

Effects of childhood malignancy treatment on quality of life: Preliminary results of the QOLOP project

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Abstract

The most common health problems of patients who underwent childhood malignancy treatment are psychosocial and cognitive disorders. The project QOLOP (Quality of Life Longitudinal Study of Pediatric Oncology Patients) is a prospective longitudinal study whose purpose is to identify areas of reduced quality of life in children with cancer, including both objective indicators (mobility, function of sense organs, social involvement), and subjective well-being (emotional experience, life satisfaction).

This study analyzes data from 49 childhood cancer survivors aged 8 to 14 years that were compared with data obtained from control group, pupils of elementary schools in Brno, Czech Republic. The study focused on the following four life domains: conventional involvement, parent-child interactions, depressiveness and self-perceived quality of life. Compared to children from control group, childhood cancer survivors showed lower involvement in social activities, lower degree of depressiveness and higher satisfaction with their health, belief, appearance and ability to attend school. No differences between child-parent interactions were found between the groups. Certain results were unexpected (such as lower depressiveness in cancer survivors) and are discussed in detail.

Keywords: cancer, quality of life, childhood

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, Mladosičová, 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 July 2008, when this study was in its preparatory stage, 100 cancer survivors, 233 clinically healthy elementary school children and 155 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 49 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 overall life satisfaction.

METHODS

Sample

The sample consisted of 49 (27 girls / 22 boys) 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 (34 persons, 21 boys / 13 girls) and 13 to 14 years (15 persons, 6 boys / 9 girls). Out of 233 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.

General life satisfaction we measured with Life Satisfaction Scale from the The Minneapolis-Manchester Quality of Life Instrument (Bhatia et al., 2002, Bhatia et al., 2004), which were constructed specially for child cancer survivors.

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.

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

		Group	All		8-12 years		13-14 years	
			m(SD)/median	U	m(SD)/median		m(SD)/median	U
Conventional involvement		Onco	0,53(0,38)/0,50	1275,0*	0,55(0,40)/0,50	526,,5**	0,50(0,34)/0,50	157,0
		Contr	0,78(0,55)/0,67		0,81(0,48)/0,83		0,72(0,67)/0,50	
Depressiveness		Onco	1,29(0,21)/1,27	1413,5**	1,34(0,21)/1,33	852,5	1,19(0,14)/1,14	65,0**
		Contr	1,44(0,29)/1,37		1,40(0,28)/1,37		1,50(0,29)/1,44	
Parenting	Involv.	Onco	3,02(0,53)/3,00	1777,5	3,07(0,48)/3,08	924,5	2,90(0,64)/3,00	148,5
		Contr	2,89(0,68)/2,83		3,01(0,69)/3,08		2,63(0,60)/2,50	
	Warmth	Onco	3,61(0,39)/3,60	1574,0*	3,64(0,35)/3,60	853,0	3,54(0,46)/3,80	108,0*
		Contr	3,37(0,60)/3,60		3,49(0,55)/3,60		3,10(0,61)/3,20	
	Control	Onco	2,75(0,61)/2,63	1623,5	2,77(0,59)/2,63	703,5*	2,72(0,67)/2,75	184,5
		Contr	2,93(0,65)/3,00		3,03(0,64)/3,06		2,70(0,61)/2,75	
	Incons.	Onco	2,15(0,70)/2,20	1628,0	2,18(0,78)/2,10	837,0	2,08(0,51)/2,20	116,0*
		Contr	2,35(0,68)/2,40		2,30(0,68)/2,40		2,45(0,66)/2,60	
Life satisfaction		Onco	-	-	1,72(0,55)/1,67	910,0	2,03(0,62)/2,10	143,0
		Contr	-		1,76(0,50)/1,67		2,38(0,81)/2,40	

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

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. As concerns the quality of parent-child interactions, in the younger group parents exercise less control over cancer survivors, in the older group cancer survivors report higher parental warmth and consistency of parenting than their peers. No significant differences were observed between cancer survivors and control group in general life satisfaction.

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.

As concerns the quality of parent-child interactions, the results for both age groups differ to such a degree that we are going to comment on them separately. In the younger group we have not observed any substantial differences between cancer survivors and healthy children – with the exception of parental control: parents exercise less control over cancer survivors. This conclusion is seemingly paradoxical, however, it may be explained by the previous finding – cancer survivors have less outdoor activities and therefore they do not need to be controlled by their parents so much (e.g. with whom they socialize, whether they are at home in time etc.). In the older group cancer survivors report higher parental warmth and consistency of parenting than their peers. At the age of 13 to 14 children already have a tendency to break free from their parents. Higher parental warmth as well as consistency of parenting may be considered an expression of the parents' increased concern for their sick child.

The most interesting observation concerns the level of depressiveness – in the younger age bracket, there is no difference between cancer survivors and the control group, and in the older age bracket the degree of depressive symptoms self-reported by cancer survivors is statistically even significantly lower than that of the healthy population. Moreover we have observed this finding repeatedly. We arrived at the same conclusion in our previous project devoted to the impact of chemotherapy on cognitive function in childhood cancer patients (Neurocognitive functioning in children cancer survivors, Czech Science Foundation – GACR, No. 406/05/0603, 2006-2008).

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 in the paediatric oncology center, usually within half-a-year after the cancer treatment, some children

can go on using antidepressants prescribed by their pediatrician. In any case, these explanations require further research.

Finally, as regards overall life satisfaction, we have not found any difference between cancer survivors and the control group.

Conclusion

The sequelae of the treatment reflect in the life of former patients but, as emerges from the results, the effect is not very strong or serious. This fact is supported with the results which show no significant differences in general life satisfaction. The childhood cancer survivors are less involved in social and after-school activities but they show better quality of parent-child relationships (warmth and consistency of parenting). This testifies that the disease does not have to decrease the quality of life only, but can also lead to some benefits.

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

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