Changing pediatric cancer care: development and implementation of electronic patient and parent reported outcomes

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Chapter 4
Screening for psychosocial risk in Dutch families of a child with cancer: reliability, validity, and usability of the Psychosocial Assessment Tool

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ABSTRACT

Objective
The Psychosocial Assessment Tool (PAT) was developed to screen for psychosocial risk in families of a child diagnosed with cancer. The current study is the first describing the cross-cultural adaptation, reliability, validity, and usability of the PAT in an European country (Dutch translation).

Methods
A total of 117 families (response rate 59%) of newly diagnosed children with cancer completed the PAT2.0 and validation measures.

Results
Acceptable reliability was obtained for the PAT total score (a=.72) and majority of subscales (0.50–0.82). Two subscales showed inadequate internal consistency (Social Support a=.19; Family Beliefs a=.20). Validity and usability were adequate. Of the families, 66% scored low (Universal), 29% medium (Targeted), and 5% high (Clinical) risk.

Conclusions
This study confirms the cross-cultural applicability, reliability, and validity of the PAT total score. Reliability left room for improvement on subscale level. Future research should indicate whether the PAT can be used to provide cost-effective care.
INTRODUCTION

The diagnosis of cancer is a particularly severe threat and a potentially traumatic event\(^1\,^2\). Multiple stress reactions can be seen in patients and their families, ranging from a normal adaptive response to symptoms of anxiety and depression, sometimes reaching the level of psychopathology\(^3\). Although there is variability, consistent evidence demonstrates that pathological levels of distress are not the normative response in children or their parents, either during or after treatment\(^3\,^4\). A small, but substantial, number of families show problems in adapting to the new circumstances or present risk factors for developing psychological difficulties\(^5\). The way people react after a diagnosis varies and is dependent on many factors\(^5\). First, disease-related risk factors, such as severity, treatment intensity, and number and length of hospital admissions can influence family adaptation\(^5\,^6\). Second, socio-ecological factors play a role in adjustment, such as family functioning, parental cognitions and coping, social support, financial problems, and prior stressful life events\(^5\,^10\). Finally, child factors, such as behavioral problems and temperament, also affect family adjustment\(^5\,^11\). Assessing risk factors across these levels makes it possible to predict future psychosocial distress and to intervene accordingly.

In terms of psychosocial treatment, all families should be offered at least minimal psychosocial services to support adaptive responses, but it is important to focus especially on the families who are at greatest risk for problems, as they can benefit most from tailored psychosocial intervention\(^2\). Tailoring such care at an early phase for those families who need it most, might prevent escalation of distress. Given current economic constraints and limited availability of psychosocial services, it is particularly important to allocate resources in a cost-effective way and incorporate this into standards of care.

The Psychosocial Assessment Tool (PAT) is a brief parent-reported screening tool aimed at detecting families at risk for psychosocial difficulties in pediatric oncology. It assesses both child and family distress, and evidence-based risk and protective factors for developing distress\(^12\). The PAT is a unique screener of family stress. Most screening approaches are directed toward psychopathology rather than normative distress and are not intended to identify people with less severe problems who might benefit from psychosocial interventions\(^13\). Available screening instruments, such as the distress thermometer\(^14\), are focused on the individual, either child or parent, instead of the family system as a whole. An advantage of the PAT is that the content is based on both scientific research and clinical experience. The PAT maps on to the Pediatric Psychosocial Preventative Health Model (PPPHM), which conceptualizes three levels of risk\(^2\). The majority of families are resilient and able to adapt adequately when confronted with health-related stressors (Universal group). A smaller group of families is at risk for developing psychosocial distress (Targeted group). Another small group of families shows multiple risk factors for serious ongoing and escalating psychosocial distress (Clinical group). This classification and additional information on the risk and protective factors are intended to inform practice so as to provide personalized, family-based, and cost-effective psychosocial care\(^3\).

Research in the United States, Canada, and Australia showed the PAT to be a reliable and valid screening instrument, adequate for use shortly after the diagnosis of childhood cancer\(^12\,^15\,^16\).
Use has proven to be feasible both during the acute phase\textsuperscript{12,15,16} and in survivorship\textsuperscript{17}. Recently, the use of the PAT has also been extended to other disease groups\textsuperscript{18}. All studies showed somewhat similar distribution of scores into the three PPPHM categories: between 50\% and 70\% fell within the universal group, between 18\% and 36\% in the targeted group, and between 3\% and 16\% in the clinical group\textsuperscript{12,15-17,19,20}. Concerning the reliability of the PAT, the alpha of the total score is consistently acceptable; however, moderate to low alphas have been reported on three of the seven subscales, namely “Structure and Resources,” “Social Support,” and “Family Beliefs”\textsuperscript{12,15,19,21}. Previous research also indicated that a PAT score at diagnosis predicts the use of psychosocial services during treatment\textsuperscript{4,22}.

The present study is the first to culturally validate the PAT in a European country. The first aim is to cross-culturally adapt the PAT for usage in the Netherlands using the methods outlined by Beaton et al.\textsuperscript{23}. In their view, cross-cultural adaptation contains both the process of translation and adaptation of a questionnaire for use in another setting and is completed in six stages: (1) initial translation, (2) synthesis of translations, (3) back translation, (4) expert committee, (5) pilot testing, and (6) submission of documentation. Then, this study aims to investigate the reliability and validity of the total PAT score and its subscales in a Dutch pediatric oncology sample. Finally, the usability of the Dutch version of the PAT, as rated by the parents, will be explored. Minor cultural differences in the PAT were expected. In the Netherlands, distances to the hospital are relatively short and all families have obligatory public health insurance. We expect that after minor textual adjustments, the PAT will be valid, reliable, and usable. We also expect to find similar risk classification as was found in previous research on the PAT.

**Method Procedure**

Families of newly diagnosed patients were asked to participate in this study in four pediatric oncology centers in the Netherlands: Emma Children’s Hospital/AMC Amsterdam, Radboud University Medical Center Nijmegen, Sophia Children’s Hospital/Erasmus MC Rotterdam, and VU University Medical Center Amsterdam. During a 19-month period between June 2012 and December 2013, pediatric oncologists identified newly diagnosed patients. Inclusion criteria were (1) a confirmed first diagnosis of a pediatric cancer in a child to the age of 19 years, (2) speaking fluently Dutch, and (3) receiving curative treatment. Eligible families were approached by the investigators during the first weeks after diagnosis either during inpatient hospitalization, outpatient clinic visit, or by phone and were given both written and oral information about the study. After both parents and patient (when 12 years) provided written informed consent, they were asked to register on the Web site (www.hetklikt.nu) to complete the PAT and validation questionnaires digitally around 1 month after diagnosis. In the Netherlands, it is obligatory for children >12 years of age to also give consent. All Medical Ethical Committees of the participating hospitals approved this study.
Participants

A total of 259 children were diagnosed with cancer from June 2012 to December 2013, of which 227 families were eligible for participation according to our inclusion criteria (Figure 1). Of those, 197 could be invited to participate of which 117 families (59% final response rate) completed the questionnaires at baseline (M=33.9 days postdiagnosis; SD=9.24; Range=16–59). To avoid selective overrepresentation of families and to minimize family burden, only one parent per family was asked to complete the measures. No differences were found between responders (N=117) and nonresponders (N=80) with respect to age, gender, and diagnostic subcategory (hematological, neuro-oncological, or solid tumor). Details about the socio-demographic characteristics of the sample are listed in Table I.
Table 1. Demographic and Illness information of sample (N = 117)

<table>
<thead>
<tr>
<th>Variables</th>
<th>N / M</th>
<th>% / SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>51</td>
<td>43.6</td>
</tr>
<tr>
<td>Male</td>
<td>66</td>
<td>56.4</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 2 years</td>
<td>15</td>
<td>11.9</td>
</tr>
<tr>
<td>2-5 years</td>
<td>34</td>
<td>29.9</td>
</tr>
<tr>
<td>6-10 years</td>
<td>25</td>
<td>21.4</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>43</td>
<td>36.8</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hematological</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>30</td>
<td>25.6</td>
</tr>
<tr>
<td>Hodgkin’s lymphoma</td>
<td>8</td>
<td>6.8</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>13</td>
<td>11.1</td>
</tr>
<tr>
<td>Neuro-oncological</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain/CNS tumor</td>
<td>19</td>
<td>16.2</td>
</tr>
<tr>
<td><strong>Solid</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ewing’s sarcoma</td>
<td>7</td>
<td>6.0</td>
</tr>
<tr>
<td>Neuroblastoma</td>
<td>8</td>
<td>6.8</td>
</tr>
<tr>
<td>Rhabdomyosarcoma</td>
<td>6</td>
<td>5.1</td>
</tr>
<tr>
<td>Wilm’s tumor</td>
<td>8</td>
<td>6.8</td>
</tr>
<tr>
<td>Osteosarcoma</td>
<td>11</td>
<td>9.4</td>
</tr>
<tr>
<td>Other solid tumor</td>
<td>7</td>
<td>6.0</td>
</tr>
<tr>
<td><strong>Time since diagnosis (days)</strong></td>
<td>33.9</td>
<td>9.24</td>
</tr>
</tbody>
</table>

**Note.** Education level of the parent was classified according to the International Standard Classification of Education: low = level 0-2, medium = level 3-5, high = level 6-8.[42]

Measures

Psychosocial Assessment Tool (PAT 2.0)

The PAT[12] is composed of seven subscales: Family Structure and Resources, Family Social Support, Family Problems, Parent Stress Reactions, Family Beliefs, Child Problems, and Sibling Problems. Each subscale includes 3–15 items, which are scored dichotomously (risk=1/no risk=0). Scores on the seven subscales were calculated by dividing the number of high-risk items by the total number of items in the respective domain, yielding a subscale score from 0.00 to 1.00. The subscale scores were summed to create a total score of 0.00–7.00. PAT total scores ranging
from 0.00 to 0.99 were considered universal, 1.00 to 1.95 targeted, and 2.0 clinical. Internal consistency of total PAT score was good (α=.81), and subscales ranged from acceptable to good (α=.59– .81). Minor cultural differences were expected compared with the US PAT. For example, in the Netherlands, all families have public health insurance, which covers most treatment costs, and live within 2 hr of an academic medical center. Parents also get a minimum of 2 weeks paid leave to care for their ill child. The item on health insurance coverage was therefore not included. Omission of this item on health insurance did not affect scoring.

PAT-Netherlands (PAT-NL) Usability Questionnaire To assess the usability of the PAT in the Dutch population, a five-item questionnaire was developed. Parents rated each item on a visual analogue scale (VAS) scale ranging from 0 (totally disagree) to 100 (totally agree). (Example of questions: “Did you think the questions in the PAT were clear?”).

**Validation Measures**

Each PAT subscale, except for the Structure and Resources subscale, was validated using parent-report standardized instruments to measure the similar construct (see Table III).

*Inventory Social Reliance*

The Inventory Social Reliance (ISR) is an inventory designed to identify the social network of a person. The five items measuring perceived social support were used. Items are scored on a 4-point Likert scale. Internal consistency for the ISR in the current sample was excellent (α=.94).

*Strengths and Difficulties Questionnaire*

The Strengths and Difficulties Questionnaire (SDQ) is a valid and reliable instrument to assess parental report of psychosocial problems and strengths of the patient. There are 25 items on five subscales: hyperactivity/attention deficit, emotional problems, problems with peers, behavioral problems, and prosocial behavior. All items are scored on a 3-point scale to the extent of agreement (not true, somewhat true, certainly true). For the current study, we used the SDQ to assess problems in the patient as well as in the siblings using two versions, one for 3-year-old children and one for 4–16-year-old children. Because we only used it for validation, parents also completed the SDQ for patients and siblings aged 17–18 years. Internal consistency for the SDQ in the current sample was good (α=.71) for the 3-year patient version, 3-year sibling version (α=.75), and for both the 4–16-year patient and sibling version (α=.66).

*Hospital Anxiety and Depressions Scale*

The Hospital Anxiety and Depressions Scale (HADS) is a valid and reliable self-report 14-item instrument to assess symptoms of anxiety and depression. Items are scored on a 4-point Likert-type rating scale. Internal consistency for the HADS in the current sample was excellent (α=.91).

*Parenting Stress Index-Short Version*

The Parenting Stress Index (PSI)-short version is composed of 25 items, rated on a 6-point Likert scale, assessing perceived parental stress in the nurturing of their child. Parents of patients aged 2–18 years completed the PSI. Internal consistency for the PSI in the current sample was excellent (α=.92).
Illness Cognitions Questionnaire-Parent Version

The Illness Cognitions Questionnaire-parent version (ICQ-P)\textsuperscript{10,29} consists of three subscales, that is, helplessness, acceptance, and perceived benefits to assess parental cognitions regarding the child’s illness. Each of the three subscales is composed of six items rated on a 4-point Likert scale. Internal consistency for the ICQ-P in the current sample was excellent (helplessness $a= .83$, acceptance $a= .89$, perceived benefits $a= .87$).

Statistical Analyses

In the process of culturally adapting the PAT, guidelines of Beaton et al.\textsuperscript{23} were followed. First, the PAT was professionally translated into Dutch (forward translation) by two independent translators (Bureau Bothof). Both translations were compared and synthesized into one version. This version was then translated back to English by an independent native English speaker. This back-translated English version was reviewed and approved by the developer of the PAT. Then, a pilot study was performed to test this version. A total of 25 parents completed the PAT before the start of this study. Internal consistencies between $a= .40$ (family beliefs) and $a= .85$ (sibling problems) were found. Given this preliminary evidence of success in adaptation, the Dutch PAT was approved for usage in the present study. First, reliability was calculated for the PAT2.0 total and subscale scores\textsuperscript{12} using Cronbach’s alpha. Owing to the diversity of items within one scale, the small number of items in some subscales, and previous results on the internal consistency of the different subscales of the PAT, a Cronbach’s alpha of .50 was considered acceptable\textsuperscript{30}. For scales where the initial internal consistency was inadequate ($a< .50$), individual items were further examined with respect to variability and inter-item correlations.

When an item was not normally distributed and/or had zero variance, the scoring of the item was adapted or the item was removed from the calculation of the PAT total score as described below. Second, descriptive statistics were calculated for PAT total and subscale scores. Third, content validity and criterion-related validity were examined using Pearson correlations between each PAT subscale, except for the Structure and Resources subscale, and the standardized validation instrument corresponding to that scale. Criterion validity was tested by correlating the PAT total score with standardized measures of parent distress, family functioning, child functioning, and sibling functioning (HADS, PSI, ISR, ICQ-P, SDQ, and SDQ-sibling) version using Pearson correlations. Medium correlations ($r= .30$) will be interpreted as meaningful. To identify a medium correlation, a sample of 111 analyzable participants will provide 95% power to differentiate a statistical significant correlation from no correlation at the 0.05 significance level\textsuperscript{31}. With a sample size of $N= 117$ this study provides adequate power.

The distribution of PAT total scores into the three risk categories was calculated. This distribution of total scores for mothers and fathers separately was then compared with the distribution found in previous studies with the PAT using cross-tabs. Fisher’s exact test was interpreted owing to small $N$ in one cell ($N< 5$). Finally, descriptive statistics for the usability questionnaire were used to evaluate parents’ opinion regarding the PAT. All statistical analyses were conducted using the Statistical Package for Social Sciences version 20. In this study, no missing data were possible because of our electronic test environment. $p$-values (two-sided tests) .05 were considered statistically significant. Pearson correlations $>.1$ were considered small, $>.3$ medium, and $>.5$ large\textsuperscript{30}.
RESULTS

Reliability

Internal consistency for the PAT total score was acceptable (α=.69, Table II). For four of the seven subscales, an acceptable alpha coefficient was obtained (α=.50–.82). For the subscales Structure and Resources, Social Support, and Family Beliefs, initial internal consistencies were unacceptable (α=.31, α=.19, α=.20, respectively). After further examination of these subscales, in agreement with the developer of the PAT, some cultural adaptations in the subscale Structure and Resources were made. The items “age person of completing form,” “number of children,” and “transport to hospital” were removed owing to limited spread. In the Netherlands, none of the families scored at risk on these items. For the item “financial problems,” also the option “minor problems” was considered as a risk factor in the Netherlands. As a result, for the Dutch population only the items “number of adults,” “marital status,” “education level,” “financial problems,” and “areas financial problems” were used for calculating the Structure and Resources subscale and the total score. After these cultural adaptations the internal consistency of the Structure and Resources subscale was acceptable, α=.65, and the PAT total score increased to α=.72.

Mean PAT Scores

Descriptive statistics were calculated for the PAT total and subscale scores (Table II). After minor cultural adaptations, the mean score on the Dutch PAT was M=0.80, with a standard deviation (SD) of 0.62. Total scores ranged from 0.00 to 3.10, and median score was Med=0.65.

<p>| Table II. Descriptive Statistics and Reliability of the PAT2.0 (Dutch translation) |
|----------------------------------|------------------|----------------|------------------|------------------|</p>
<table>
<thead>
<tr>
<th>PAT 2.0 scale</th>
<th>Scale range</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
<th>95% CI</th>
<th>Internal consistency (cultural adaptation)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAT Total</td>
<td>0-7</td>
<td>.80</td>
<td>.62</td>
<td>.00-3.10</td>
<td>.69 - .91</td>
<td>.69 - .72</td>
</tr>
<tr>
<td>1. Structure/resources</td>
<td>0-5</td>
<td>.41</td>
<td>.87</td>
<td>0-4</td>
<td>.25 - .57</td>
<td>.31 - .65</td>
</tr>
<tr>
<td>2. Social support</td>
<td>0-4</td>
<td>.20</td>
<td>.46</td>
<td>0-2</td>
<td>.12 - .28</td>
<td>.19 - .19</td>
</tr>
<tr>
<td>3. Child problems</td>
<td>&lt; 2 years age (N = 15)</td>
<td>0-8</td>
<td>2.27</td>
<td>1.83</td>
<td>0-6</td>
<td>1.94 - 2.60</td>
</tr>
<tr>
<td></td>
<td>≥ 2 years age (N = 102)</td>
<td>0-15</td>
<td>3.31</td>
<td>3.11</td>
<td>0-12</td>
<td>2.75 - 3.87</td>
</tr>
<tr>
<td>4. Sibling problems</td>
<td>&lt; 2 years age (N = 11)</td>
<td>0-8</td>
<td>.56</td>
<td>.73</td>
<td>0-2</td>
<td>.43 - .69</td>
</tr>
<tr>
<td></td>
<td>≥ 2 years age (N = 86)</td>
<td>0-15</td>
<td>1.46</td>
<td>1.92</td>
<td>0-8</td>
<td>1.11 - 1.81</td>
</tr>
<tr>
<td>5. Family problems</td>
<td>0-8</td>
<td>.75</td>
<td>1.02</td>
<td>0-4</td>
<td>.56 - .94</td>
<td>.50 - .50</td>
</tr>
<tr>
<td>6. Stress reaction</td>
<td>0-3</td>
<td>.36</td>
<td>.68</td>
<td>0-3</td>
<td>.24 - .48</td>
<td>.55 - .55</td>
</tr>
<tr>
<td>7. Family beliefs</td>
<td>0-4</td>
<td>.59</td>
<td>.71</td>
<td>0-3</td>
<td>.46 - .72</td>
<td>.20 - .20</td>
</tr>
</tbody>
</table>
Chapter 4

**Criterion-Related Validity**

The correlations of the PAT total score with validation measures can be found in Table III. The total PAT score was significantly related to all of the validation measures ($r=0.23-0.61$), with the exception of the ICQ-P perceived benefits ($r=0.07$). All correlations were medium to large, except for the ICQ-P helplessness ($r=0.23$).

**Content Validity**

With respect to content validity, each subscale of the PAT was significantly associated with the corresponding validating measure ($r=0.20-0.80$), with the exception of Family Beliefs and ICQ-P helplessness ($r=0.14$; see Table III). For the subscales Child Problems, Sibling Problems, and Stress Reaction, correlations were large; for the subscale Family Problems, correlation was medium; and for the subscales Social Support and Family Beliefs, correlations were small.

### Table III. Correlations of PAT Total Score (Criterion-Related Validity) and Subscale Scores (Content Validity) with Validation instruments

<table>
<thead>
<tr>
<th>PAT 2.0 scale</th>
<th>Validation instrument</th>
<th>Correlation</th>
<th>P-values</th>
</tr>
</thead>
<tbody>
<tr>
<td>PAT Total</td>
<td>ISR</td>
<td>-0.38</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>SDQ</td>
<td>0.61</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>SDQ-sibling version</td>
<td>0.49</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>HADS-total</td>
<td>0.46</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>HADS-anxiety</td>
<td>0.47</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>HADS-depression</td>
<td>0.41</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>PSI</td>
<td>0.56</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>ICQ-P helplessness</td>
<td>0.23</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td>ICQ-P acceptation</td>
<td>-0.35</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>ICQ-P perceived benefits</td>
<td>-0.07</td>
<td>0.45</td>
</tr>
</tbody>
</table>

1. Structure/resources
   - ISR
   - SDQ
2. Social support
   - ISR
   - SDQ
3. Child problems
   - SDQ-sibling version
4. Sibling problems
   - HADS-total
5. Family problems
   - HADS-anxiety
   - HADS-depression
6. Stress reaction
   - PSI
7. Family beliefs
   - HADS-total
   - HADS-anxiety
   - HADS-depression
   - ICQ-P helplessness
   - ICQ-P acceptation
   - ICQ-P perceived benefits

*Note.* ISR = Inventory Social Reliance, SDQ = Strengths and Difficulties Questionnaire, HADS = Hospital Anxiety and Depression Scale, PSI = Parenting Stress Index, ICQ-P = Illness Cognitions Questionnaire-parent version. $N = 117$
Table IV. Percentage of Mothers and Fathers in respectively Universal, Targeted, and Clinical Group

<table>
<thead>
<tr>
<th></th>
<th>Universal</th>
<th>Targeted</th>
<th>Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mothers (%)</td>
<td>Fathers (%)</td>
<td>Mothers (%)</td>
</tr>
<tr>
<td>Pai et al.12</td>
<td>55</td>
<td>67</td>
<td>32</td>
</tr>
<tr>
<td>McCarthy et al.16</td>
<td>62</td>
<td>75</td>
<td>27</td>
</tr>
<tr>
<td>Barrera et al.15</td>
<td>60</td>
<td>60</td>
<td>35</td>
</tr>
<tr>
<td>Sint Nicolaas et al., this study</td>
<td>68</td>
<td>63</td>
<td>27</td>
</tr>
</tbody>
</table>

Note. United States completion time M = 7 days, mothers N = 132, fathers N = 73
Australia completion time M = 18 days, mothers N = 135, fathers N = 85
Canada completion time M = 14-28 days, mothers N = 42, fathers N = 25
Netherlands completion time M = 34 days, mothers N = 77, fathers N = 40

Classification by PPPHM Universal, Targeted, and Clinical Groups

The 117 families were distributed as follows based on PAT total scores: 66% (n=77) Universal, 29% (n=34) Targeted, and 5% (n=6) Clinical. Table IV shows the breakdown by parent gender. The classification of mothers in the Universal, Targeted, and Clinical group in the Netherlands was comparable with the United States, Canada, and Australia (Table IV) (Fisher’s Exact Test p-values ranging p=.10–1.00). Regarding the classification of the fathers’ PAT scores, no differences were found with the United States, Canada, and Australia (Fisher’s Exact Test p-values ranging p=.11–1.00).

Usability of the PAT

On a VAS-scale ranging from 0 to 100 (0=totally disagree, 100=totally agree), parents rated the comprehensibility (M=79.72, SD=18.55), clarity (M=79.72, SD=19.50), and appropriateness (M=61.72, SD=21.23) of the PAT positively. In addition, parents did not find it unpleasant to complete the PAT (M=19.82, SD=23.49). The length of the questionnaire was considered acceptable (M=68.18, SD=23.47).

DISCUSSION

Conducting family risk assessment in pediatric oncology is an important and helpful step in providing comprehensive care to patients and their families. This study is, to our knowledge, the first to describe the validation of the PAT in a European country. New aspects of this study compared with previous published research are the online administration of the PAT and the parental assessment of the usability of the PAT. In general, the Dutch version of the PAT is reliable, valid, and applicable for use in a pediatric oncology setting. Importantly, the families themselves
reported that the PAT was acceptable to them. This makes systematic screening for risk and resilience factors possible to facilitate the provision of cost-effective targeted and family-based care for those families in the Netherlands who need it most32.

The PAT has been validated in several countries around the world12,15-17,19,20. Similar findings have been reported regarding its generalizability. However, questions remain regarding the applicability of the PAT in a European country. Dutch health care is structured differently compared with other countries in which the PAT has already been validated. Given the small size of the country, distances are relatively small and health care is easy to reach for anybody33. Also, all Dutch citizens are obliged to have health insurance that covers most of the medical costs. Hospitalization is mainly restricted to the time required for treatment or management of complications34. Many medical treatments are offered in an outpatient manner, and travel distances are no more than 1.5hr. In most cases, children are thus not separated from their home and relatives for a long period and are close to their home situation. For families in financial need, transportation can be arranged by social workers. Furthermore, Dutch parents are able to have a paid sick leave for a certain period35. Nonetheless, there are still families with risk factors placing them in the Targeted and Clinical levels in the Netherlands. This implies that the risk factors identified by the PAT are universal, and that the PAT is applicable, also in a Western European country like the Netherlands.

The reliability on total scale level was good but lower than expected: the initial study on the PAT in the United States reported somewhat higher levels of internal consistency12. The PAT score seems to be applicable in Western European countries, such as the Netherlands, and the majority of the subscales confirmed adequate reliability and validity; however, the content of some subscales lacks adequate internal consistency and content validity. It is difficult to interpret these findings, as we know that there is great diversity of items within the subscale Structure and Resources and Social Support, which made it difficult to reach optimal internal consistency36. It is also known that internal consistency increases with the number of items per scale36, while the subscales Social Support and Family Beliefs include only four items. Because inadequate internal consistencies were found consistently for the subscale Family Beliefs12,17,19,20 and in this study also for Social Support, a more detailed look is necessary. Confirmatory factor analysis in a larger sample also could be helpful in examining whether all subscales represent themselves as theoretically hypothesized.

This study used an online version of the PAT. This might have contributed to diminishing burden for the families because they can complete the questionnaire any time, in the hospital, at home, or in the waiting room of the outpatient clinic. Web-based measures have advantages compared with paper-and-pencil data collection, with regards to completeness of data, less proneness for social desirability answering, and higher cost-effectiveness37. It is likely that parents of children with cancer will have the same preference. However, there may be some families for whom paper forms are more feasible or acceptable.

There are some limitations of this study. Although our sample size is sufficiently large to conduct reliability and validity analyses, it was not adequate for conducting a confirmatory factor analysis. Another limitation is the possible underestimation of families with high levels of distress. The exclusion of families of a child who already had entered end-of-life care at diagnosis
together with the families who were not invited by the medical doctor to participate owing to psychosocial reasons/medical complications, which might be the most distressed and at-risk families, possibly reflect an underestimation. Next to this, we excluded families with insufficient knowledge of the Dutch language. The parents in our study were highly educated compared with the Dutch general population (25% low, 40% medium, 35% high)\textsuperscript{38}, and almost all parents were married, which raises questions about the representativeness of our sample group. However, we did not find differences in the number of “high risk” families compared with the United States, Australia, and Canada.

This study can be regarded as an additional step in the overall international, multi-cultural validation of the PAT. Some important questions have been answered with this study; however, future research is needed to address some issues, which still remain unknown. In a next study, the applicability of the PAT to other ethnic groups in the Netherlands should be tested using interpreters or translated versions of the Dutch PAT. Future studies also need to assess the best moment to assess the PAT in acute pediatric oncology care. Findings on the test–retest reliability of the PAT showed good correlation, indicating that there was no difference in score between the measurement 1 week and 3 weeks after diagnosis\textsuperscript{12}. It seems reasonable and recommendable to ask parents to complete the PAT around 2 weeks after diagnosis, a period in which stress reactions are normalizing, but this needs to be studied. A prospective study is needed to confirm the PAT cutoff scores to differentiate between low (Universal), medium (Targeted), and high (Clinical) risk families in the Netherlands. This prospective study can also be used to define which risk factors contribute most to psychological distress. It is possible that there are also additional risk factors, which are not measured by the PAT at this moment, such as personality, which is proven to be an important predictor of distress\textsuperscript{39}. Another future direction for research is whether families with risk factors at one or multiple domains are equally at risk for developing problems\textsuperscript{40}. An important next step is to extend the applicability of the PAT to other patient groups. With the Dutch translation available, it is possible to investigate the usability of the PAT in other patient groups after only minor adjustments in the cancer-specific questions. Finally, we can enhance the applicability of the PAT by investigating its cost-effectiveness.

Increasing attention is being paid to the psychosocial well-being of patients and their families in pediatric care; however, it is often hard to estimate the risk for developing problems\textsuperscript{41} and to select families at risk. The PAT can be used as a valid instrument to identify psychosocial risk in a systematic and identical manner for all new families, supporting the clinical estimation of the health care team.

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Chapter 4

Reference list


Screening for psychosocial risk in Dutch families of a child with cancer: reliability, validity, and usability of the psychosocial assessment tool


