International Comparison of Contributions to Psychosocial Research on Survivors of Childhood Cancer: Past and Future Considerations

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Objective To compare the methods and designs, constructs, publication rate, and location of studies in the past 15 years of pediatric psycho-oncology research, across geographic areas and over time. Methods Three recently published reviews on psychological consequences of surviving childhood cancer were reanalyzed according to (1) inclusion of young or older survivors, (2) 5-year periods of publication, (3) country/area (North America, Europe, or Australia), (4) journal type, (5) number of survivors, (6) design of the study, (7) inclusion of a control group, (8) diagnosis, and (9) the use of standardized instruments on different domains. Results The comparisons show some descriptive differences depending on the origin of study, as well as differences over time. Over the years an increase in research from Europe/Australia over that from North America is shown. In most studies more constructs are measured during the more recent publication period. Conclusions If we are to conduct exemplary work in this area, it is vital to establish national and international organizations for psychologists to parallel those already established for physicians. More attention should be focused on development of interventions for survivors in the future.

Key words childhood cancer; pediatric psychology; review; international comparison; psychological consequences.

Survival rates of children with cancer have increased dramatically over the last decades. Today approximately two thirds of children with cancer survive their illness. In the developed countries, about 1 in every 1,000 adults reaching the age of 20 will be a long-term survivor. This progress in medical care has changed the focus of research in pediatric psycho-oncology from descriptions of the impact of an impending death of the child to the impact on the quality of life (QoL) of the child and the family during and after treatment.

In developed Western countries, the advances in medical treatment are a result of an organized effort in study groups (e.g., the Children's Oncology Group in the United States, the United Kingdom Children's Cancer Study Group, the Société Internationale d’Oncologie Pédiatrique [SIOP]), as well as of centralized treatment in hospitals specializing in pediatric oncology. These efforts have resulted in considerable similarity in treatment protocols and survival rates in different countries. However, increased survival raises many new questions, including: What are the costs in terms of late effects on physical, cognitive, social, and emotional functioning? What are the chances of infertility? To what extent will participation in society be hindered by a history of cancer treatment? In addition, ethical questions are raised regarding the need to inform parents and the children about (possible) late effects. Further questions can be asked about the kind of supportive care needed and how this care can be offered. In this respect, the documents published by the international working committee of SIOP are of interest. These documents offer guidelines to the clinician and coworkers to meet the demands arising from the rights of the child and the parents in obtaining optimal medical and psychosocial care. This committee...
has already published guidelines for care of long-term survivors (Masera et al., 1996), which stress that each treatment center should offer a counseling center for serious medical and psychosocial problems. Moreover, the committee recommends preventive as well as supportive programs for long-term survivors with specific adjustment problems. Implementation of these guidelines will be encouraged if they are supported by findings of empirical research. At the time the guidelines for survivors were written, the studies done on late effects of childhood cancer were very limited. Three reviews have recently been published by European authors about psychological consequences of surviving childhood cancer. Stam, Grootenhuis, and Last (2001) selected English-language studies published since 1985 that were particularly focused on social and emotional adjustment of young survivors (18 years of age or younger at the time of study). Langeveld, Stam, Grootenhuis, and Last (2002) focused on young adult survivors (mainly at least 18 years old at the time of investigation) and QoL domains pertinent to them. Eiser, Hill, and Vance (2000) reviewed studies about psychological consequences since 1990. These reviews give us the opportunity to compare the results of current research in pediatric psycho-oncology, because they provide information about the type of cancer, age at evaluation and diagnosis, control group, instruments, and results of relevant studies. In this article, the focus is on the research done in the field of survivors of childhood cancer from 1985 until 2000, and especially on emotional and social adjustment. The question is: What are the differences and similarities in the topics, focus, and methods used in the studies included in these reviews from (1) the different developed countries and (2) over time? Finally, possible directions of further research will be discussed.

Evaluation of the Reviews

In order to gain insight into the similarities and differences among studies, we decided to reexamine the data presented in the aforementioned reviews. In total, Stam et al. (2001) included 45 articles about 39 studies; Langeveld et al. (2002) included 31 articles about 30 studies; and Eiser, Hill, and Vance (2000) included 20 articles.

The review by Stam et al. (2001) was carried out in the following way. Studies published in English since 1985 in journals and books in the field of social sciences, pediatrics, and nursing were identified using computer-based searches in Medline and PsychInfo. The following keywords were used: cancer/neoplasms, survivors, late effects/longterm effects, adolescence/childhood, psychology/psychiatry. In addition, references cited in the identified studies were searched for relevant information. The review is particularly focused on social and emotional adjustment. Results about physical, neuropsychological, or intellectual functioning of the cancer survivors are not reported, and studies exclusively dealing with functioning in these domains were excluded. The review is focused on young survivors, age 18 or younger at time of study. All types of cancer were included, and there was no strict criterion about length of survival. Although a 5-year period without treatment can be considered as a criterion for survival of childhood cancer, several investigators also consider children with shorter duration of survival. This is due partly to the different survival perspectives for different diagnoses in childhood cancer. An ideal study sample should include a control group of healthy peers and the use of standardized instruments. Because the application of all these criteria would have resulted in too few studies, the investigators decided to include studies using standardized instruments and having a sample size of at least 20 survivors. All 45 articles from 39 studies found are listed in Appendix I.

Langeveld et al. (2002) selected the articles for the review as follows. A literature search of English-language studies for the years 1985–2001 was conducted using the databases of Medline, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Embase, and PsychInfo. Key terms included childhood cancer, long-term survivors, and late effects and were combined with dimensions often included as components of QoL, including psychological/social adjustment, employment/health insurance, schools/learning, and QoL/health status. Relevant articles were then hand-searched for further pertinent references. This review has been conducted according to the methodological criteria for the inclusion of studies in the field of psychosocial pediatric oncology recommended by Eiser, Hill, and Vance (2000). These criteria are (1) well-validated and reliable measures, (2) a well-matched control group or comparison with culturally appropriate measurement norms, (3) information about demographics and illness and treatment factors (at least cancer diagnosis and time since diagnosis), (4) respondent rate, and (5) use of appropriate rigorous statistical tests. Additional selection criteria included studies in which survivors were the primary source of QoL information, by means of either interviews or completion of self-report questionnaires. Studies with no more than 20% proxies as the primary source of information were included in this review; 7 studies were based on survivors diagnosed before 20 years of age; and 8 studies were based on survivors at least 5 years after completion of therapy. Initially, the selection of the
studies in this review was conducted by two reviewers based on the above-mentioned methodological criteria. However, it was found that in most studies, survivors' social functioning (e.g., education, employment) was not measured with standardized, well-validated instruments. Because they did not want to exclude the social aspects of survivors' QoL, the investigators decided to include these studies in the review as well, aware of their methodological limitations. A total of 31 articles of 30 empirical studies were found that met the inclusion criteria (see Appendix II). Additional references have been added to this manuscript, including papers published later (see Appendix III). For Appendix III, we searched Medline and PubMed for references with comparable key words as the two reviewers described before. Articles were not hand-searched for additional references, so the appendix does not presume to be conclusive.

Articles in the review by Eiser, Hill, and Vance (2000) were included on the basis of (1) publication since 1990, (2) English language only, and (3) use of standardized measures and statistical tests to compare scores with population norms or matched controls. The review included only four studies that were not covered in the other two reviews. These four studies were excluded based on exclusion criteria used in the other two reviews (Eiser et al., 1997; Kupst et al., 1995; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993; Stern, Norman, Zevon, 1993).

In the reviews headed by Stam and by Langeveld, a table was published that includes summaries of the type of cancer, age at evaluation and diagnosis, and information about the control group, instruments, and results. All the data from these tables have been analyzed by the first and second author, on the basis of inclusion of young (<18 years of age at time of investigation) or older survivors (≥18 at time of investigation); 5-year period of publication (1986–1990, 1991–1995, 1996–2000); origin of the study (North America, Europe, or Australia); journal type (medical, psychological/psychiatric, or Journal of Pediatric Psychology); number of survivors (20–40, 41–99, ≥100); design (cross-sectional or longitudinal); inclusion of a control group; diagnosis (ALL and/or lymphomas, brain tumors, mixed, or only sarcomas); and (9) whether or not standardized instruments were used on the following domains:

- global emotional functioning (e.g., General Health Questionnaire, Profile of Mood States, Symptom Checklist);
- self-esteem/self-concept (e.g., Rosenberg Self-esteem; Piers-Harris Self-concept scale);
- anxiety (e.g., State-Trait Anxiety Inventory, Revised Children's Manifest Anxiety Scale);
- depression (e.g., Child Depression Rating Scale);
- quality of life (e.g., Short Form–12, Health Utility Index, Pediatric Oncology Quality of Life Scale);
- family functioning (e.g., Family Adaptability and Cohesion Evaluation Scale);
- coping (Nowicki-Strickland Locus of Control; control belief scale; social support scales);
- posttraumatic stress (e.g., Impact of Events);
- intellectual functioning (IQ tests or educational attainment); and
- personality (e.g., Personality Inventory for Children).

Additionally, we analyzed whether researchers measured behavioral symptoms (Child Behavior Checklist [CBCL]) in their study. Only standardized questionnaires were categorized, with the exception of educational attainment. Studies that consisted of only interviews (mainly about survival aspects such as problems with life insurance, job discrimination, or sexual issues) were included in the reviews but not categorized.

All aforementioned data were entered into an SPSS (Statistical Package for Social Sciences) database. In the case of studies published in more than one article, we counted the inclusion of survivors, number of survivors, design, control group, diagnosis, and instruments used per study. The 5-year period and journal type were counted for number of articles. For all variables among the studies, we compared differences in methods and constructs/instruments for study origin (North America, Europe, Australia) and the 5-year periods of publication (see above), using chi-square tests.

Results

In total, 76 articles involving 69 separate studies were analyzed. Of these 69 studies, 48 (70%) were carried out in the United States, 16 (23%) in Europe, 4 (6%) in Australia, and 1 (1%) in Canada. Of the 16 studies carried out in Europe, 5 (31%) were in the United Kingdom, 3 (19%) in the Netherlands, 3 (19%) in Finland, 2 (13%) in Sweden, and 1 each (all 6%) in Israel, Austria, and Norway. Five studies reported data in 2 articles (3 studies from the United States, 1 from Australia, and 1 from Canada), and material from an Australian study was published in 3 journals. For further analysis, we grouped together the studies from North America (United States/Canada) and the studies from Europe,
In each of the 5-year periods of 1986–1990 and 1991–1995, 21 articles (28%) were published. There was an increase in publication between 1996 and 2000, with 34 articles (45%). Forty-two (55%) of all the 76 articles were published in medical journals, whereas 34 of the articles were published in psychological journals (22%), the *Journal of Pediatric Psychology* (17%), and psychiatric journals (5%).

Although there is some variation in survival in Europe (Gatta et al., 2003), the studies included in both reviews originate from countries with similarities in survival rates. The comparisons shown in Table I and Table II show the descriptive differences according to origin of study, as well as differences over time.

**Table I. Similarities and Differences in Survivor Studies Between North America and Europe/Australia**

<table>
<thead>
<tr>
<th>Origin of Study</th>
<th>North America, no. (%)</th>
<th>Europe/Australia, no. (%)</th>
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<tbody>
<tr>
<td></td>
<td>(n = 53 articles)</td>
<td>(n = 23 articles)</td>
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<tr>
<td></td>
<td>(n = 49 studies)</td>
<td>(n = 20 studies)</td>
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<tr>
<td>Type of journal</td>
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<tr>
<td>Medical</td>
<td>24 (45)*</td>
<td>18 (90)</td>
</tr>
<tr>
<td>Psychological/psychiatric</td>
<td>16 (30)</td>
<td>5 (10)</td>
</tr>
<tr>
<td><em>Journal of Pediatric Psychology</em></td>
<td>13 (25)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Publication in study period</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1986–1990</td>
<td>18 (34)*</td>
<td>3 (13)</td>
</tr>
<tr>
<td>1996–2000</td>
<td>18 (34)</td>
<td>16 (70)</td>
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<tr>
<td>Study (n = 69)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Young survivors (review Stam)</td>
<td>30 (61)</td>
<td>9 (45)</td>
</tr>
<tr>
<td>Older survivors (review Langeveld)</td>
<td>19 (39)</td>
<td>11 (55)</td>
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<tr>
<td>Number of survivors (n = 69)</td>
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<tr>
<td>20–40</td>
<td>14 (29)</td>
<td>8 (40)</td>
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<tr>
<td>41–99</td>
<td>17 (35)</td>
<td>8 (40)</td>
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<tr>
<td>≥100</td>
<td>18 (37)</td>
<td>4 (20)</td>
</tr>
<tr>
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<tr>
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<td>46 (94)</td>
<td>18 (90)</td>
</tr>
<tr>
<td>Longitudinal</td>
<td>3 (6)</td>
<td>2 (10)</td>
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<tr>
<td>Use of control group (n = 69)</td>
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<tr>
<td>30 (61)</td>
<td>15 (75)</td>
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<tr>
<td>Diagnosis (n = 69)</td>
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<tr>
<td>Leukemia and/or lymphoma</td>
<td>12 (26)</td>
<td>7 (35)</td>
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<tr>
<td>Brain tumors</td>
<td>4 (8)</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Mixed</td>
<td>30 (61)</td>
<td>9 (45)</td>
</tr>
<tr>
<td>Sarcomas</td>
<td>3 (6)</td>
<td>3 (15)</td>
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<tr>
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<td></td>
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<tr>
<td>Self–esteem</td>
<td>13 (27)</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Global emotional functioning</td>
<td>14 (29)</td>
<td>8 (40)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>8 (16)</td>
<td>4 (20)</td>
</tr>
<tr>
<td>Depression</td>
<td>5 (10)</td>
<td>2 (10)</td>
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<tr>
<td>Quality of life</td>
<td>1 (2)</td>
<td>4 (20)**</td>
</tr>
<tr>
<td>Family functioning</td>
<td>11 (22)</td>
<td>2 (10)</td>
</tr>
<tr>
<td>Coping</td>
<td>8 (16)</td>
<td>3 (15)</td>
</tr>
<tr>
<td>Posttraumatic stress</td>
<td>11 (22)</td>
<td>0 (0)*</td>
</tr>
<tr>
<td>IQ or educational attainment</td>
<td>10 (20)</td>
<td>8 (40)</td>
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<tr>
<td>Behavior symptoms</td>
<td>12 (25)</td>
<td>5 (25)</td>
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<tr>
<td>Personality</td>
<td>5 (10)</td>
<td>2 (10)</td>
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*yes = standard instrument used in domain. Chi-square test: *p < .05; **p < .01.*

**North America Versus Europe/Australia**

Comparison between these two geographic areas on the different variables is presented in Table I. The researchers from Europe/Australia have published significantly more in medical journals. Evaluating the 76 articles that
were included in the two reviews, it is shown that only studies from the United States and Canada were published in the *Journal of Pediatric Psychology*. Number of publications over time remained stable for U.S./Canadian researchers, whereas publications from Europe/Australia during 1996–2000 more than tripled. This difference for origin of study and 5-year period is significant. Studies with a large number of survivors and particularly with young survivors are more often from the United States. Most of the 76 studies were cross-sectional (94% in North America and 90% in Europe/Australia), and most included a control group (61 vs. 75%, respectively). Most of the populations under study included mixed diagnoses, but in some of these studies, patients with brain tumors or tumors of the central nervous system were excluded. Comparing the measurements used, it becomes clear that in Europe/Australia self-esteem, global emotional functioning, QoL, and IQ/educational attainment are more often included as outcome measures. For only two measurements were significant differences shown for origin of study. In the United States and Canada, posttraumatic stress disorder has been significantly more often studied compared with Europe/Australia, which in turn has significantly more often studied QoL. The interest in anxiety, depression, coping, CBCL parameters, and personality is equal in both geographic areas.

### Table II. Similarities and Differences in Survivor Studies by Publication Period

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<tr>
<td><strong>Type of journal (N = 76)</strong></td>
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<tr>
<td>Medical</td>
<td>15 (71)</td>
<td>10 (48)</td>
<td>17 (50)</td>
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<tr>
<td>Psychological/psychiatric</td>
<td>4 (19)</td>
<td>9 (43)</td>
<td>8 (24)</td>
</tr>
<tr>
<td><em>Journal of Pediatric Psychology</em></td>
<td>2 (10)</td>
<td>2 (10)</td>
<td>9 (27)</td>
</tr>
<tr>
<td><strong>Number of survivors in study (N = 69)</strong></td>
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<td></td>
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<tr>
<td>20–40</td>
<td>4 (21)</td>
<td>6 (32)</td>
<td>12 (39)</td>
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<tr>
<td>41–99</td>
<td>8 (42)</td>
<td>7 (37)</td>
<td>10 (32)</td>
</tr>
<tr>
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<td>9 (29)</td>
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<tr>
<td>Young survivors (review Stam)</td>
<td>10 (48)</td>
<td>13 (62)</td>
<td>22 (65)</td>
</tr>
<tr>
<td>Older survivors (review Langeveld)</td>
<td>11 (52)</td>
<td>8 (38)</td>
<td>12 (35)</td>
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<tr>
<td><strong>Design (N = 69)</strong></td>
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<td></td>
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<tr>
<td>Cross-sectional</td>
<td>17 (90)</td>
<td>18 (95)</td>
<td>29 (94)</td>
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<tr>
<td>Longitudinal</td>
<td>2 (11)</td>
<td>1 (5)</td>
<td>2 (7)</td>
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<td><strong>Use of control group (N = 69)</strong></td>
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<td><strong>Diagnosis (N = 69)</strong></td>
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<td>2 (11)</td>
<td>2 (7)</td>
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<tr>
<td>Mixed</td>
<td>13 (68)</td>
<td>13 (68)</td>
<td>12 (40)</td>
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<tr>
<td>Sarcomas</td>
<td>1 (5)</td>
<td>1 (5)</td>
<td>4 (13)</td>
</tr>
<tr>
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<tr>
<td>Total use</td>
<td>30 (M = 1.4)</td>
<td>46 (M = 2.2)</td>
<td>93 (M = 2.7)</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>4 (21%)</td>
<td>10 (53)</td>
<td>7 (23)</td>
</tr>
<tr>
<td>Global emotional functioning</td>
<td>8 (42)</td>
<td>3 (16)</td>
<td>11 (36)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0 (0)</td>
<td>3 (16)</td>
<td>9 (29)*</td>
</tr>
<tr>
<td>Depression</td>
<td>3 (16)</td>
<td>2 (11)</td>
<td>2 (7)</td>
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<tr>
<td>Quality of life</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>5 (16)*</td>
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<td>Family functioning</td>
<td>3 (16)</td>
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<td>2 (11)</td>
<td>5 (26)</td>
<td>4 (13)</td>
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<tr>
<td>Posttraumatic stress</td>
<td>1 (5)</td>
<td>2 (11)</td>
<td>8 (26)*</td>
</tr>
<tr>
<td>IQ or educational attainment</td>
<td>4 (21)</td>
<td>7 (37)</td>
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<td>Personality</td>
<td>2 (11)</td>
<td>2 (11)</td>
<td>3 (10)</td>
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</table>

*p < .05. yes = standard instrument used in domain. M = mean.*
Publication Period
The information about the review articles analyzed over time periods is presented in Table II. Over time, publication in medical journals has decreased, whereas publication in the *Journal of Pediatric Psychology* has increased. There is a small decrease of large studies including more than 100 survivors (37→32→29%) and studies including older survivors (52→38→35%). The inclusion of mixed diagnoses has decreased, and the studies focusing on children with ALL and/or lymphoma or sarcomas have increased slightly. A clear increase is seen in the number of outcome measures used. The mean number of measurements increases from 1.4 to 2.2 to 2.7 in studies over time. Looking at the results of the measurements used in the different publication periods, a significant increase of interest is shown for measuring anxiety, QoL, and posttraumatic stress. A decreased interest is visible for measuring depression, but this is not a significant difference. The use of self-esteem measurements, family functioning, coping, IQ, and CBCL increased in the period 1991–1995 and decreased again afterward. Measurement of personality stayed around the same over time. Only the measurement of global emotional functioning decreased in the midperiod and increased again thereafter. These differences did not reach significance.

Discussion
Given the overlap in organization of specialist centers and many key clinical trials, medical care of children with cancer is broadly equivalent wherever they are treated in the developed world. We found in our analysis of psychosocial research in survivors similarities as well as remarkable differences in themes. A relatively long history of collaboration between oncologists in North America and Europe/Australia has done much to ensure a uniform high standard of care throughout the developed world but has not led to an elaborated and comprehensive program of studies on psychosocial late effects of cancer treatment in childhood. It is not surprising that similar research questions dominate the literature on both sides of the Atlantic. For the most part, researchers read the same English-language journals. Consequently, methods, theories, and objectives of research are broadly comparable. There are disadvantages to this in that the focus of research may be too narrow or based on a restricted range of theories, not specifically developed for work with children with cancer. It is important to keep in mind that in the reviews analyzed in this paper, articles were included focusing on psychosocial research until approximately 2000. Thereafter, a number of additional reports have been published.

Although QoL research has become a major focus of attention in pediatric outcome research, the analysis of the reviews here shows that research with QoL instruments remains limited. To date, most studies have focused on broad adjustment issues such as depression and anxiety, educational attainment, and social functioning. Only five of the analyzed studies included a QoL instrument, and this research was carried out recently. Only just recently have more studies been published focusing on QoL. Eiser, Vance, Horne, Glaser, and Galvin (2003) used a cancer-specific questionnaire. It is reasonable to believe that in the future, more research will be carried out in the QoL area. Since no standardized instrument exists at present that can be applied with equal relevance in different European pediatric populations, the collaborative European KidScreen project aims to develop a standardized screening instrument for children’s QoL. This instrument, which is almost ready for implementation, can be used in representative national and European health surveys (Ravens-Sieberer et al., 2001). It will help to contribute to a better understanding of perceived health in children and adolescents and to identify populations at risk. However, it is a generic instrument and is not necessarily sensitive to the specific issues of surviving childhood cancer.

Looking at the reviews, it seems that children with brain tumors have often been excluded from research. Only five studies included children with brain tumors, focusing on their psychosocial adjustment (see Appendix I: Carlson-Green, Morris, & Krawiecki, 1995; Carpentieri, Mulhern, Douglas, Hanna, & Fairclough, 1993; Glaser, Nik Abdul Rashid, & Walker, 1997; Radcliff, Bennet, Kazak, Foley, & Philips, 1996; Vannatta, Gartstein, Short, & Noll, 1998). In other studies with mixed diagnoses, these children are often excluded. However, more recently, neurocognitive and intellectual late effects and psychosocial functioning have been described for these children (Carpentieri et al., 2003; Zebrack et al., 2004), and this is an area of growing research for other pediatric diagnoses as well (e.g. Brown, Sawyer, Antoniou, Toogood, & Rice, 1999; von der Weid et al., 2003).

Future Research
There remain a number of limitations in quality of psychosocial research in childhood cancer survivors. Given the low incidence of the disease, collaboration is essential
in order to conduct studies with adequate statistical power. Recruitment of adequate sample sizes is dependent on collaboration among a number of centers, but collaboration is necessarily dependent on individual interests of staff, as well as availability of research nurses to help with data collection. This can vary from center to center and means that not all centers are equally representative. Centers also differ in availability of funding for research. This could influence the focus of the research in pediatric oncology and should be considered in future cross-cultural analyses. In all research, representativeness of samples is critical, yet many studies struggle to recruit 50% of eligible patients. In part, this problem arises from the amount of research that families are asked to participate in and is a further reason for collaboration. Furthermore, more studies are needed from more diverse countries, such as those with lower survival rates. Psychosocial research is limited in countries like Estonia, with a survival rate of 45%, compared with Nordic countries, with a survival rate of more than 75% (Gatta et al., 2003).

To determine the relative influence of age, illness, and treatment variables statistically, the size of a research sample has to be adequate. This demand poses a problem because the total number of children with cancer is small, and variations in age, illness, and treatment are relatively large. Large-scale studies may be important in identifying certain risk factors, but studies focused on homogeneous subgroups of patients will provide more information about the significance of risk factors involved for that population. In designing these studies, collaboration is needed at a national and international level. This is further dependent on the availability of parallel forms of measures in different languages. To date, the costs of translation and the formidable amount of work involved have proved to be major obstacles. This shortsightedness has resulted in an almost complete lack of measures suitable for international collaboration and is particularly a problem for work involving newly diagnosed patients (since evaluation of trials requires multisite collaboration), as well as for work involving survivors.

Keeping in mind the need to develop interventions to support young childhood cancer survivors, well-designed studies are needed to detect more precisely the predictors of adjustment. Apart from illness- and treatment-related factors, the role of coping, family functioning, and survivors’ functioning at diagnosis are variables that are important to investigate in relation to adjustment. In previous research the relation between family functioning and coping of children with cancer (Grootenhuis & Last, 2001) and their parents (Sloper, 2000) has already been investigated. It is important to note that for childhood cancer survivors, only a few intervention studies have been published e.g., (Kazak et al., 1999; Eiser, Hill, & Blacklay, 2000). Some of these studies included only a small number of patients, and little evidence has been found for the effect of different programs. We believe it should be an international priority to summarize the effects that have been found with interventions and to try to devote more time and money to the development of focused intervention programs for childhood cancer survivors.

Investigating the predictors of survivors’ adjustment requires a longitudinal research design (preferably from diagnosis to survivorship), a substantial sample size because of the statistical power, and the use of standardized instruments with available norm data. To increase sensibility, cancer-specific measures are recommended, as well as generic measures to allow comparison between survivors and control groups or the general population.

Future research efforts should be directed toward the mediating factors of psychosocial functioning that have received relatively little attention in previous studies, including the roles of coping and adaptation, social relationships, and family variables. Considering the fact that many survivors are functioning reasonably well and that not much difference is found between results in survivors and their peers (e.g., Barakat et al., 1997; Apajasalo et al., 1996), it would be interesting and advisable to investigate the role of denial and response-shift (changes of internal standards occurring in patients undergoing therapy). Further, it would be interesting to know whether and how survivors meet developmental tasks in growing up. More insight is therefore needed into the relation between the survivors’ course of life and their functioning in later life. In anticipation of this, a retrospective questionnaire was developed to measure survivors’ developmental history, that is, the course of life of adolescents and young adults (Grootenhuis, Stam, Destree-Vonk, Heymans, & Last, 2003).

Although the focus of the reviews studied in this article was not on cognitive functioning, it is remarkable that not many studies about cognitive functioning in (young) adult survivors of childhood cancer were found, in contrast with the large number of studies in children. It is not yet known what may happen to aging brains long after exposure to cranial radiation therapy and/or chemotherapy in childhood (Kingma, Rammeloo, van Der Does-van den Berg, Rekers-Mombarg, & Postma, 2000). Furthermore, in the adult cancer literature it is suggested that more research is needed because neuropsychological symptoms, in particular memory and...
concentration problems, are frequently reported by cancer patients treated with chemotherapy, even years after completion of treatment (Schagen et al., 1999).

We believe that it is of utmost importance to bridge the gap between the continents to support survivors more adequately. Therefore, we propose that the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology try to commit more researchers in the field of pediatric psychosocial oncology. They could organize satellite-symposia through the SIOP or the International Psycho-Oncology Society to increase international discussion of psychosocial research in pediatric oncology. Only when research findings are being shared will we be able to profit from each other’s findings.

Conclusions
When considering the achievements of pediatric oncology, it is customary to point to the establishment of international trials as a major contributing factor. The coordination of national databases is also important. If we are to conduct psychosocial exemplary work in this area, it is vital to establish national and international organizations for psychologists to parallel those already established for physicians. Opportunities need to be made available for social scientists to visit prestigious centers to learn from their strategies and experiences. International conferences focusing on issues of childhood cancer will also be important, since currently it may be difficult to justify travel expenses to general conferences, or those involving adults with cancer, when attention to issues of childhood cancer is relatively scant. Only by improving training for behavioral scientists, providing opportunities for work exchange, and increasing national, if not international, collaboration will we have the resources to develop reliable and valid measures and conduct work of the highest clinical and theoretical value. The benefits will be for the children and families but will also lead to a more professional and informed workforce.

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References


Appendix I. All 45 Articles From 39 Studies From the Review by Stam et al. (2000)


Appendix II. All 31 Articles From 30 Studies From the Review by Langeveld et al. (2002)


Appendix III. Additional Studies Published in 2000 and Thereafter


Langeveld, N. E., Grootenhuis, M. A., Voute, P. A., de Haan, R. J., & van den Bos, C. (2003). No excess...


