavior and certain forethought can be only useful.

The finding that childhood cancer survivors show less depressiveness symptoms than children from control group was rather unexpected. However, it is almost sure

that this result was not accidental, as it was observed also in our previous study on the effect of chemotherapy on cognitive function in children and adolescents (Neurocognitive functioning in children cancer survivors, Czech Science Foundation – GACR, No. 406/05/0603, 2006-2008) where cancer survivors showed lower degree of depressiveness as compared with general population.

There are several explanations of this result that will have to be further investigated in future studies. First, exceptional life experience associated with anti-cancer therapy could strengthen children's psychological hardiness. Second, criteria of perception of mental strain in childhood cancer survivors have changed, which means that what other children see as stressful situation causing negative reactions, cancer survivors perceive as non-stressful circumstances. Third, it could be the act of dissimulation: children fear that the disease could recur, so they suppress potential negative signals such as mood swings, anhedonia, fatigability etc. Fourth, cancer survivors can be on antidepressants which are indicated in certain diagnoses as part of anti-cancer therapy. Although they are gradually discontinued (six months after the therapy at the latest), some children can go on using antidepressants prescribed by their pediatrician.

As far as the importance of individual life domains is concerned, cancer survivors gave more weight to values "to have leisure time activities" (group of children aged 13 to 14 years) and "to be able to go to school" (8 to 12 years). Here, specific experience of children who were isolated from normal life for a long time is clearly reflected, as they emphasize values that can seem normal (ordinary, everyday) to healthy children. Cancer survivors were also more satisfied with individual life domains, namely their health and belief (8 to 12 years), ability to attend school (8 to 12 years) and their own appearance, as compared with children from control group. Higher well-being in these domains can be interpreted as the contrast to the experience of disease.

Conclusion

Differences in self-perceived quality of life between childhood cancer survivors and healthy population reflect specific experience of children treated for an oncological disease: cancer survivors less involve in social activities (hobbies, leisure time) than children from control group, give more weight to values "to have leisure time activities" and "to be able to go to school", and are also more satisfied with their health, belief and ability to attend school. No significant differences were observed between cancer survivors and control group in self-perception of child-parent interaction.

The only unexpected finding was that childhood cancer survivors show less depressiveness symptoms than children from control group. Several explanations are suggested: strengthened psychic hardiness of cancer survivors, changed criteria for perception of strain, dissimulation (fear of the disease relapse) or taking antidepressants. However, these explanations require further research.

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