

Mental Pain in Israeli Adult Childhood Cancer Survivors and Its Effects on their Quality of Life

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Abstract

The objectives were to study the mental pain of adult pediatric cancer survivors. In view of the findings that despite the fact that pediatric cancer survivors were found to be fairly well adapted there are contrary indications and even evidence for suicide ideation in these survivors. The hypotheses were that pediatric cancer survivors would manifest enhanced mental pain at present, report high levels of mental pain in the past and that the mental pain scores would be related negatively with their quality of life. The participants were 91 pediatric cancer survivors of both genders, whose mean age at diagnosis was 12 years and mean current age was 26 years, 13 years on the average since the end of treatment. They were administered the mental pain questionnaire concerning the present and the past, the questionnaire of mental pain tolerance, and the multidimensional inventory of quality of life. Regression analyses showed that the scales of mental pain predicted significantly quality of life and most of its domains. The major predictors were mental pain at present. The main implication is that interventions designed to reduce mental pain are likely to contribute a lot to improving the quality of life of pediatric cancer survivors.

Keywords: Childhood cancer; Childhood cancer survivors; Mental pain; Mental pain tolerance; Quality of life

Introduction

The purpose of the present study is to examine, most probably for the first time, the incidence of mental pain and mental pain tolerance in adult survivors of childhood cancer and its impact on their quality of life (QOL). Cancer is the second commonest cause of death in children in the Western world. In parallel to the increase in incidence rates since the middle of the last century, also the probability of survival has consistently risen over the past decades and has reached the levels of 81-85% [1-4].

The large and increasing number of survivors of childhood cancer has given impetus to the study of late effects of the disease and its treatments. Endocrinological, cardiological, orthopedic and neurocognitive effects, to mention just a few, have been extensively reported in the literature [5,6]. Medical problems are very frequent among childhood cancer survivors [7] and include even increased risk of early death of 7% at 30 years [8]. In recent years attention of researchers has turned also to the psychological sequelae of the diagnosis and treatment of childhood cancer. There are many reasons to expect psychosocial effects following the disease and treatments. The disease represents a serious emotional shock to children who are unexpectedly exposed to the fear of imminent death, removal from their familiar environment and routine, and necessity to undergo long term treatments, such as chemotherapy, surgery and radiotherapy, often involving pain, stress, anxiety and uncertainty for them and mostly for their parents too. These experiences take their toll and have been reported to cause negative emotions, such as anxiety, depression and anger, as well as behavioral difficulties and deterioration in the children's QOL while the treatments continue [9]. Moreover, even after the successful completion of treatments the need for medical follow-ups and for treatment of different medical side effects may be expected to reinforce the memories of adverse events in the past and enhance the fear of recurrence and other negative possibilities for the future [10,11].

However, the results of studies of the late psychosocial effects of childhood cancer are not unambiguous. Indeed, there are studies reporting that in comparison to regular subjects pediatric cancer

survivors have a lower QOL, lower self-concept [12], more depression, anxiety, pain, and insomnia [13], suffer more from fatigue, emotional symptoms [14], and posttraumatic stress, are less likely to have partners or to be married [15], and tended at least in the past to be more often rejected from work, study and military service institutions [16].

But, on the other hand, a large number of studies reported that in comparison to control subjects from the regular population survivors of pediatric cancer do not manifest more distress [17], do not report more problems except for a minority [18], most of them enjoy good health and wellbeing [19], score high on QOL [20], have a good psychological health and life satisfaction [21], achieve the major standard life goals [22], do not have more aggression, anti-social behaviors and drug abuse [23] and many even reported post traumatic growth [24,25]. The survivors sometimes refer to problems that may bother them concerning for example school or employment but do not cause depression or uncommon stress [22].

It is likely that some of the reasons for the discrepancies in findings may be due to methodological issues, such as differences in the assessment tools; some may be differences in medical variables, such as the precise diagnosis and the kind of administered treatments; some may be demographic, such as the precise age at which the child became sick; and still others may be due to the impact of parents, support and the coping strategies of the children [26].

However, it is also likely that some of the experiential aspects of

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the survivors' distress have not been sufficiently exposed. Notably, many of the studies of survivors focused on behavioral issues, such as studying, alcohol drinking, substance abuse, antisocial behavior, work, marrying, divorcing etc. It is plausible that an individual would perform satisfactorily all these and similar tasks and yet feel distressed.

Considerations of this kind have inspired us to focus on assessing the survivors' mental pain. An additional consideration that there is a lot of evidence about the prevalence of suicide ideation and even suicidal attempts in pediatric cancer survivors [10,27-29]. The discrepancy between the evidence about good QOL and suicidal ideation led to the hypothesis that pediatric cancer survivors may be suffering from mental pain. Notably, mental pain is a construct whose role in regard to suicide has been emphasized from the very beginning [30,31].

Mental pain – which has also been called psychic pain, psychological pain, psychache, emotional pain, spiritual pain or suffering - is a negative emotional experience of psychological origin with existential and spiritual connotations. In contrast to physical pain it is not localized and is not directly related to noxious physical stimuli [32]. It has been described in different forms, such as longing for a beloved one following a traumatic loss [33,34]; a transformation of physical pain in states when the physical ego is weakened (e.g., in dreams, schizophrenia) [35]; an awareness of the disruption of one's sense of wholeness and social unity [36]; a sense of emptiness reflecting loss of meaning in life [37]; self-disappointment due to a discrepancy between one's self image and one's ideal self [38] or between one's low achievements and high aspirations [39]; a negative modification in the image, definition and functioning of the self [40]; a combination of several distressful emotions such as guilt, shame, defeat, humiliation, disgrace, grief, hopelessness, and rage resulting from the frustration of basic needs essential for living, such as to be loved, to have control, to protect one's self-image, and to feel secure [41]; a sense of woundedness, loss of self, loss of control and disconnection from a loved one that culminate in an alarming awareness of "brokenness of the self" [42].

An analysis of the major definitions of mental pain led Meerwijk and Weiss [43] to the conclusion that mental pain is an unpleasant feeling resulting from a negative self-appraisal due to the inability to get or maintain something linked to one's basic psychological needs. Mental pain seems to reflect dissatisfaction with oneself as a human being, on the spiritual and existential levels of being. It is reminiscent of Shneidman's [44] conclusion that mental pain concerns "how much you hurt as a human being". Thus, it appears to be an inescapable aspect of human existence related to the three facets of existential anxiety - the anxiety generated by one's awareness of possible non-being, by guilt and self-condemnation for not being what one should have been, and by not being or doing something meaningful [37,45-47].

Mental pain is considered as a unique subjective experience, different from depression and anxiety with which it was found to share some cognitions [40]. Thus, the negative mood associated with mental pain does not justify considering it as a sign of psychopathology. It may however be so strong or the loss of life's meaning may be so complete that escape in the form of suicide may become unavoidable [31,41].

The ability to cope with mental pain has been conceptualized in the form of the construct of mental pain tolerance [31,40]. The three major aspects it assesses are congestion, coping and the ability to contain the mental pain. Low tolerance is assumed to result in attempted suicide [31,40].

Several studies confirmed the relation of mental pain with suicide. Thus, a study with medical patients showed that mental pain actually

predicted suicidality. In a regular sample multiple regression analysis showed that mental pain, especially loss of control, and tolerance for mental pain, especially the ability to contain it, have a significant contribution to suicide risk, independently of depression [48]. In a sample of high-risk students regression analyses showed that at baseline and at follow-up, mental pain was the only unique contributor to the prediction of suicide ideation two years later, in contrast to depression and hopelessness. When examining change over time, change in mental pain was the only factor that added significant unique variance to the prediction of change in suicide ideation [49]. Among a high-risk group, such as homeless men, analyses revealed that mental pain was a stronger predictor of suicide ideation than was depression, hopelessness, or life meaning [50]. An internet survey of 5988 Chinese undergraduates showed that mental pain was an independent predictor of suicide ideation, and even of suicide behavior at the beginning, and that it mediated the relation of life satisfaction to suicide [51].

In sum, the three following major aspects concerning pediatric cancer survivors were considered: first, the difficulties the pediatric cancer survivors have undergone in the course of treatment that would lead one to expect serious psychosocial effects in later life; second, the relative good adjustment and QOL that many of them have attained as survivors; and third, the evidence about the prevalence of suicidal cognitions in many survivors. Thus, it was assumed that in order to get a more comprehensive picture of the psychological situation it is advisable to examine a deeper lying experiential layer. Mental pain is the construct chosen for this purpose, both because it reflects a humanly relevant kind of suffering and because it may be related to suicidal tendencies.

The hypotheses referred to the following assessed variables: mental pain at present, mental pain tolerance at present, mental pain in the past as reported by the subjects retrospectively and QOL at present.

The first hypothesis was that mental pain both at present and in the past would be high (above the median of the response scale). The second hypothesis was that mental pain at present as well as in the past would be related negatively to QOL at present and would function as predictors of QOL. The third hypothesis was that mental pain tolerance would be related negatively to QOL and would function as a predictor of QOL independently of mental pain. All three hypotheses refer to mental pain and QOL in general because the available data do not enable specifying precise predictions concerning the different scales.

Method

Participants

There were 91 subjects (50 men and 41 women), who had been diagnosed in the past with various types of pediatric cancer: Lymphoma 41 (45%), leukemia 21 (23%) and other- 29 (32%). The major inclusion criterion was being an adult (over 18 years old), having completed the treatment protocol and displaying no physical or laboratory evidence of cancer recurrence. During the data collection period (18 months), 236 cancer survivors matched the eligibility criteria, of which 122 agreed to participate, out of which 31 were later excluded from the sample because they did not return the questionnaire at all or returned it only partly filled or refused to sign an informed consent form. Thus, the final response rate was 38%.

The respondents included 92% Israel-born, of which 2% were Arab-Israelis, and 98% were Jewish (78% were by self-report secular Jews, and 19% religious Jews). The majority (71%) were unmarried. Mean age at diagnosis was 12 years (range: 1-23 years) and mean current age

was 26 years (range: 18-43 years). Mean time elapsed since the end of treatment was 13 years (1-38 years).

Tools

The subjects were administered three tools:

(a) A background information questionnaire designed to provide basic demographic and medical data about the subjects (e.g., gender, date of birth, cancer diagnosis in the past);

(b) The scale of mental pain [40] which provides scores about mental pain at present, mental pain in the past (during diagnosis and treatments) and tolerance for mental pain at present. The questionnaire for mental pain at present and in the past differed only in terms of the instructions which referred either to the present or the past. The scale of mental pain includes 45 items, each with 5 response alternatives ('strongly disagree' to 'strongly agree', scored as 1 to 5, respectively). The questionnaire provides scores for the nine following scales: (1) Loss of control: e.g. "I lack of control over what is happening inside me"; (2) Irreversibility of pain: e.g. "Something in my life changed forever"; (3) Emotional flooding: e.g. "There is a storm of emotions in me"; (4) Narcissistic wounds: e.g. "No one is interested in me"; (5) Estrangement: e.g. "It is as if I was not real"; (6) Confusion: e.g. "I cannot concentrate"; (7) Need for social support: e.g. "I need support from my surroundings"; (8) Emptiness: e.g. "I have no desire for anything"; (9) Freezing: e.g. "It's like I'm paralyzed". The overall mental pain score was taken as the mean across all items. The questionnaire had been validated in studies of suicide [48]. The internal reliability scores in the current study were Cronbach $\alpha = 0.96$ for current mental pain and $\alpha = 0.97$ for past mental pain.

The mental pain tolerance section of the questionnaire consisted of 20 items, each rated on the same five-point Likert scale options as the scale of mental pain at present. It provides scores on the three following scales: (1) Congestion—the extent to which the pain occupies a person, the extent to which the person can ignore the pain and concentrate on other things (e.g. "I just cannot stand the pain"); (2) Coping—the long-term capacity to manage the pain, so that when a person feels there is no hope for the pain to stop, and that they cannot act to obtain relief, then the pain experience can be unbearable and devastating (e.g. "I can do nothing to reduce the pain"); and (3) Containment—refers to feeling the pain without having to secure immediate relief in any way possible, including impulsive behaviors, such as attempted suicide (e.g. "I feel I have to get rid of the pain immediately"). A higher score on mental pain tolerance reflected a higher capacity for mental pain tolerance. This section of the questionnaire was validated in studies of suicide [40]. Its internal reliability in the current study was $\alpha = 0.96$.

(c) The Multidimensional Quality of Life Inventory [52]. I have been validated in studies of cancer survivors of different ages and large numbers of healthy subjects [52]. It is regularly used to evaluate the QOL of cancer survivors in follow-up at the medical center hosting the current study. The questionnaire comprises 62 questions answered by checking one of four options, ranging from 1 (the most positive) to 4 (the most negative). The questionnaire provides scores for the following 14 scales: family relations, fun activity, work activity, negative feelings, positive feelings, cognitive functioning, physical functioning, social activity and social relations, body image, sense of mastery and independence, self-esteem, motivation, stress and basic needs. A high score indicates higher QOL. The questionnaire's internal reliability score in previous studies was 0.76-0.90 for the total score and 0.72-0.86 for the subscales [52] and in the current study $\alpha = 0.96$.

Procedure

Participation was offered to all pediatric cancer survivors who met the inclusion criteria, at their routine follow-up visit to the outpatient clinic in a major medical center in Israel, during the data collection period. Subjects were asked to complete the questionnaire while waiting for their routine check-up at the survivors' hematology-oncology clinic. The described recruiting procedure in the course of check-ups corresponds to that commonly applied in studies with pediatric cancer survivors who are known to exercise denial in regard to their past painful experiences [53,54]. The study protocol was approved by the institutional ethics committee.

Results

Table 1 shows the means, Sds and correlations between the total sums of the major variables of the mental pain questionnaire. For mental pain at present the highest scores are in the scales of estrangement and emotional flooding, whereas the lowest are in narcissistic wounds and need for social support. Concerning mental pain in the past, the highest scores are in the scales of confusion and loss of control, the lowest in self-esteem and narcissistic wounds. Notably, mental pain at present is lower than mental pain in the past but the differences are not significant. The score of mental pain tolerance is however higher than the scores of mental pain in the present or the past. Further, mental pain in the

Variables of the study	Present		Past		Cor. Pres. & Past
	Mean	Std. D	Mean	Std. D	
Mental Pain : Loss of control	1.810	0.721	2.837	1.013	0.588***
Mental Pain: Irreversibility of pain	1.855	0.833	2.833	1.053	0.458***
Mental Pain: Emotional flooding	2.230	0.927	3.356	1.085	0.630***
Mental Pain: Narcissistic wounds	1.373	0.678	2.108	1.016	0.492***
Mental Pain: Estrangement	2.917	0.579	2.829	0.948	-0.055
Mental Pain: Confusion	1.864	0.825	2.836	1.098	0.535***
Mental Pain: Need for social support	1.420	0.590	2.103	0.988	0.467***
Mental Pain: Emptiness	1.686	0.872	2.483	1.215	0.426***
Mental Pain: Freezing	1.411	0.827	2.324	1.119	0.501***
Mental Pain: Total score	1.758	0.574	2.480	0.886	0.440***
Mental Pain Tolerance: Congestion	3.683	0.894	--	--	
Mental Pain Tolerance: Coping	3.734	0.738	--	--	
Mental Pain Tolerance: Containment	3.102	1.026	--	--	
Mental Pain Tolerance: Total score	3.618	0.662	--	--	
QOL: Family	3.746	0.343	--	--	
QOL: Fun	3.645	0.758	--	--	
QOL: Work activity	3.399	0.401	--	--	
QOL: Negative feelings	3.368	0.610	--	--	
QOL: Positive feelings	3.620	0.515	--	--	
QOL: Cognitive functioning	3.487	0.414	--	--	
QOL: Physical functioning	3.650	0.380	--	--	
QOL: Social functioning	3.465	0.667	--	--	
QOL: Body image	1.797	0.584	--	--	
QOL: Sense of mastery	3.575	0.402	--	--	
QOL: Self esteem	3.399	0.477	--	--	
QOL: Motivation	3.385	0.725	--	--	
QOL: Stress	3.176	0.575	--	--	
QOL: Basic needs	3.511	0.418	--	--	
QOL: Total score	3.490	0.375	--	--	

*** $p < 0.001$

Note: Z tests were performed to test for skewness and kurtosis in the data distributions. All variables were found to be normally distributed within the range of ± 1.96 ($p < 0.05$). QOL=Quality of life.

Table 1: Means and Sds of the major study variables: Mental pain and Quality of life.

present and in the past are correlated positively and significantly. The only exception is the scale of estrangement whose scores in the present and the past are not correlated significantly.

Table 1 shows also the means for the different scales of QOL. These are mostly high (above 2, the median of the response scale), with the highest means being for family (3.746), physical functioning (3.650), and fun (3.645) and the lowest for body image (1.797).

Checking the inter correlations between the 9 scales of the mental pain questionnaire showed that the correlations range from 0.757 (between loss of control and irreversibility) to 0.237 (between estrangement and emptiness) and are positive and significant except for 'estrangement' which correlates negatively with the other scales except 'narcissistic wounds' and 'emptiness' (the correlation with the former is 0.188, ns, and with the latter 0.257, $p < 0.05$). The correlations among

the three scales of mental pain tolerance are as follows: congestion with coping .456 ($p < 0.0001$), congestion with containment 0.462 ($p < 0.0001$) and coping with containment -0.020 (ns). Mental pain at present as well as mental pain in the past are correlated negatively with mental pain tolerance (-0.576, -0.227, $p < 0.0001$, respectively). Hence the higher is mental pain the lower is mental pain tolerance.

The scores of the scales of mental pain in the present and the past are correlated negatively and significantly with QOL and with the mental pain tolerance, although tolerance and QOL are not correlated significantly with each other.

Checking the gender differences between the means of the variables of the study showed that in the six following cases the differences were significant: the QOL scales of negative feelings and stress, mental pain at present and its scales of reversibility, control and flooding (women

Dependent Variable	R ²	F of whole model	R ² change	F change	Significant coefficients of predictors			
						B	(St. error)	Beta
Predictors: Gender and the 9 scales of mental pain								
QOL total	0.603	9.110 (10,60)****	0.600	10.073 (9,60)***	Wounds Emptines	-0.247 -0.157	(0.081) (0.063)	-0.438*** -0.362*
Family	0.288	2.430 (10,60)*	0.281	2.631 (9,60)*	Emptiness	-0.146	(0.077)	-0.368*
Fun	0.371	3.539 (10,60)***	0.353	3.737 (9,60)***	Wounds	-0.615	(0.205)	-0.539**
Work	.262	2.126 (10,60)*	0.258	2.331 (9,60)*	None			
Negative feelings	0.517	6.416 (10,60)****	0.490	6.758 (9,60)****	Wounds Emptiness	-0.300 -0.292	(0.145) (0.112)	-0.326* -0.414**
Positive feelings	0.557	7.549 (10,60)****	0.557	8.387 (9,60)****	Wounds	-0.470	(0.117)	-605****
Physical functioning	0.344	3.145 (10,60)**	0.344	3.494 (9,60)**	None			
Social functioning	0.476	5.444 (10,60)****	0.471	5.995(9,60)****	Wounds	-0.744	(0.165)	-0.739****
Body image	0.439	4.535 (10,60)****	0.429	4.922 (9,60)****	Control Wounds Confusion Estrang. Emptiness	-0.360 -0.356 0.162 166 0.241	(0.168) (0.108) (0.079) (0.084) (0.116)	-0.443* -0.495** 0.277* 0.202* 0.360*
Mastery	0.462	5.153 (10,60)****	0.462	5.726 (9,60)****	None			
Self esteem	0.557	7.554 (10,60)****	0.556	8.380(9,60)****	Wounds Confusion Estrang. Emptiness	0.559 -0.382 -0.231 -0.175	(0.150) (0.110) (0.117) (0.084)	-0.643**** -0.538*** -0.231* -0.317*
Motivation	.392	3.865 (10,60)****	0.390	4.276 (9,60)****	Wounds	-0.359	(0.193)	-0.329*
Stress	0.470	5.325 (10,60)****	0.420	5.389 (9,60)****	Self Confusion	-0.267 -0.199	(0.135) (0.105)	-0.249* -0.281*
Basic needs	0.461	5.125 (10,60)****	0.459	5.676 (9,60)****	Wounds	-0.215	(0.105)	-0.345*
Predictors: Gender and the 3 scales of tolerance of mental pain								
QOL total	0.266	7.696 (4,85)****	0.251	9.685 (3,85)****	Congestion Coping	-0.158 0.104	(0.051) (0.054)	-0.385 ** 0.209*
Negative feelings	0.304	9.294 (4,85)****	0.271	11.048 (3,85)****	Congestion Coping	-0.244 0.205	(0.079) (0.085)	-0.370** 0.256*
Positive feelings	0.195	6.791 (4,85)***	0.193	6.791 (3,85)****	Coping	0.216	(0.083)	0.298**
Mastery	0.208	5.594 (4,85)****	0.196	7.011 (3,85)****	Congestion	-0.206	(0.062)	-0.425***
Self-esteem	0.280	8.253 (4,85)****	0.275	10.822 (3,85)****	Congestion	-0.273	(0.070)	-0.477****
Motivation	0.166	4.234 (4,85)**	0.160	5.437 (3,85)**	Congestion Coping	-0.196 0.222	(0.103) (0.110)	-0.252* 0.235*
Stress	0.370	12.477 (4,85)****	0.316	14.205 (3,85)****	Gender Congestion	-0.204 -0.276	(0.095) (0.070)	-0.186* -0.449****
Basic needs	0.110	2.630 (4,85)*	0.107	3.392 (3,85)*	None			
Predictors: Gender, Tolerance of mental pain, Mental pain at present, Mental pain in the past								
QOL total	0.504	21.563 (4,85)****	0.489	27.898 (3,85)****	MP present	-0.429	(0.065)	-0.671****
Family	0.479	6.323 (4,85)****	0.199	7.328 (3,85)****	MP past MP present	0.088 -0.339	(0.045) (0.082)	0.211* -0.525****

Fun	0.493	6.821 (4,85)****	0.234	8.742 (3,85)****	Gender MP present	0.367 -0.687	(0.143) (159)	0.255* -0.547****
Work	0.165	4.197 (4,85)**	0.163	5.546 (3,85)****	MP present	-0.303	(0.096)	-0.420 **
Negative feelings	0.415	15.095 (4,85)****	0.382	18.528 (3,85)****	Tolerance of MP MP present	0.207 -0.499	(0.083) (0.114)	0.235* -0.486****
Positive feelings	0.363	12.123 (4,85)****	0.361	16.084 (3,85)****	MP present	-0.578	(108)	-0.621****
Cognitive functioning	0.174	4.473 (4,85)**	0.174	5.964 (3,85)***	MP present	-0.376	(0.096)	-0.519****
Physical functioning	0.293	8.827 (4,85)****	0.289	11.601 (3,85)****	MP present	-0.411	(0.083)	-0.603****
Social functioning	0.249	7.048 (4,85)****	0.248	9.373 (3,85)****	MP present	-0.624	(0.143)	-0.548****
Mastery	0.361	12.010 (4,85)****	0.349	15.459 (3,85)****	MP present	-0.429	(0.087)	-0.570****
Self esteem	0.371	12.559 (4,85)****	0.367	16.536 (3,85)****	Tolerance of MP MP present	0.212 -0.404	(0.083) (0.102)	0.275* -0.455****
Motivation	0.249	7.048 (4,85)****	0.243	9.185 (3,85)****	MP present	-0.509	(0.153)	-0.420****
Stress	0.434	16.302 (4,85)****	0.380	19.028 (3,85)****	Tolerance of MP MP present	0.309 -0.343	(0.085) (0.104)	0.372**** -0.359****
Basic needs	0.400	14.143 (4,85)****	0.396	18.888 (3,85)****	MP past MP present	-0.100 -0.504	(0.043) (0.078)	-0.222* -0.723****

P=Mental pain *p<0.05 **p<0.01 ***p<0.001 ****p<0.0001

Table 2: Results of regression analyses with the quality of life scales and total score as dependent variables and three sets of predictors: gender and the nine scales of mental pain in the present; gender and the three scales of tolerance of mental pain; gender, total scores of mental pain tolerance, mental pain in the present, and mental pain in the past.

scored higher in the former four variables). Therefore gender was included in the forthcoming regression analyses.

Tables 2 and 3 present the significant results of the regression analyses with predictors representing different sets of mental pain variables and the QOL scores as dependent variables. Table 2 presents the results for the following predictors: the 9 scales of mental pain, the three scales of mental pain tolerance and the totals for mental pain at present and in the past and mental pain tolerance.

Table 2 shows that one or more of the 9 scales of mental pain function as significant predictors of QOL and 13 of its 14 scales (all except cognitive functioning). This indicates close relations between mental pain aspects and QOL. In all cases the contribution of the predictors was highly significant beyond the control for gender. The amount of variance of QOL accounted for by mental pain ranged from 60% in regard to the total sum of QOL to 26% in regard to work. Scales with high levels of variance accounted for include positive feelings (56%) and negative feelings (52%). In regard to three of the QOL scales only the overall impact was significant while none of the mental pain scales had a significant contribution (i.e., work, physical functioning and mastery).

The mental pain scales that played the most prominent role in regard to QOL were narcissistic wounds (significant predictor in 8 cases) and emptiness (in 5 cases). In the case of 11 cases (overall QOL and 10 QOL scales) the number of mental pain predictors was 1 or 2. In two cases (Body image and Self-esteem) the number of significant mental pain predictors was higher (i.e. 5 and 4, respectively).

Notably, in regard to all QOL scales except one the relations of the mental pain scores to the QOL scores were negative, which indicates that the higher the scores in mental pain at present the lower are the QOL scores in the different scales. The one exception is the scale of body image which is affected positively by three mental pain scales: confusion, estrangement and emptiness.

The contribution of the mental pain tolerance to QOL is smaller than of mental pain (second part of Table 2). Tolerance contributed significantly to the total score of QOL and to seven of its 14 scales. In all cases the contribution of the predictors was highly significant beyond the control for gender. The amount of variance accounted for

ranged from 37% in regard to stress to 11% in regard to the scale of basic needs. Again, the amount of variance accounted for in the case of negative feelings was relatively high (30.4%) but not that of positive feelings (only 19.5%). Of the three scales of mental pain tolerance, only two – congestion (negative effect) and coping (positive effect) had significant effects on QOL, congestion in 6 cases and coping in 3. In one case gender had a significant effect, whereby women scored higher than men on stress.

The last part of Table 2 presents the findings in regard to three predictors: total sums of mental pain at present, mental pain in the past and mental pain tolerance. The three predictors had significant contributions to the total score of QOL and to 13 of the 14 scales (all except body image). In all cases the contribution of the predictors was highly significant beyond the control for gender. The variance accounted for by the predictors was relatively high and amounted to 50.4%, 49.3% and 47.9% for the QOL total, fun and family scale, respectively. The lowest amounts of variance accounted for were in regard to the scales of work (16.5%) and cognitive functioning (17.4%). The predictor with a significant contribution in all cases was mental pain at present. In all cases, higher scores of mental pain at present are related to lower scores in QOL. Mental pain tolerance and mental pain in the past had significant contributions only in three and two cases, respectively. The effect of tolerance on QOL was in all cases positive, and that of mental pain in the past negative in regard to basic needs and positive in regard to family. Gender had a significant contribution only in one case, whereby men scored higher than women on fun.

In order to get another possibly more complete perspective on the impact of mental pain in the past in regard to QOL, we used a variable that takes into account the correlation between mental pain in the present and in the past (Table 1). The resulting variable is the residual between mental pain in the present and mental pain in the past. Thus, it provides information about the predictive power in regard to quality of life of the differences between mental pain in the present and in the past. A positive B value indicates that the part of the variance of mental pain in the present beyond that shared by the score in the present with the score of mental pain in the past, contributes positively to the QOL at present, while a negative B value indicates that the part of the variance of mental pain in the present beyond that shared by the score in the present with

Dependent Variable	R ²	F of whole model	R ² change	F change	Significant coefficients of predictors			
					B	(St. error)	Beta	
Predictors: Gender and residual scores of MP at present minus MP in the past: the 9 scales								
QOL total	0.547	7.117 (10,59)****	0.544	7.870 (9,59)****	Wounds Self Emptiness	-0.357 -0.207 -0.167	(0.083) (0.096) (0.071)	-0.550**** -0.265* -0.348*
Family	0.302	2.556 (10,59)*	0.296	2.785 (9,59)**	Emptiness	-0.161	(0.080)	-0.369*
Fun	0.558	2.674 (10,59)****	0.291	2.776 (9,59)**	Wounds	-0.592	(0.207)	-0.451 **
Negative feelings	0.404	4.0000 (10,59)****	0.380	4.182 (9,59)****	Wounds Confusion Emptiness	-0.441 0.274 -0.285	(0.155) (0.145) (0.131)	-0.419** 0.311* -0.368*
Positive feelings	0.534	6.749 (10,59)****	0.533	7.498 (9,59)****	Wounds Emptiness	-0.530 -0.209	(0.116) (0.098)	-0.595**** -0.318*
Physical functioning	0.270	2.179 (10,59)*	0.270	2.420 (9,59)*	None			
Social functioning	0.435	4.537 (10,59)****	0.430	4.981 (9,59)*	Control	-0.904	(0.166)	-0.781
Body image	0.355	3.135 (10,59)**	0.345	3.391 (9,59)**	Wounds Confusion Emptiness	0.490 -0.401 0.358	(0.155) (0.145) (0.132)	489** -0.474** 0.484 **
Mastery	0.457	4.965 (10,59)****	0.457	5.517 (9,59)****	Wounds Confusion Self Emptiness	-0.313 0.188 -0.266 -0.189	(0.098) (0.091) (0.113) (0.083)	448** 0.321* -0.318* -0.368*
Self esteem	0.425	4.364 (10,59)****	0.424	4.839 (9,59)****	Wounds Self	-0.398 -0.260	(0.119) (0.138)	-0.482*** -0.262*
Motivation	0.419	4.255 (10,59)****	0.417	4.702 (9,59)****	Control Self	-0.555 -0.568	(0.182) (0.210)	-0.442 ** -0.377**
Stress	.397	3.883 (10,59)****	.360	3.912 (9,59)**	Wounds	-0.341	(0.146)	-0.345*
Basic needs	0.533	6.743 (10,59)****	0.532	7.477 (9,59)****	Control Self Confusion	-0.374 -0.366 0.258	(0.044) (169) (138)	-0.518**** -0.309* 0.312*
Predictors: Gender, tolerance of mental pain score and the residual of mental pain at present minus mental pain in the past								
QOL total	0.467	25.111(3,86)****	0.452	36.462 (2,86)****	Res MP Tol	-389 0.138	(0.065) (0.049)	-0.546**** 0.248 **
Family	0.229	8.516 (3,86)****	0.199	11.100 (2,86)****	Res MP	-0.335	(0.079)	-0.467****
Fun	0.171	5.923 (3,86)***	0.163	8.395 (2,86)****	Gender Res MP	0.307 -0.577	(0.147) (0.160)	0.213* -0.413***
Work	0.144	4.823(3,86)**	0.143	7.161 (2,86)***	Res. MP	-0.269	(0.093)	-0.335 **
Negative feelings	0.387	18.060 (3,86)****	0.354	24.777 (2,86)****	Res MP Tolerance	-0.442 0.292	(0.112) (0.084)	-0.387*** 0.328***
Positive feelings	0.333	14.290 (3,86)****	0.331	21.319 (2,86)****	Res MP	-0.525	(0.106)	-0.506****
Cognitive functioning	0.158	5.395 (3,86)**	0.158	8.093 (2,86)***	Res MP	-0.347	(0.093)	-0.429****
Physical functioning	0.214	7.823 (3,86)****	0.210	11.504 (2,86)****	Res MP	-0.348	(0.015)	-0.458***
Social functioning	0.198	7.091 (3,86)****	0.198	10.603 (2,86)****	Res MP	-0.540	(0.143)	-0.426****
Mastery	0.354	15.715 (3,86)****	0.342	22.740 (2,86)****	Res MP	-0.408	(0.085)	-0.487****
Self esteem	0.358	15.962 (3,86)****	0.353	13.633 (2,86)****	Res MP Tolerance	0.370 0.262	(0.100) (0.075)	-0.374**** 0.349****
Motivation	0.196	6.974 (3,86)****	0.190	10.133 (2,86)****	Res MP Tolerance	-0.417 0.224	(0.152) (0.114)	-0.309** 0.213*
Stress	0.424	21.071 (3,86)****	0.370	27.572 (2,86)****	Res MP Tolerance	-0.311 0.256	(0.102) (0.076)	-0.292*** 0.429****
Basic Needs	0.392	18.509 (3,86)****	0.389	27.509 (2,86)****	Res MP	-0.485	(0.076)	-0.624****

MP=Mental pain; Res=Residual *p<0.05 **p<0.01 ***p<0.001 ****p<0.0001

Table 3: Results of regression analyses with the quality of life scales and total score as dependent variables and two sets of predictors: gender, tolerance of mental pain score and the residual of mental pain at present and mental pain in the past; and Gender and residual scores of MP at present minus MP in the past for the 9 scales of mental pain.

the score of mental pain in the past, contributes negatively to the QOL at present. Table 3 presents the results for two sets of predictors. In the first part the predictors are gender and the residual scores between mental pain in the present and mental pain in the past for each of the 9 scales of mental pain. In the second part of the table, the predictors are gender, the total score for mental pain tolerance and the total score of the residuals between mental pain at present and in the past.

The first part of the table shows that the residual scores had a significant effect in regard to 12 QOL scales and the total QOL score, with the highest amounts of explained variance manifested in regard to fun (55.8%), positive feelings (53.3%) and basic needs (53.3%), and the lowest in regard to physical functioning (27%). In most cases the effects of the residuals were negative, indicating that the part of the variance of mental pain in the present beyond that shared by the score in the

present with the score of mental pain in the past, contributes negatively to the QOL at present. The only exceptions are in regard to the scale of confusion (the residuals increase QOL in regard to negative feelings, mastery and basic needs) and the scale of narcissistic wounds (increase the score of body image).

The second part of Table 3 shows some differences in the QOL scales impacted by the predictors, as compared to the results in the first part of the table: work, cognitive functioning, mastery and self-esteem are added to the list of scales impacted by mental pain residuals, whereas body image is a scale that turns out not to be impacted by the studied predictors. The table shows significant results in regard to 13 QOL scales and the total sum of QOL, ranging from 46.7% variance accounted for (in QOL total) to 15.8% (in cognitive functioning). In all cases residual mental pain showed up as a significant predictor, decreasing QOL except in the case of self-esteem. In regard to 5 scales tolerance showed up as a significant predictor, increasing QOL.

Discussion

The results provide only partial support for the first hypothesis. They show that concerning mental pain at present, the total score and the scores in seven of the scales are below the median of the response scale, and only in two scales (emotional flooding and estrangement) the scores are higher than this median. In contrast, as indicated in the first hypothesis, regarding mental pain in the past, the scores of the total sum and of each of the nine scales are above the mean of the response scale items. Hence, mental pain in the present tends to be low and that in the past tends to be high. However, mental pain in the present and in the past are correlated positively and significantly. This indicates that mental pain seems to be a kind of a total experience, grounded in the past and manifested in the present. Yet, both mental pain in the present and in the past are correlated negatively with mental pain tolerance, which seems to be a factor moderating mental pain, more in regard to mental pain at present than in the past.

The results provide almost complete support for the second hypothesis insofar as mental pain in the present is concerned. The scores of mental pain in the present served as significant predictors of QOL accounting for high amounts of variance in QOL (as high as 60% in regard to the total QOL score, and above 50% in regard to self-esteem, positive feelings and negative feelings). The impact of mental pain in the present on QOL was evident in 13 of the 14 scales of QOL (all except cognitive functioning). As predicted, the impact was negative in all except one case (body image), which will be discussed later. The significant and negative impact of mental pain at present on QOL remained evident also when it was checked together with the two other predictors of mental pain tolerance and mental pain in the past. Further, the negative impact of mental pain in the present in regard to QOL remains even when it is checked in terms of the residual values of mental pain in the present and the past, so that only that part of mental pain in the present which is not shared by the mental pain in the past is considered.

The statement about the negative impact of mental pain at present on QOL can be further specified in terms of the involved scales on both sides. Insofar as mental pain is concerned the two scales with the strongest impact on QOL were narcissistic wounds and emptiness, whereas those with the lowest impact were freeing and irreversibility of pain that had no significant impact on QOL at all. Insofar as QOL is concerned, the scales that were most strongly impacted negatively by mental pain in the present were positive feelings, negative feelings, family, fun, stress and basic needs. In contrast, the minimally impacted

QOL scales were work, cognitive functioning, as well as body image that in one regression analysis turned out to be positively impacted by mental pain, possibly due to a reaction formation.

The impact of mental pain in the past when tested together with the mental pain at present and tolerance, turned out to be significant only in two cases (positive in regard to family, and negative in regard to basic needs). Thus, it seems that the impact of mental pain in the past is overshadowed by the strong impact of mental pain in the present with which it is positively correlated.

The results provide some degree of support for the third hypothesis which deals with the impact of mental pain tolerance on QOL. When examined separately, the three scales of mental pain tolerance are related positively to the total sum of QOL and seven of the scales of QOL, especially negative feelings and stress, but to a lower degree than mental pain in the present. Further, only two of the three scales of mental pain tolerance have a significant impact on QOL, particularly congestion. The excluded scale is containment, which incidentally is not correlated with the tolerance scale of coping. When examined in conjunction with mental pain at present and mental pain in the past, tolerance maintains its positive independent impact on QOL only in regard to three scales (negative feelings, self-esteem and stress). Again, when examined in conjunction with the residuals of mental pain in the present and the past, tolerance maintains its independent positive impact on only three scales of QOL (self-esteem, motivation and stress). Thus, the findings provide support for the third hypothesis insofar as there is evidence for tolerance's independent positive impact on specific aspects of QOL is considered, but this impact is more limited in amount and extent than the impact of mental pain in the present.

A further aspect of the findings that needs to be mentioned is the limited effect of gender. Although some aspects of the mental pain variables differed significantly between the gender groups, in the regression analyses which controlled for gender, the significant impact of gender on the effect of mental pain variables on QOL was limited to the two following cases: women scoring higher on stress when the nine mental pain at present scales were the predictors; men scoring higher on fun when tolerance, mental pain at present and mental pain in the past were the predictors.

The major implication of the findings is that mental pain in the present as reported by survivors of pediatric cancer has a massive identifiable negative impact on QOL, both when considered in its totality in general terms as well as in terms of specific scales, mainly those that refer to family life, positive feelings, negative feelings and stress. Notably, the affected domains do not include work, and cognitive functioning which are precisely the aspects of the survivors' functioning that are most often examined in many studies. In contrast, the affected domains are primarily emotional and may be less often manifested and spoken about openly than work and cognition. These remarks may account for the apparent discrepancy, discussed in the introduction, between the favorable findings of many studies about the adaptation of the survivors of pediatric cancer, and the indications about their emotional suffering.

Two further issues related to mental pain in the present deserve to be noted. The first concerns mental pain in the past. Mental pain in the present is distinguishable yet related with mental pain in the past. The findings indicate that as such mental pain in the past, as reported in the present, is to a large extent part and parcel of mental pain in the present, insofar as it is correlated positively with mental pain in the present and its effects are overshadowed by those of mental pain in the present. It

may be assumed to be difficult for a person to differentiate between mental pain in the past and in the present. The origin of the mental pain is probably in the past, in the experience of the disease and the treatments undergone because of it. However, this original pain is likely to have been fed by additional experiences that have accumulated in the course of the years, up to the present.

The other issue concerns mental pain tolerance. The findings suggest that mental pain tolerance has a beneficial effect on QOL. This effect may be assumed to be mediated by the moderating impact that mental pain tolerance has on mental pain. However, the impact of mental pain tolerance is limited to specific aspects of QOL and on the whole seems to be weaker than that of mental pain in the present.

Accordingly, the major implication of the findings is that in order to increase the QOL of pediatric cancer survivors it is advisable to devise interventions focused on reducing the experienced mental pain. The findings indicate that the interventions should target primarily the aspects of mental pain which are related to narcissistic wounds and to the sense of emptiness. Further, the interventions may be based partly on elaborating the memories the survivors have of the mental pain in the past. Finally, they may also benefit from mobilizing the factor of mental pain tolerance, enhancing in particular the aspects of coping and congestion.

There are several findings of our study that require clarification in future studies: the lack of correlation between mental pain in the present and past in the scale of estrangement (Table 1); the fact that several scales of mental pain and of mental pain tolerance had no impact on QOL; and the apparently positive effect of some mental pain scales on body image.

Concerning the positive effects on body image it may be hypothesized that the reason for this unexpected result could be the fact that nowadays impairments in body image may be corrected at least to some extent by diets, plastic surgery and clothing. This assumption could be examined in further research.

There are two major issues that need to be discussed in order to set the findings of the reported study in the proper perspective: the low response rate in the study and reporting in the present of the experience of mental pain in the past.

Many investigators have noted and discussed the difficulties that characterize the recruitment of survivors of pediatric cancer for studies [55-57]. The survivors tend to be reluctant to respond positively to requests to participate in studies years following their recovery, mainly because they would like to avoid recall of their past pain, fears and suffering and minimize the chances that the memory of the painful experiences may be revived. Hence, a low response rate in studies of this kind is to be expected. Indeed, response rates as low as 49% and 43.6% were reported for example by Rosoff et al. [58], 47% by McClellan et al. [59] and 47.5% by Casagrande et al. [60], and Gianinazzi et al. [61]. A recent review [62] presents further similar examples. Notably, response rates as low as 45% or even 39% were obtained in some studies dealing with topics of quality of life or health, respectively [62] which resemble the themes in the present study. The issue of low response rates needs to be studied in order to be better understood and for getting improved response rates.

The second issue that deserves clarification concerns the retrospective recall of past experiences. It needs to be emphasized that the authors do not assume that recall at present represents the past experience in any way. Assessing the present recall of the

past mental pain was designed merely to examine the manner in which the survivors represent to themselves the past events. These representations are important insofar as they constitute a component in the narrative that the survivors construct of their past and forms a part of the conceptual and emotional complex of memories, emotions and attitudes concerning their biography and anamnesis with which they cope and on the basis of which they construct at present their future life narrative [63]. Memories of past traumata are an essential part of one's autobiographical memory, were shown to contribute to one's self identity and help in the process of making sense of the past for the purpose of improved quality of life [64,65].

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