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Quality of Life in Children Surviving Cancer: A Personality and Multi-Informant Perspective

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Objective To describe quality of life (QoL) of children surviving cancer in relation to their personality, using self- and maternal reports and examining differences with healthy referents.

Method Sixty-seven children who survived childhood cancer were compared with eighty-one healthy children on QoL and personality characteristics. **Results** Children who survived cancer reported higher QoL than healthy children, whereas there were no differences for personality. Two main effects emerged for informant with children rating themselves as less neurotic and more conscientious than their mothers. The correspondence between mothers and children was substantially higher for survivors for QoL and personality ratings. QoL and trait measures share substantial variance, and personality traits significantly predict QoL. Parental personality ratings explained child QoL beyond children's personality ratings.

Conclusions Personality traits contribute to quality of life, indicating that personality significantly influences child's quality of life beyond the experience of a negative life event such as surviving cancer and its treatment. From a diagnostic perspective, parental trait ratings are informative in addition to children's ratings of personality to understand children's QoL.

Key words quality of life; personality; children; cancer.

Recent epidemiological statistics suggest that approximately 131 out of every 100,000 children will have to deal with the life-threatening condition of cancer (World Health Organization, 2000). Although mortality rates are highly divergent across pathological subtypes, the 5-year survival rate for all childhood cancers combined increased from 55.7% in 1974–1976 to 77.1% in 1992–1997 (National Cancer Institute, 2002). Despite this, children sometimes have to deal with physical sequelae directly related to the disease or the therapeutic interventions, including problems associated with growth and endocrine function; sensory function; fertility; and liver, cardiac, and kidney damage (Eiser, 1998). Longitudinal studies over an interval of more than 20 years suggest that about one third of the survivors had one or more serious therapy-related physical problems (Humpl, Fritsche, Bartels, & Gutjahr, 2001).

Although numerous studies have examined the psychological aspects of childhood cancer, it remains unclear how the disease and its side and late effects affect children's psychological development and adjustment (Calaminus & Kiebert, 1999). The present study attempts to explore whether children who have survived cancer differ in both state and trait psychological outcomes from their healthy peers, considering self- and parent reports. The state measure is represented by quality of life (QoL) and is assumed to result from psychological evaluation processes that are essentially temporary in nature. In contrast, the child's personality is considered to be stable and represents a trait variable. This personality and multi-informant perspective should enhance our understanding of childhood functioning and long-term adaptation to cancer survival.

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State–Trait Outcome

Childhood studies on QoL are a relatively new field of research (Calaminus, Weinspach, Teske, & Gobel, 2000), with considerable significance for understanding children's psychosocial functioning and development (Noll et al., 1999). Research findings suggest that childhood cancer survivors do not experience impaired well-being and QoL or more behavioral maladjustment compared with population norms or matched controls (Barakat et al., 1997; Eiser, Hill, & Vance, 2000; Noll et al., 1997), especially when survival is longer than 2 years. Applying survey and interview methodology, Zebrack (2000) concluded that long-term survivors experience positive QoL outcomes, despite physical and psychosocial long-term sequelae, suggesting that children's interpretation of and the meanings they attribute to this life-threatening event is crucial for their self-reported stress, strain, and well-being levels. Sawyer, Antoniou, Rice, and Baghurst (2000) found a higher prevalence of psychological problems in both children and parents immediately after diagnosis, but these differences disappeared at subsequent assessments.

Considering that subjective QoL is most useful for the selection of an appropriate treatment for the individual patient (Wallander, Schmitt, & Koot, 2001), a detailed examination of this psychological state is important for clinical practice. Studies in adults have demonstrated that well-being measures, thought to reflect primarily states, also have a dispositional component (Diener, Suh, Lucas, & Smith, 1999), suggesting a need to study states and traits in conjunction. Moreover, children's personality characteristics can serve as protective factors for state outcomes such as QoL (Patterson & Blum, 1996). A focus on trait differences in childhood is therefore important for QoL assessment and research.

Until recently, researchers conceived childhood individual differences mainly in terms of temperamental characteristics (Mervielde & Asendorpf, 2000) rather than personality traits, which were used primarily to denote enduring dispositions in adults. The structure of adult traits has been the subject of intense investigation over the past decades, resulting in a consensus on the validity of the five-factor model (FFM) as a framework to describe adult personality differences. The model refers to five broad factors: extraversion, agreeableness, conscientiousness, neuroticism, and intellect or openness to experience. Developmental studies have further demonstrated that the FFM is also valid to describe individual differences in childhood and adolescence (Buyst, De Fruyt, & Mervielde, 1994; De Fruyt & Furnham, 2000;

De Fruyt, Mervielde, Hoekstra, & Rolland, 2000; Digman, 1963; Digman & Inouye, 1986; Havill, Allen, Halverson, & Kohnstamm, 1994; John, Caspi, Robins, Moffit, & Stouthamer-Loeber, 1994; Kohnstamm, Halverson, Mervielde, & Havill, 1998; Mervielde & Asendorpf, 2000; Mervielde & De Fruyt, 2000), with sometimes slightly different labels for the factors. For example, the Hierarchical Personality Inventory for Children (HiPIC) (Mervielde & De Fruyt, 1999), developed to assess traits of children aged 6 to 12 years, has five domain scales: extraversion, benevolence, conscientiousness, emotional instability or neuroticism, and imagination. These labels better reflect the characteristic behavior of children in the eyes of their parents, who are most often used as primary informants of children's traits. However, from both a conceptual and an empirical point of view, the FFM dimensions defined for childhood show a clear resemblance to those of the adult FFM (De Fruyt et al., 2000). Extraversion, conscientiousness, and emotional instability have similar labels in adult and childhood FFM measures, whereas the benevolence dimension of the HiPIC is the childhood equivalent of the agreeableness domain, better reflecting the differentiation between the well versus less-manageable child in the perception of parents. Finally, imagination is a higher-order dimension referring to facets of openness and intellect, labels suggested in the adult FFM literature for the fifth factor.

Until today, there have been no carefully designed studies on the impact of stressful life events on personality structure and trait levels in childhood or adolescence, contrary to similar studies for adults. The recent availability of a comprehensive FFM inventory for children (Mervielde & De Fruyt, 1999) opens new perspectives on the research of both personality structure and QoL in children who survived cancer.

Multi-Informant Perspective

In their systematic review of general psychological consequences of childhood cancer, Eiser et al. (2000) argued that no studies compared parent and child ratings on the same psychological outcome measure. Then, Eiser and Morse (2001) published a systematic review regarding health-related QoL and demonstrated that agreement between parents and chronically ill children was higher compared with parents and healthy children. The present study extends this research and considers different informant perspectives on psychological states (QoL) and personality traits; in other words, how children describe themselves versus how they are perceived

by their parents. Adopting multiple observers not only is desirable from a scientific perspective to enhance reliability and validity (De Fruyt & Furnham, 2000; Eiser & Morse, 2001), but also parallels clinical assessment practice, in which different informants are used for exploring children's problems.

In studies of children's QoL (Eiser & Morse, 2001; Sneeuw et al., 1999), parents are usually considered as primary informants. Levi and Drotar (1999) examined whether differences in parent-child reports varied as a function of the child's health condition, comparing self- and parent reports of health-related QoL of children with cancer versus healthy children, demonstrating larger discrepancies between reports for chronically ill children. Sawyer, Antoniou, Toogood, and Rice (1999), however, found good agreement between parent and adolescent reports of health status, although parents of adolescents actually receiving treatment for cancer reported a greater impact of the intervention on their adolescent's physical functioning. Calaminus and Kiebert (1999) argued that interobserver agreement findings are inconclusive, demonstrating that parents sometimes under- or overestimate complaints and problems compared with children/adolescent self-reports. Sawyer et al. (1999) concluded that it cannot be assumed that reports from parents are necessarily an accurate reflection of children's and adolescents' feelings and cognitions. Given the assumed impact on family functioning, it is recommended that these different informant perspectives be assessed, although more research is warranted on factors affecting interobserver agreement (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 1999; Newby, Brown, Pawletko, Gold, & Whitt, 2000).

In personality assessment also (De Fruyt & Furnham, 2000; Hofstee, 1994), there is a growing tendency to rely on multiple observers who are well acquainted with the target subject. As an indispensable alternative to self-ratings in the case of children younger than 12, parents and teachers are often used as primary informants. Adult research has demonstrated that agreement between self- and acquaintances' reports is dependent on the targeted behavior, and accuracy of the prediction is dependent on the criterion employed. Self-reports outperform observer reports for the prediction of emotional experience and extraversion-related behavior, but not neuroticism-related behaviors (Spain, Eaton, & Funder, 2000). There is no research available addressing these issues in children.

Starting from this multi-informant perspective, we first of all hypothesized that QoL of children surviving cancer would be higher, given their assumed positive

reevaluation of daily life and their relatively long period of remission. Secondly, relying on the adult literature, we hypothesized that there would be no significantly different trait scores in a less favorable direction (e.g., higher scores for neuroticism, lower scores for the extraversion facets of energy and optimism) for survivors compared with healthy referents, because personality is assumed to be relatively stable and independent of stressful life events. Thirdly, we expected that trait characteristics would share substantial variance with QoL. And finally, we hypothesized that correspondence between self- and parent ratings would be stronger for more observable characteristics such as trait behavior, but lower for QoL, which is presumed to be more state affected. The present study complements and extends previous work in this area, focusing on (1) both states and traits and their interrelationships; (2) adoption of a comprehensive personality descriptive model, the FFM for children; and (3) taking into account different observer perspectives in self- and parent reports.

Method

Participants

All children diagnosed with cancer between 1989 and 1998 and successfully treated in the oncology department of a large university hospital ($N = 142$) were identified from the center's database. Full records of their disease and treatment histories were available. Inclusion criteria were age between 8 and 14 years and a physical condition without evidence of disease, that is, free of signs related to cancer for 3 consecutive years. Exclusion criteria were mental retardation and a history of chronic disease other than cancer. Questionnaires, an informed consent form, and an invitation letter to participate in a study on QoL and personality characteristics in children surviving cancer were sent to the children and their parents at home. The initial mailing was followed by a phone call from the researchers inviting the families to participate and reminding them to return questionnaires using an enclosed postage-paid envelope. Parents and children were given detailed written instructions about how to complete the questionnaires. The instructions emphasized that parent and child should complete the questionnaires independently. Specific guidelines were provided for children needing assistance to complete the questionnaires (e.g., parents were allowed to explain an item when specifically requested by their child, but they could not help the child with making ratings). Both parents and children were assured that all information would be treated

as confidential and would serve only research purposes. Written informed consent was obtained from all children and parents at the moment of assessment. All participants could further contact the researchers to obtain additional information or to express concerns or queries.

Forty-seven percent of the parents ($N = 67$) agreed to participate and returned questionnaires. The children (39 boys, 28 girls) had an average age of 10.34 years ($SD = 1.38$; range, 8–13). The mean time between initial diagnosis and the actual assessment was 7.7 years (range, 3–13), and children were on average 3.3 years at the time of diagnosis. Children had suffered from different forms of cancers, including lymphoblastic and acute nonlymphoblastic leukemia ($n = 30$), Hodgkin's disease and non-Hodgkin's lymphoma ($n = 8$), and several solid tumors including brain tumor, neuroblastoma, Wilm's tumors, and sarcoma ($n = 29$).

The comparison group consisted of 81 healthy children (38 boys, 43 girls) between 8 and 12 (mean age = 9.85 years, $SD = 1.14$) recruited from two primary schools in Antwerp. Exclusion criteria were mental retardation and the presence or a history of a chronic health condition. Children were invited by the classroom teacher and one of the researchers to participate, and detailed written information about the study was provided to their parents. After written informed consent had been obtained from both the parents and the children, questionnaires and instructions were distributed in the classroom. Four classes were contacted, and all of the pupils and their parents agreed to participate in the study. They were assured that all information would be treated confidentially and would serve only research purposes. Signed informed consent forms and completed questionnaires were returned via the class teacher in sealed envelopes. The referent group could be assumed to be relatively representative of the general population of school-age children, because public schools in Belgium usually have a heterogeneous population with respect to race, ethnicity, and socioeconomic status. The children and their parents all completed the same questionnaires at home to enhance comparability with the disease group. In both samples, mothers served as parental informants.

Questionnaires

Pediatric Quality of Life Inventory (PedsQL™) 4.0 Generic Core Scales

The PedsQL (version 4.0, ages 8–12) is a 23-item questionnaire developed to assess health-related QoL in children using self- and parent reports. Its Generic Core

Scales (Varni, Seid, & Kurtin, 2001) include four subscales assessing QoL: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). Items are presented on a 5-point scale (0 = *never a problem* to 4 = *almost always a problem*), and subjects are requested to rate how much trouble they experienced during the past month with health and activities (e.g., *I hurt or ache*, *It is hard for me to run*) or feelings (e.g., *I feel afraid or scared*). Items are reverse-scored and linearly transformed to a 0 to 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better health-related QoL. Previous research underscored the reliability and validity of the PedsQL to assess QoL in chronic populations (Varni, Seid, & Kurtin, 2001). In the present study, we used the authorized Dutch adaptation of the instrument, translated first by Koot and Bastiaansen (1998) and then by two bilingual retranslators. A recent study with this Dutch PedsQL (Bastiaansen, Koot, Bongers, Varni, & Verhulst, in press) concluded that it is a valid and useful instrument to measure QoL in children referred for psychiatric problems.

The psychometric scale characteristics for the present sample were acceptable for both the children's and parent's ratings, with Cronbach alpha coefficients across subscales ranging between .66 (functioning at school) and .72 (physical functioning) for children's self reports, and between .71 (functioning at school) and .81 (physical functioning) for the parent ratings. A composite QoL score was also computed, being the sum of the four subscales, with reliabilities of .85 (child ratings) and .87 (parent ratings).

Hierarchical Personality Inventory for Children

The HiPIC (Mervielde & De Fruyt, 1999) is a Dutch personality inventory assessing of five trait domains—extraversion, benevolence, conscientiousness, emotional instability or neuroticism, and imagination—and 18 facets, hierarchically organized under these domains. The extraversion domain includes subscales of energy, expressiveness, optimism, and shyness; the benevolence domain comprises the subscales of altruism, dominance, egocentrism, compliance, and irritability; in the conscientiousness domain are the subscales of concentration, perseverance, order, and achievement striving; the emotional instability domain includes the subscales of anxiety and self-confidence; and, finally, the imagination domain comprises the subscales of creativity, intellect, and curiosity. The inventory includes 144 items that closely represent the personality descriptive content reflected in parental descriptions of trait differences in children aged 6 to 12 years. All items refer to a specific

observable behavior and have a similar grammatical format, formulated in the third person singular, without negations, and excluding personality descriptive adjectives. Although the HiPIC was initially constructed as an observer instrument, recent work has demonstrated that it is also reliable and valid to assess personality in childhood and adolescence using self-ratings (De Fruyt et al., 2000), even with children as young as 8 years (Mervielde & De Fruyt, 2002). The standard HiPIC item format, phrased in the third person singular without a subject, enables both self- and parent reports without changing the wording of the items. The factor structure of the exploratory analysis was clearly replicated in both the child and the parent ratings (combining survivor and healthy-referent ratings), with 17 of the 18 facet scales loading the targeted components for the parent ratings and 12 of the 18 for the child ratings, explaining 76.5% and 66.5% of the variance, respectively. The median Cronbach alphas for the self- and parent-reported facet scales were .69 and .86, respectively.

Statistics

QoL and personality facet and domain differences (domain scores reflected aggregated facet scores) between survivors and healthy individuals and between informant sources were examined using analysis of variance (ANOVA), with informants (self versus parent) as a within-subjects factor and disease versus healthy-referent group as the between-subjects factor. Age and child sex were considered as covariates in all analyses. Differences in personality facets were considered significantly different at $p < .01$ given the large number of comparisons. Agreement between informants was investigated through Pearson correlation coefficients. Finally, incremental validity of observer ratings and common variance of state-trait measures were examined using stepwise hierarchical regression analysis.

Results

Quality of Life

The mean self-described and parent-reported QoL scores of cancer survivors and healthy referents are reported in Table I. The ANOVA demonstrates a main effect for sample, indicating that survivors have significantly higher QoL than their referent peers ($F = 14.00$, $p < .001$). This significant difference extends to all QoL subscales except social functioning. Referents reported more problems with physical, emotional, and school functioning (all significant at $p < .01$). Cohen effect sizes

were .87 for the composite QoL index and .82, .74, and .49 for the physical, emotional, and school functioning facets of QoL, respectively. In contrast, there was only one main effect of informant for emotional functioning, demonstrating that children reported lower QoL than their parents for this scale ($F = 4.69$, $p < .05$). Finally, the Sample \times Informant interactions were significant for the total QoL scale and all subscales ($F = 10.50$, $p < .001$; $F = 8.86$, $p < .01$; $F = 4.32$, $p < .05$; and $F = 8.72$, $p < .01$, for physical, emotional, social, and school functioning, respectively), with the healthy-referent children reporting worse QoL than their parents compared with child cancer survivors and their parents.

Given the wide diversity in diagnoses, QoL ratings of children diagnosed with higher expected survivorship and restricted late effects (i.e., leukemic/Hodgkin's/non-Hodgkin's patients) were further compared with children who had diagnoses with higher morbidity and mortality and worse expected late effects (i.e., solid tumor/brain tumor/Wilm's tumor/sarcoma patients). The results of this analysis showed no significant differences between low- versus high-risk groups on the total QoL and the subscale scores.

Personality

The HiPIC self-reported and parental mean domain ratings of survivors and healthy referents are also described in Table I. The ANOVA showed no main effects of sample on personality domain and facet scores (the latter are not reported in Table I). There were two main effects of informant for neuroticism ($F = 8.25$, $p < .001$) and conscientiousness ($F = 4.41$, $p < .05$): Parents described their children as more neurotic than did the children themselves, whereas children described themselves as more conscientious than their parents rated them. At the facet level, there was a main effect of informant on only anxiety ($F = 12.36$, $p < .001$), with parents providing higher anxiety ratings than did the children themselves.

There were significant Informant \times Sample interactions for extraversion and imagination, with the parents of the healthy referents providing higher extraversion ratings ($F = 13.91$, $p < .001$) than their children compared with parents and children of the survivor group. Survivors provided higher self-ratings on imagination than their parents ascribed to them ($F = 14.98$, $p < .001$) compared with the healthy referents and their parents. At the facet level, there were significant Informant \times Sample interactions for expressiveness, shyness, creativity, and intellect, with healthy children rating themselves as more shy ($F = 10.24$, $p < .01$), less creative ($F = 11.50$,

Table I. Mean Self- and Parent Ratings on Personality and Quality of Life (QoL) of Children Surviving Cancer Versus Healthy Referents

		Survivors	Referents	Sample	Rater	Rater × Sample
QoL (total score)	Self	77.10	66.03	14.00***		14.82***
	Parent	76.69	73.73			
Physical functioning	Self	81.23	68.66	10.02**		10.50**
	Parent	83.85	81.31			
Emotional functioning	Self	72.44	59.44	12.44**	4.69*	8.86**
	Parent	69.73	65.16			
Social functioning	Self	78.18	70.11			4.32*
	Parent	76.42	74.30			
School functioning	Self	76.44	65.91	10.27**		8.72**
	Parent	76.75	74.15			
Extroversion	Self	28.0	26.4			13.91***
	Parent	27.9	29.2			
Benevolence	Self	27.7	27.4		4.41*	
	Parent	26.7	26.6			
Conscientiousness	Self	25.6	26.3		8.25**	
	Parent	24.0	25.0			
Neuroticism	Self	20.1	21.2			
	Parent	22.1	22.0			
Imagination	Self	28.2	27.2			14.98***
	Parent	28.2	30.2			

* $p < .05$; ** $p < .01$; *** $p < .001$.

$p < .001$), less expressive ($F = 18.01$, $p < .001$), and lower on intellect ($F = 16.59$, $p < .01$) than their parents rated them compared with child cancer survivors and their parents. A similar analysis was done for the low-versus the high-risk groups, demonstrating no significant differences for the five personality domains and their facets.

Informant Agreement

The present study obtained self- and parent ratings of QoL and personality. Without exception, parents' and children's ratings in the overall group corresponded substantially and significantly (all $p < .01$). The Pearson correlation between self- and parent-reported total QoL ratings was .49. HiPIC domain ratings also converged strongly, with coefficients of .52, .32, .46, .45, and .51 for neuroticism, extraversion, imagination, and conscientiousness, respectively. At the facet level, correlations were .47 and .48 for the neuroticism facets, and ranged between .20 (expressiveness) and .44 (energy) for extraversion; .27 (curiosity) and .51 (creativity) for imagination; .29 (dominance) and .48 (compliance) for benevolence; and .30 (perseverance) and .56 (order) for the facets of conscientiousness.

Comparing self- and parent ratings between healthy children and survivors further demonstrates that corres-

pondence was more than twice as high (after r to z transformation) for the survivors relative to the healthy sample, with correlations of .70 (total QoL), and .70, .65, .73, .70, and .74 (HiPIC domains) for the survivors versus .32 (total QoL), and .35, .09, .29, .29, and .27 (HiPIC domains) for the healthy-referent controls. There were no sizable differences in agreement on QoL versus personality traits.

Incremental Validity

Hierarchical regression analysis was applied to evaluate the state-trait character of the QoL construct, with self-reported QoL as the criterion for the first analyses and self-reported HiPIC trait scores entered first, followed by parental HiPIC ratings in a next step. Such analyses not only provide estimates of the total explained state variance by trait measures, but also examine whether different informant perspectives contribute over each other to predict the criteria of interest. The order of the predictor sets was also reversed, with parental trait ratings entered first, followed by children's trait self-reports to examine shared informant effects. A second set of analyses was conducted with parental QoL as the criterion.

Inspection of the standardized beta coefficients reported in Table II demonstrates that self-reported

Table II. Stepwise Hierarchical Multiple Regression Results for Quality of Life (QoL) Child Ratings Predicted by Child/Parent and Parent/Child Trait Ratings

	QoL (Child Ratings)			QoL (Child Ratings)	
	Step 1	Step 2		Step 1	Step 2
Step 1: Child ratings			Step 1: Parent ratings		
Extraversion	.11	.11	Extraversion	-.13	-.11
Benevolence	.16*	.10	Benevolence	.05	.04
Conscientiousness	.07	-.04	Conscientiousness	.21*	.26**
Neuroticism	-.38**	-.33**	Neuroticism	-.37**	-.17
Imagination	.21*	.30**	Imagination	.02	-.14
Step 2: Parent ratings			Step 2: Child ratings		
Extraversion		-.11	Extraversion		.11
Benevolence		.04	Benevolence		.10
Conscientiousness		.26**	Conscientiousness		-.04
Neuroticism		-.17	Neuroticism		-.33**
Imagination		-.14	Imagination		.30**
R ²	.38**	.43**	R ²	.16**	.43**
R ² change		.07**	R ² change		.28**

* $p < .05$; ** $p < .01$.

benevolence, neuroticism, and imagination ratings contribute to the prediction of self-reported QoL, explaining 38% of the total variance. Parental ratings significantly contribute on top of them ($p < .01$), explaining an additional 7%, resulting in 43% of total explained variance in the state measure. Two of the self-reported HiPIC domains, neuroticism and imagination, remain significant, whereas parental-rated conscientiousness positively added to the prediction. When reversing the order of predictors, 16% of the variance of child-reported QoL is explained by parental ratings of personality, with conscientiousness and neuroticism as significant predictors, amounting to 43% when adding child ratings of personality. More specifically, child-reported neuroticism and imagination contributed to child-reported QoL. Only parental conscientiousness remained significant after the second step.

A similar analysis, but now with the parental QoL ratings as the criterion and parental HiPIC ratings in the first step, followed by self-reported HiPIC ratings in the second step, is reported in Table III. Inspection of the standardized beta coefficients shows that three of the FFM—extraversion, benevolence, and neuroticism—significantly predict parental ratings of children's QoL, explaining 29% of the parental QoL variance. Moreover, including self-reported HiPIC ratings does not lead to a significant increase in the explained variance. Finally, only self-reported neuroticism predicted parental QoL ratings, explaining 11% of the variance. Adding parental ratings results in a total amount of explained vari-

ance of 31%, with only benevolence as a significant predictor.

Discussion

The present study corroborates previous findings on the long-term effects of surviving cancer, suggesting that QoL is stabilized at a level comparable to that found among children and parents in the general community (Barakat et al., 1997; Eiser et al., 2000; Noll et al., 1997; Sawyer, Antoniou, Toogood, & Rice, 1997). In the present study, survivors reported even higher QoL than the healthy referents, suggesting that negative life events, such as life-threatening diseases, do not necessarily lead to long-term impairment of well-being but can also generate positive effects. A possible explanation for this observation can be found in Zebrack's study (2000) of positive outcomes from the disease, partially as a function of the meaning that survivors attribute to their disease and treatment experiences. Moreover, the interaction effects demonstrated that only the healthy-referent children reported lower QoL than their parents, whereas there were no significant informant differences in the survivor group. This finding suggests that this positive appraisal not only operates in children, but also extends to their parents.

Studies in chronically ill populations, using children as informants, have consistently reported surprisingly high levels of positive functioning (Phipps & Steele, 2002). Although these reports may be a valid reflection of reality, it might be possible that the self-reports of children with a chronic disease are biased in some way, due to the

Table III. Stepwise Hierarchical Multiple Regression Results for Quality of Life (QoL) Parent Ratings Predicted by Parent/Child and Child/Parent Trait Ratings

	QoL (Parent Ratings)			QoL (Parent Ratings)	
	Step 1	Step 2		Step 1	Step 2
Step 1: Parent ratings			Step 1: Child ratings		
Extraversion	.19*	.19	Extraversion	.11	.05
Benevolence	.23**	.26**	Benevolence	.10	-.05
Conscientiousness	.17	.18	Conscientiousness	.10	.01
Neuroticism	-.22*	-.15	Neuroticism	-.20*	-.11
Imagination	-.04	-.08	Imagination	.00	.08
Step 2: Child ratings			Step 2: Parent ratings		
Extraversion		.05	Extraversion		.19
Benevolence		-.05	Benevolence		.26**
Conscientiousness		.01	Conscientiousness		.18
Neuroticism		-.11	Neuroticism		-.15
Imagination		.08	Imagination		-.08
R ²	.29**	.31**	R ²	.11**	.31**
R ² change		.03	R ² change		.21**

* $p < .05$; ** $p < .01$.

“illusion of mental health” (Shedler, Maymen, & Manis, 1993). A repressive-adaptive style, primarily as a function of defensive processes, might explain the increased QoL ratings. Future research should include measures of defensiveness to examine such a repressing effect.

The present data further contribute to recent adult empirical research demonstrating that life events do not necessarily influence mean-level ratings or are associated with personality change (Costa, Herbst, McCrae, & Siegler, 2000) in a less desirable direction. Survivors and healthy referents did not differ in their scores for the five domains and the 18 more specific personality facets. There were, however, a number of informant effects and Sample \times Informant interactions, suggesting that it is important to consider the source of information in professional assessment practice and research. Parents tend to provide higher ratings on neuroticism, more specifically on anxiety, whereas children describe themselves as higher on conscientiousness. The interactions further suggest that the parents of the healthy referents provided higher ratings on extraversion, whereas survivors rated themselves higher on imagination than their parents. An explanation for the latter finding might be that parents of children surviving cancer consider their child to be more rational and down-to-earth given the hard reality they are confronted with. However, before we can interpret such differences, these patterns have to be confirmed in independent research.

The present study further examined agreement between self- and parent ratings. The results demonstrated higher correlations for the survivors compared

with the healthy referents, suggesting that parent's and children's descriptions were thus more convergent for the survivors. These findings confirm previous conclusions of Eiser et al. (2000) that there is higher agreement between parents and chronically ill children on QoL ratings compared with parents and healthy children. We did not find differences in agreement on state versus more trait-oriented measures. Although self-reporting is considered the standard for measuring perceived QoL (Varni, Seid, & Kurtin, 2001), the present findings regarding the group of survivors suggest that parents can be assumed to give accurate reflections of their child's QoL. Moreover, there remain strong arguments for obtaining information from parents in clinical practice, given that it is the parents' perception of their child's QoL that influences the use of health care.

Finally, the validity of personality traits in predicting QoL was examined taking into account different informant perspectives. Self-reported QoL was to a considerable extent predicted by self-reported trait measures, but parental ratings still contributed in addition to the self-reports. Several FFM traits contributed to the prediction of QoL, suggesting that QoL is a comprehensive and broad construct, related to diverse aspects of stable individual differences, including neuroticism, benevolence, conscientiousness, and imagination. A roughly similar picture was observed for the parent-reported QoL, best predicted by parent-rated traits, although the child-rated personality did not additionally contribute to the explanation of parent-rated QoL. QoL and trait ratings covary stronger when rated by the same

observer, suggesting the presence of common informant effects. However, traits and QoL still covary when rated by different observers, suggesting considerable overlap in the constructs.

In sum, the analyses suggest that QoL, assumed to reflect more temporary states, has a substantial trait component that has been demonstrated to be rather stable. Therefore, it is recommended to complement QoL assessment (in research, but also in clinical practice) with personality measurement, in order to further differentiate among cancer survivors reporting impaired QoL. Although the present results suggest that survivors experience improved QoL for a considerable time after diagnosis of the disease, one should be sensitive to within-group differences and hence screen for individuals among the survivors with impaired QoL scores. From the state-trait perspective, therapeutic intervention and counseling will be largely different for those children reporting impaired QoL with higher scores on neuroticism and lower scores on imagination, benevolence, and conscientiousness than for children having the opposite pattern of trait scores. Furthermore, an additional therapeutic goal may be to increase the child's and parents' awareness that QoL is related to the more stable personality traits of the child. Therefore, the therapeutic goal setting regarding improving QoL needs to incorporate the child's trait profile so that realistic expectations can be set.

The present study has a number of limitations that should be taken into account when reflecting on the results. Firstly, we have no information on the reasons why families of children who survived cancer refused to participate, so it is impossible to exclude the possibility that our final sample is a selected one, limiting the generalizability of our findings.

Secondly, while the mean QoL score of the present sample of survivors is very similar to that obtained by Varni, Burwinkle, Katz, Meeske, and Dickinson (2002), there are remarkable differences in the mean PedsQL score of the present sample of healthy children and the means of the healthy children described in Varni et al. (2001) and in Bastiaansen et al. (in press), with the present sample (self- and parent ratings) reporting lower QoL (about one standard deviation) compared with the two other samples. This finding might suggest that the present sample is an atypical comparison group that is not representative of the Flemish population of school-age children without chronic health problems. However, no differences in mean personality scores were observed between the present sample of healthy children and a

large HiPIC normative group ($N = 2,463$) of the general Flemish school-age population (De Fruyt, Mervielde, & De Clercq, in press), suggesting that the present group of healthy children actually is representative of healthy Flemish children at the trait level. Assuming that the present sample of healthy children is indeed an atypical comparison group and that the true QoL scores of healthy Flemish children would be comparable to those of Varni et al. (2002) and Bastiaansen et al. (in press), the conclusion would be that QoL ratings of survivors are lower than those of healthy controls, suggesting that the condition of having survived cancer does lead to impaired QoL. However, this line of reasoning is somewhat speculative given previous findings obtained with different questionnaires that children surviving cancer reported no impaired levels of well-being and QoL (Barakat et al., 1997; Eiser et al., 2000; Noll et al., 1997; Zebrack, 2000). Ultimately, only new research examining QoL in healthy Flemish school-age children can resolve the issue of representativeness.

Thirdly, although parents and children were asked to complete the questionnaires independently and explicit instructions were included for the parents to assist their children when necessary, we cannot exclude that parents did influence their child's ratings, reflected in the high coefficients of agreement. However, similar trends have been observed in other studies examining childhood cancer survivors and their parents (Varni et al., 2002).

A fourth limitation was the heterogeneous composition of the sample in terms of medical diagnoses, symptom severity, and diverse treatments. Calaminus et al. (2000), for example, demonstrated that QoL scores among cancer patients varied as a function of hematological disorders versus solid tumors. Although we examined differences between high- and low-risk groups in the present study, we cannot exclude that more fine grained comparisons between diagnostic categories may demonstrate differences. Such analyses, however, will require more subjects for each diagnostic category than were available for the present analyses.

Fifthly, the absence of long-term consequences does not imply that QoL or behavior is not affected for a short time interval, for example immediately after diagnosis, or during the eventual manifestation of late effects in adolescence or young adulthood. To be in a better position to examine such developmental trajectories and processes as the effects of a repressive-adaptive style, it is recommended to conduct longitudinal research, involving different observers, including the child, peers, parents, and eventually teachers or psychologists as informants. Multiple informants, and especially professional assessors

relying on structured interviews, might be helpful to screen out overreporting of functioning in the positive direction due to positive (re)appraisal of what both the child and the parent have experienced as individuals and a family in the past.

In addition to using multiple informants, future research should focus on cognitive mechanisms and attribution processes of children who have survived cancer as a function of long-term QoL outcomes. Finally, more precise assessment of the recovery trajectory is essential, including detailed assessments of absence at school, remedial actions, health sequelae, and side effects from the therapeutic interventions. These last data should preferably be diagnosed by a physician or medical staff or derived from the medical file. These additional data should advance our understanding of health-related QoL and provide empirical ground to advance a more articulated theoretical distinction between QoL and disease impact (Wallander et al., 2001).

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References

- Barakat, L. P., Kazak, A. E., Meadows, A. T., Casey, R., Meeske, K., & Stuber, M. L. (1997). Families surviving childhood cancer: A comparison of posttraumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology*, 22, 843–859.
- Bastiaansen, D., Koot, H. M., Bongers, I. L., Varni, J. W., & Verhulst, F. C. (in press). Measuring quality of life in children referred for psychiatric problems: Psychometric properties of the PedsQL™ 4.0 Generic Core Scales. *Quality of Life Research*.
- Buyst, V., De Fruyt, F., & Mervielde, I. (1994). Parental descriptions of children's personality: A five-factor model classification. *Psychologica Belgica*, 34, 231–255.
- Calaminus, G., & Kiebert, G. (1999). Studies on health-related QoL in childhood cancer in the European setting: An overview. *International Journal of Cancer*, 12, 83–86.
- Calaminus, G., Weinspach, S., Teske, C., & Gobel, U. (2000). Quality of life in children and adolescents with cancer. First results of an evaluation of 49 patients with the PEDQOL questionnaire. *Klinische Padiatrie*, 212, 211–215.
- Costa, P. T., Jr., Herbst, J. H., McCrae, R. R., & Siegler, I. C. (2000). Personality and midlife: Stability, intrinsic maturation and response to life events. *Assessment*, 4, 365–378.
- De Fruyt, F., & Furnham, A. (2000). Advances in the assessment of the five-factor model. *Psychologica Belgica*, 40, 51–75.
- De Fruyt, F., Mervielde, I., & De Clercq, B. (in press). *Handleiding voor de Hiërarchische Persoonlijkheidsvragenlijst voor Kinderen (HiPIC)* [Manual for the Hierarchical Personality Inventory in Children (HiPIC)]. Ghent, Netherlands: Ghent University Department of Developmental, Personality, and Social Psychology.
- De Fruyt, F., Mervielde, I., Hoekstra, H. A., & Rolland, J.-P. (2000). Assessing adolescents' personality with the NEO-PI-R. *Assessment*, 7, 329–345.
- Diener, E., Suh, E. M., Lucas, R. E., Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin*, 125, 276–302.
- Digman, J. M. (1963). Principal dimensions of child personality as inferred from teachers' judgments. *Child Development*, 34, 43–60.
- Digman, J. M., & Inouye, J. (1986). Further specification of the five robust factors of personality. *Journal of Personality and Social Psychology*, 50, 116–123.
- Eiser, C. (1998). Practitioner review: Long-term consequences of childhood cancer. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 39, 621–633.
- Eiser, C., Hill, J. J., & Vance, Y. H. (2000). Examining the psychological consequences of surviving childhood cancer: Systematic review as a research method in pediatric psychology. *Journal of Pediatric Psychology*, 25, 449–460.
- Eiser, C., & Morse, R. (2001). Can parents rate their child's health-related quality of life? Results of a systematic review. *Quality of Life Research*, 10, 347–357.

- Havill, V. L., Allen, K., Halverson, C. F., & Kohnstamm, G. A. (1994). Parents' use of big five categories in their natural language descriptions of children. In C. F. Halverson, G. A. Kohnstamm, & R. P. Martin (Eds.), *The developing structure of temperament and personality from infancy to adulthood* (pp. 371–386). Hillsdale, NJ: Erlbaum.
- Hoekstra-Weebers, J. E., Jaspers J. P., Kamps, W. A., & Klip, E. C. (1999). Risk factors for psychological maladjustment of parents of children with cancer. *Journal of the American Academy of Child and Adolescent Psychiatry*, 38, 1526–1535.
- Hofstee, W. K. B. (1994). Who should own the definition of personality? *European Journal of Personality*, 8, 149–162.
- Humpl, T., Fritsche, M., Bartels, U., & Gutjahr, P. (2001). Survivors of childhood cancer for more than twenty years. *Acta Oncologica*, 40, 44–49.
- John, O. P., Caspi, A., Robins, R. W., Moffit, T. E., & Stouthamer-Loeber, M. (1994). The “little five”: Exploring the nomological network of the five-factor model of personality in adolescent boys. *Child Development*, 65, 160–178.
- Kohnstamm, G. A., Halverson, C. F., Jr., Mervielde, I., & Havill, V. L. (1998). *Parental descriptions of child personality: Developmental antecedents of the big five?* Hillsdale, NJ: Erlbaum.
- Koot, J. M., & Bastiaansen, D. (1998). *PedsQL™: Kwaliteit van Leven Vragenlijst voor Kinderen [PedsQL™: Pediatric Quality of Life Inventory]*. Unpublished manuscript, University Hospital, Rotterdam.
- Levi, R. B., & Drotar, D. (1999). Health-related QoL in childhood cancer: Discrepancy in parent–child reports. *International Journal of Cancer*, 12, 58–64.
- Mervielde, I., & Asendorpf, J. (2000). Variable-centered and person-centered approaches to childhood personality. In S. Hampson (Ed.), *Advances in personality psychology* (vol. 1, pp. 37–76). Philadelphia: Taylor & Francis.
- Mervielde, I., & De Fruyt, F. (1999). Construction of the Hierarchical Personality Inventory for Children (HiPIC). In I. Mervielde, I. Deary, F. De Fruyt, & F. Ostendorf (Eds.), *Personality psychology in Europe*. Proceedings of the Eighth European Conference on Personality Psychology (pp. 107–127). Tilburg, Netherlands: Tilburg University Press.
- Mervielde, I., & De Fruyt, F. (2000). The “big five” personality factors as a model for the structure of children's peer nominations. *European Journal of Personality*, 14, 91–106.
- Mervielde, I., & De Fruyt, F. (2002). Assessing children's traits with the Hierarchical Personality Inventory for Children. In B. De Raad (Ed.), *Big five assessment* (pp. 129–142). Seattle, WA: Hogrefe & Huber.
- National Cancer Institute. (2002). *Research on childhood cancers: CancerMail from the National Cancer Institute*. Retrieved June 8, 2004, from <http://cancerweb.ncl.ac.uk/cancernet/400397.html>
- Newby, W. L., Brown, R. T., Pawletko, T. M., Gold, S. H., & Whitt, K. (2000). Social skills and psychological adjustment of child and adolescent cancer survivors. *Psycho-Oncology*, 9, 113–126.
- Noll, R. B., Gartstein, M. A., Vannatta, K., Correll, J., Bukowski, W. M., & Davies, W. H. (1999). Social, emotional, and behavioral functioning of children with cancer. *Pediatrics*, 103, 71–78.
- Noll, R. B., MacLean, W. E., Whitt, J. K., Kaleita, T. A., Stehbens, J. A., Waskerwitz, M. J., et al. (1997). Behavioral adjustment and social functioning of long-term survivors of childhood leukemia: Parent and teacher reports. *Journal of Pediatric Psychology*, 22, 827–841.
- Patterson, J., & Blum, R. W. (1996). Risk and resilience among children and youth with disabilities. *Archives of Pediatrics and Adolescent Medicine*, 150, 692–698.
- Phipps, S., & Steele, R. (2002). Repressive adaptive style in children with chronic illness. *Psychosomatic Medicine*, 64, 34–42.
- Sawyer, M., Antoniou, G., Rice, M., & Baghurst, P. (2000). Childhood cancer: A 4-year prospective study of the psychological adjustment of children and parents. *Journal of Pediatric Hematology Oncology*, 22, 214–220.
- Sawyer, M., Antoniou, G., Toogood, I., & Rice, M. (1997). Childhood cancer: A two-year prospective study of the psychological adjustment of children and parents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 1736–1743.
- Sawyer, M., Antoniou, G., Toogood, I., & Rice, M. (1999). A comparison of parent and adolescent reports describing the health-related QoL of adolescents treated for cancer. *International Journal of Cancer*, 12, 39–45.
- Shedler, J., Maymen, M., & Manis, M. (1993). The illusion of mental health. *American Psychology*, 48, 1117–1131.
- Sneeuw, K. C. A., Aaronson, N. K., Sprangers, M. A. G., Detmar, S. B., Wever, L. D. V., & Schornagel, J. H. (1999). Evaluating the quality of life of cancer patients: Assessments by patients, significant others, physicians and nurses. *British Journal of Cancer*, 81, 87–94.

- Spain, J. S., Eaton, L. G., & Funder, D. C. (2000). Perspectives on personality: The relative accuracy of self versus others for the prediction of emotion and behavior. *Journal of Personality, 68*, 837–867.
- Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL™ in pediatric cancer: Reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, multi-dimensional fatigue scale, and cancer module. *Cancer, 94*, 2090–2105.
- Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ version 4.0 Generic Core Scales in healthy and patient populations. *Medical Care, 39*, 800–812.
- Wallander, J. L., Schmitt, M., & Koot, H. M. (2001). Quality of life measurement in children and adolescents: Issues, instruments, and applications. *Journal of Clinical Psychology, 57*, 571–585.
- World Health Organization. (2000). *Automatic Childhood Cancer Information System*. Retrieved June 8, 2004, from <http://www-dep.iarc.fr/accis.htm>
- Zebrack, B. (2000). QoL of long-term survivors of leukemia and lymphoma. *Journal of Psychosocial Oncology, 18*, 39–59.