Improving the Quality of Life of Children with Cancer

Multidisciplinary Case Management Training Program
for the care and treatment and of Pediatric Cancer in CEE countries

www.casemanagement-projecthope.org

Program Curriculum and Recommendations

Executive Summary

Despite recent developments, the gap between Eastern and Western Europe childhood cancer survival rates and quality of care often persists. This one-year program aims to improve the quality of life of children suffering from cancer and reduce the burden of childhood cancer in four countries of CEE (CzR, Hu, Ro, Pol) via better coordination of medical and psychosocial care. Through a practice-oriented international training program for multidisciplinary teams that includes coaching and mentoring, health and social service providers will increase their knowledge and skills. A locally adapted and validated curriculum, best practice recommendations and patient information leaflets will also be produced and disseminated.

Krakow, September 2011

Issued by Program Senior Technical Advisory Group, SenTAG

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The program was funded by Bristol-Myers Squibb Foundation
as part of the Bridging Cancer Care initiative in Europe
www.casemanagement-projecthope.org
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Background

Cancer is among the leading causes of death in children and adolescents in Europe.\(^1\) There have been considerable advances in the diagnostics and the treatment of childhood cancer, according to data from the EUROCARE Working Group, survival rates have increased for all cancers combined: 5-year survival increased from 65% in children diagnosed in the 1983-1985 sub group to 75% in 1992-1994 sub group.\(^2\) Despite these recent developments, there is a wide gap persisting between the survival rates in Eastern and Western Europe (See Table 1).

Table 1. National estimates of incidence five-year observed cumulative survival (0-14)

<table>
<thead>
<tr>
<th></th>
<th>Incidence</th>
<th>Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>Europe (average)</td>
<td>130.9</td>
<td>63</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>124.9</td>
<td>50(^3)</td>
</tr>
<tr>
<td>Hungary</td>
<td>119.6</td>
<td>57</td>
</tr>
<tr>
<td>Poland</td>
<td>106.5</td>
<td>68</td>
</tr>
<tr>
<td>Romania</td>
<td>101.8</td>
<td>33</td>
</tr>
</tbody>
</table>

Source: ACCIS (Automated Childhood Cancer Information System http://www-dep.iarc.fr/accis/data.htm

It is notable that in the Czech Republic, Hungary and Romania, the observed 5-year survival rates are significantly lower for nearly all kinds of cancer. In review of cancer mortality rates and trends over the period 1980–2000 for the 10 accession countries to the European Union (EU)\(^4\), it has become clear that lower survival rates in Eastern Europe may also be attributable to poorer quality of treatment and care and inadequate access to diagnostic and treatment technologies. Furthermore, it needs to be taken into consideration that the burden of the disease is affecting the entire family: a child affected by cancer carries a heavy emotional weight on every member of the family and the care of a sick child requires a considerable amount of time and family resources.

\(^1\) World Health Statistics. 2009. WHO: Geneva
\(^3\) Source: National oncolgy register CzR: (1997-2006)
Pediatric Cancers can be devastating for children, their families and their friends. These conditions often require complex medical, nursing, therapeutic, educational and social care interventions from a vast array of professionals and agencies over a prolonged period of time. In an ideal world patients would take responsibility for managing their own care. For children the task may well fall to parents. For many, however, the emotional trauma experienced as their children undergo distressing treatments make it difficult for them to engage with the complex world of medicine and care environments.

**Program Innovative Approach**

The Multidisciplinary Case Management (MCM) Training - fully funded from the Bristol-Myers Squibb Foundation’s grant as part of the Foundation’s Bridging Cancer Care initiative in Europe - contributes to improving the quality of care provided to patients and the support to their families. Case management is ‘a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost-effective outcomes.’ It is a novel approach: the 2005 evidence review by the National Institute for Health and Clinical Excellence (NICE) in the UK, titled ‘NICE Guidance on Cancer Services. Improving Outcomes in Children and Young People with Cancer’, highlighted the overall lack of studies, high quality evidence and information in pediatric oncology. Nonetheless, it stated that observational evidence suggests that such care leads to improved quality of life for patients. Case management does not only lead to better quality of care, but it aims to coordinate economic and psychosocial support to the patients and their family to reduce the emotional and economic burden. The program promotes the model of case management in the CEE region building on the high quality treatment and care provided at the University Children’s Hospital of Krakow, Poland.

In addition to case management, another cornerstone of the program was the approach of Training of the Trainers. This technique - in which local health professionals are trained to train others -

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creates a pool of Master Trainers who are able to provide continuous professional education, mentoring and support to their colleagues in the local setting and promote through role modeling and coaching, the approach of case management in practice.

The aim of the Program

The aim of the Program was to improve the quality of life of children suffering from cancer and improve treatment outcomes of childhood cancer in five CEE countries via better coordination of medical and psycho-social care using case management.

Objectives

1. Develop standards in case management for pediatric cancer patients and create a locally adapted and validated curriculum for case management training, based on the in-country needs;
2. Improve the knowledge and practical skills of health and social care providers in pediatric cancer to provide case management;
3. Establish a network of health professionals working in health and social institutions that use the case management approach as a routine part of treatment and care to children with cancer.

Target Group and Beneficiaries

The primary target group of the program was the multidisciplinary teams of a Doctor, Nurse, Psychologist and Social Worker providing health and psycho-social care in institutions and in the community to children with cancer and their families. There were twelve (12) teams, three from each of the following countries: Poland, Romania, Hungary, and the Czech Republic (altogether 48 professionals from the region).
The ultimate beneficiaries are children with cancer and their families, who received better quality comprehensive care, provided via better coordination and rational use of resources in the network management model.

**Program Outputs and Outcomes**

The program promoted and enhanced implementation of the multidisciplinary model of case management for pediatric cancer patients in four countries of Central and Eastern Europe. Its impact is observed by three major achievements made by 1. developed standards in case management and locally adapted and validated curriculum for case management training; 2. improved knowledge and practical skills of health and social care providers in pediatric cancer; and 3. established network of health professionals working in health and social institutions that use the case management approach.

Final beneficiaries were around 300 children with new cases of pediatric cancer per year in each of the twelve Oncology Centers participating in the program. Annually, close to 3600 patients and their relatives are benefiting from the project by receiving quality, comprehensive clinical treatment and psychosocial care, provided via better coordination and rational use of resources by Health Professionals who are part of the Professional Network of Pediatric Cancer Case Management Health Care Providers.

Satisfaction of patients and their families being treated by Health Providers in the twelve Oncology Centers was measured by each Multidisciplinary Team and gathered by the Project Manager. Surveys and evaluation tools were developed and conducted by each MCM team individually. The overall, average percent of satisfied patients and their families measured by providing them with coordinated psychosocial and medical care during the program life is 89%.

Program major outputs are the following:

1. Trained cadre of Health Professionals/Master Trainers (#48) with increased knowledge and practical skills in pediatric cancer case management and Training of Trainer technique, who
subsequently are rolling out the training to their colleagues in the regional setting in four countries of CEE (Poland, Romania, Hungary and the Czech Republic):

- 48 Health Professionals showing 85% knowledge increase, skills and attitude improvement in using the case management approach after attending five-day Conference in Case Management Model of Care;
- Around 400 additional Health Professionals were trained or advised by the Master Trainers about case management principles and psychosocial tools;
- More than 500 referrals and 170 documents and professional resources were shared about the case management model and its practical implementation by Master Trainers with other healthcare providers (the rest of hospital medical team, doctors, nurses, clinical psychologists, social workers, play therapists, priests, teachers and other health providers (HPs) from the hospital and outside of the hospital);

Regional Oncology Centers (#12) with established and functional multidisciplinary teams, implemented projects and adopted case management tools and approaches for care and treatment of children with cancer and their families:

- 12 multidisciplinary teams of Pediatric Oncologist, Pediatric Nurse, Psycho-Oncologist, Social Worker, Family Member established in four countries from CEE region: Poland, Romania, Hungary and the Czech Republic better coordinating the clinical treatment and psychosocial services provided to the child and its family;
- 12 projects developed and implemented in Oncology Centers on different case management aspects;
- 9,000 booklets for patients and their families with information about case management and psychosocial services available in the region of CEE;

Developed standards in case management for pediatric cancer patients and a locally adapted and validated curriculum for case management training:

- Piloted and validated case management curriculum for pediatric cancer patients was developed based on recommendations and feedback received from MCM teams after the training;
• Psychosocial Assessment Tool adopted nationally in two countries (Poland and Romania) based on Children’s Hospital of Philadelphia experience;
• Six Oncology Centers adopted standards in case management for pediatric cancer patients in Poland and Romania;

Integrated Professional Network of Pediatric Cancer Case Management Health Providers:
• www.case-management-projecthope.org program website developed with information on case management model of care in pediatric oncology, program information and approach, contact information of all participating Multidisciplinary Teams, program validated and adopted curriculum, case management resources and childhood cancer epidemiology, and links to other professional organizations;
• Around 50 professional papers posted on the program site on case management model of care;
• The site is available in English as well as in all four languages of participating countries, so all interested Health Professionals can assess the professional documents, ask questions and share their experience;

Program Curriculum

The educational program event consisted of a five-day course held in Krakow, Poland (May 14th to May 18th) at University Children’s Hospital of Krakow training facility. The Curriculum was evaluated and adapted based on participant and trainer feedback as well as lessons learned from the training. The educational objectives of the training program were the following:

Day 1
• To define the problem of Pediatric Cancer in CEE in terms of the types and numbers of cases, and the main problems experienced by patients and their families
• To update managers / practitioners on current developments in the treatment and provision of care to children with Cancer in the Region
• To introduce the concept of Case Management and models of application to vulnerable patients with complex needs generally and pediatric cancer patients in particular

Day 2
• To explore the strengths and weakness of current service provision in Pediatric Cancer in the participating countries
• To begin to engage with the practical issues surrounding the organization of care for children and their families
• To explore the complexities of case management and inter-professional communication
• To examine the wider organizational issues surrounding the organization of care across disciplines, professions, organizations and agencies
• To discuss mechanisms for delivering case management interventions and evaluating its impact

Day 3
• To explore the cultural, legal and ethical issues surrounding inter-disciplinary assessment and care management
• To explore issues of consent by patients and families for information sharing
• To explore the barriers to access and difficulties encountered by socially disadvantaged, deprived or socially excluded children and families
• To explore in depth the issues relating to families who are difficult to engage and to explore practical techniques for their engagement

Day 4
• To explore the barriers to the implementation of case management in pediatric cancer in CEE Countries
• To examine the complexities of network working with a particular emphasis on communication, team building and conflict resolution
• To explore the issues around multi-disciplinary team working
• To consider mechanisms for implementing case management in Pediatric cancer across the region
Day 5

- Training the Trainers component
- Developing an implementation plan

Project Work

- Group 1: Overcoming inter-professional barriers
- Group 2: Overcoming inter-agency barriers
- Group 3: Overcoming re-imbursement barriers
- Group 4: Overcoming communication barriers

Detailed Program Curriculum

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<tr>
<th>Day 1</th>
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<tbody>
<tr>
<td>Module title:</td>
<td>An introduction to Pediatric Cancer &amp; Case Management</td>
</tr>
<tr>
<td>Day's topic:</td>
<td>Current position</td>
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</tbody>
</table>

Day's objectives:
- To define the problem of Pediatric Cancer in CEE in terms of the types and numbers of cases, and the main problems experienced by patients and their families
- To update managers / practitioners on current developments in the treatment and provision of care to children with Cancer in the Region
- To introduce the concept of Case Management and models of application to vulnerable patients with complex needs generally and pediatric cancer patients in particular

<table>
<thead>
<tr>
<th>Session time:</th>
<th>Session number</th>
<th>Session type:</th>
<th>Session topic:</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00 - 9:30</td>
<td>1</td>
<td>Presentation</td>
<td>Opening and introductions</td>
</tr>
<tr>
<td>9:30 - 10:15</td>
<td></td>
<td></td>
<td>Course overview – structure and content</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Participant’s introduction</td>
</tr>
<tr>
<td>10:15 - 11:15</td>
<td>2</td>
<td>Lecture/Discussion</td>
<td>An overview of Pediatric Cancer in CEE Countries; the nature and scale of the problem</td>
</tr>
<tr>
<td>11:15 - 12:15</td>
<td>3</td>
<td>Exercise/Case studies</td>
<td>Mapping current care - Describing how care would currently be organised in participating countries in four case studies</td>
</tr>
<tr>
<td>12:15 – 13:15</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13:15 - 14:15</td>
<td>4</td>
<td>Lecture/Discussion</td>
<td>Using a multi-disciplinary psycho - social assessment tool to establish need and organise care</td>
</tr>
<tr>
<td>14:15 - 15:15</td>
<td>5</td>
<td>Lecture/Discussion</td>
<td>Case management - What is it? How is it used? What are the benefits in Pediatric Cancer</td>
</tr>
<tr>
<td>15:15 – 15:45</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15:45 – 17:00</td>
<td>A</td>
<td>Presentation</td>
<td>Designing / developing a work based project</td>
</tr>
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**REQUIRED READINGS:**

*Program Materials*

*Case Management Resource Pack on a CD*
# Day 2

**Day 2 - Sessions 6 - 10**

**Module title:**  
An introduction to Pediatric Cancer & Case Management

**Day’s topic:**  
Managing care

**Day’s objectives:**
- To explore the strengths and weaknesses of current service provision in Pediatric Cancer in the participating countries
- To begin to engage with the practical issues surrounding the organisation of care for children and their families
- To explore the complexities of case management and inter-professional communication
- To examine the wider organisational issues surrounding the organisation of care across disciplines, professions, organisations and agencies
- To discuss mechanisms for delivering case management interventions and evaluating its impact

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<th>Session number</th>
<th>Session type</th>
<th>Session topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>09:00 - 10:00</td>
<td>6</td>
<td>Group activity</td>
<td>How do pediatric cancer patients access services in CEE? - Mapping the service network, finding, creating and obtaining community resources and addressing family anxiety</td>
</tr>
<tr>
<td>10:15 - 11:15</td>
<td>7</td>
<td>Group activity</td>
<td>Exercise in teams (analyse and address a Case study with complex psycho-social needs and report back to group on how care should have been organised)</td>
</tr>
<tr>
<td>11:15 – 11:45</td>
<td></td>
<td></td>
<td><strong>COFFEE BREAK</strong></td>
</tr>
<tr>
<td>11:45 – 12:45</td>
<td>8</td>
<td>Lecture/Discussion</td>
<td>Case management processes: Components of case management, client engagement, needs assessment, service planning and intervention</td>
</tr>
<tr>
<td>12:45 – 13:45</td>
<td></td>
<td></td>
<td><strong>LUNCH</strong></td>
</tr>
<tr>
<td>13:45 - 14:45</td>
<td>9</td>
<td>Presentation</td>
<td>Legal and policy issues: confidentiality, informed consent, rights of patients and families, policy change issues with particular reference to the balance between rights and responsibilities</td>
</tr>
<tr>
<td>14:45 – 15:45</td>
<td>10</td>
<td>Lecture/Discussion</td>
<td>Multi-disciplinary assessment formats - patient held records and multi-disciplinary care plans - Obtaining consent</td>
</tr>
<tr>
<td>15:45 – 16:15</td>
<td></td>
<td></td>
<td><strong>COFFEE BREAK</strong></td>
</tr>
<tr>
<td>16:15 – 17:00</td>
<td>B</td>
<td>Presentation</td>
<td>Preparations of projects and presentations</td>
</tr>
</tbody>
</table>

**REQUIRED READINGS:**

*Program Materials*  
*Case Management Resource Pack on a CD*
Day 3

Module title: An introduction to Pediatric Cancer & Case Management

Day’s topic: Organisational barriers

Day’s objective:
- To explore the ethical, cultural, legal and ethical issues surrounding inter-disciplinary assessment and care management
- To explore issues of consent by patients and families for information sharing
- To explore the barriers to access and difficulties encountered by socially disadvantaged, deprived or socially excluded children and families
- To explore in depth the issues relating to families who are difficult to engage and to explore practical techniques for their engagement

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<th>Session time:</th>
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<th>Session type:</th>
<th>Session topic:</th>
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</thead>
<tbody>
<tr>
<td>09:00 - 10:00</td>
<td>11</td>
<td>Lecture/Discussion</td>
<td>Developing Case Management networks and systems of care:</td>
</tr>
<tr>
<td>10:00 – 11:00</td>
<td>12</td>
<td>Exercise</td>
<td>Mapping care pathways - who needs to be involved, when and how?</td>
</tr>
<tr>
<td>11:00 – 11:30</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:30 – 12:30</td>
<td>13</td>
<td>Exercise</td>
<td>Drawing up a multi-disciplinary care plan for a patient with complex needs</td>
</tr>
<tr>
<td>12:30 – 13:30</td>
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<td></td>
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</tr>
<tr>
<td>13:30 – 14:30</td>
<td>14</td>
<td>Group Presentation</td>
<td>Feedback from four groups on their care plans</td>
</tr>
<tr>
<td>14:30 – 15:30</td>
<td>15</td>
<td>Lecture/Discussion</td>
<td>Designing / developing a work based project</td>
</tr>
<tr>
<td>15:30 – 16:00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16:00 – 17:00</td>
<td>16</td>
<td>Presentation</td>
<td>Preparing project presentation</td>
</tr>
</tbody>
</table>

**REQUIRED READINGS:**

*Program Materials*

*Case Management Resource Pack on a CD*
## Day 4

**Day 4 - Sessions 16 - 20**

### Module title:
**An introduction to Pediatric Cancer & Case Management**

### Day's topic:
**Current issues**

### Day's objective:
- To explore the barriers to the implementation of case management in pediatric cancer in CEE Countries
- To consider techniques for assessing the operational environment and facilitating organisational change
- To examine the complexities of network working with a particular emphasis on communication, team building and conflict resolution
- To explore the issues around multi-disciplinary team working
- To consider mechanisms for implementing case management in Pediatric cancer across the Region

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<tr>
<th>Session time:</th>
<th>Session number:</th>
<th>Session type:</th>
<th>Session topic:</th>
</tr>
</thead>
</table>
| 09:00 - 11:00 | 16              | Group Presentation 1-8 | 1. Project 1  
2. Project 2  
...  
8. Project 8 |
| 11:00 - 11:30 |                 |               | **COFFEE BREAK** |
| 11:30 - 12:30 | 17              | Group Presentation 9-12 | 9. Project 9  
...  
12. Project 12 |
| 12:30 - 13:30 |                 |               | **LUNCH** |
| 13:30 - 14:15 | 18              | Lecture/Discussion | Case Management: Interventions and Evaluation |
| 14:15 - 15:15 | 19              | Lecture/Discussion | Tools for assessing the operating environment, stakeholder analysis, PEST analysis, SWOT analysis Tools for facilitating the management of change |
| 15:15 - 15:45 |                 |               | **COFFEE BREAK** |
| 15:45 - 17:00 | 20              | Discussion      | Moving forward |

### REQUIRED READINGS:

*Program Materials*

*Case Management Resource Pack on a CD*
Day 5 - Sessions 21 - 25

Module title: An introduction to Pediatric Cancer & Case Management

Day’s topic: Training trainers

Day’s objective:
- To develop training and implementation plan / program next steps
- To adopt Psychosocial Assessment Tool
- To map psychosocial services and develop Patient Brochure

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<tr>
<th>Session time</th>
<th>Session number</th>
<th>Session type</th>
<th>Session topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>09:00 - 10:00</td>
<td>21</td>
<td>Group work</td>
<td>Reviewing course materials / curriculum</td>
</tr>
<tr>
<td>10:00 - 11:00</td>
<td>22</td>
<td>Presentation /Lecture</td>
<td>Developing an implementation plan Adopting Psychosocial Assessment Tool Mapping psychosocial services and develop Patient Brochure</td>
</tr>
<tr>
<td>11:00 - 12:00</td>
<td>23</td>
<td>Presentation</td>
<td>Next steps</td>
</tr>
<tr>
<td>12:00 – 13:00</td>
<td></td>
<td></td>
<td>LUNCH</td>
</tr>
<tr>
<td>13:00</td>
<td></td>
<td></td>
<td>End of program</td>
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**Program Implementation and Recommendations**

1. Create the SenTAG, Senior Technical Advisory Group consisting of the Key National Experts, representatives from all four participating countries and the various professions: oncologists, pediatric oncology psychologists, hospital educator and social worker as well as international experts on case management and pediatric oncology case management from the UK and the US. The role of The Key Experts was to develop standards in case management for pediatric cancer patients and a locally adapted and validated curriculum for case management training, based on in-country needs as well as The Program Monitoring and Evaluation Plan.

2. Create multidisciplinary teams with balanced representation of the professions actively involved in the case management process of pediatric cancer patients. The Key Country Experts played a major role in...
role in proposing, selecting and creating the best possible teams and identifying partner institutions in the four participating countries. There was a competitive application process conducted by each Country Expert to ensure the selection of the best possible participants for the program, dedicated, experienced and ready to take on responsibilities to design and promote the best model of case management for pediatric oncology care and treatment in respective country;

Ideal team members to be part of the multidisciplinary team are the following:

- Registered Nurse, experienced and dedicated
- Pediatric Oncologist, certified or in training but experienced and dedicated
- Clinical Psychologist, experienced in pediatric oncology
- Social Worker, experienced in pediatric oncology / hospital teacher
- External Organization Representative (e.g. hospice, long-term care charity), and /or Patient
- Advocacy Group Representative; Parent organization representative

3. Multidisciplinary Case Management (MCM) Team work recommendations:

- There should be an identification of primary contact person (Case Manager) for the child and the family among MCM team members;
- At the beginning of the therapy in each Oncology Center, a patient and its family should be screened for psychosocial risks. It is recommended that MCM Teams develop their own or adopt the Psychosocial Assessment Tool based on Children’s Hospital of Philadelphia experience; the tool should be standardized with simplified questions and should be designed by each Oncology Center separately to be relevant to each particular country situation.
- Each interested Oncology Center that wishes to develop and adopt their own, country specific tool relevant to the situation in their respective country should contact PAT manager at Children’s Hospital of Philadelphia for further information;
• The development of psychosocial guidelines and coordination plan for the care of each particular child’s need should be facilitated and promoted by each of the MCM teams;

• It is important at the process of diagnoses, to look at the problem from a medical point of view by physicians, while nurses should be concerned about hygiene issues, nutritional and nursing care plans, and psychologists about psychological and social coping abilities;

• There is an importance in identifying the whole family’s needs, however the patient’s needs should be put first; different needs of these families should be taken into consideration, depending on each case, stage of therapy and family conditions;

• Psychosocial needs of the mother and the other children and family members should be taken into consideration, as well as spiritual and religious aspects during the work of MCM teams;

• Primary care teams (e.g. family doctor or outpatient pediatrician and nurse) should be involved in the care and treatment process as well (a person who contacts them should be assigned – possibly Case Manager);

• Sharing responsibilities with the family and education of the family is important (a person who is responsible for this should be assigned), informing the family about patient’s rights;

• There should be a patient data registry in place in every Oncology Center;

• Patient data registry should be shared with each MCM team member, with great consideration of in-country specific law regulations on patient privacy, rights and data protection;

• Medical records should contain information and recommendations on how to handle a child in the future;

• Communication plans for family members should be developed and maintained regularly;

• It is important to map all the psychosocial services and home care services and organizations which are available for the children and families and to be able to refer the family to such organizations; it applies especially for the underprivileged families in poorer regions, where they might have limited resources and knowledge about such services. It is recommended to gather all the organizations providing psychosocial and home care services contact information into Patient Booklet and distribute among the families.
4. Assisting MCM teams in establishing a case management network of health and social service professionals and in development of the method for monitoring and evaluation of the network’s activities. Each participating MCM team was given an assignment to map the available services for patients and their families in their region and create an implementation plan for the case management project to be introduced in each respective partner institution. The purpose of the project was to help participants think through the practical implications of applying case management approaches to facilitate and enhance the care of children with cancer and the impact of their disease on their families, friends and lives in general.

The project titles are the following:

- **Overcoming inter-agency barriers**: Map the agencies or organizations potentially involved in the care of a child with cancer or their family; outline the potential barriers to the management of care across these inter-agency boundaries and suggest three strategies for overcoming these barriers.

- **Overcoming re-imbursement barriers**: Map the potential problems in the financing of case management programs in pediatric cancer; outline the key financial concerns likely to be expressed by managers and staff in participating organizations and suggest three strategies for overcoming these concerns.

- **Overcoming communication barriers**: Map the potential agencies and professionals who would be required to share information for case management to work; outline the key ethical and legal concerns likely to be expressed by managers engaged in the process and suggest three strategies for overcoming these concerns.

- **Multidisciplinary / agency assessment**: Map the physical, psychological and social issues which could potentially impact on the care of a child with pediatric cancer; develop a simple assessment questionnaire (max 21 questions) which would help staff understand the full picture of a child’s circumstance, and outline the key issues which would need to be addressed for such an assessment to be implemented.
• Case manager job description: Outline the professional staff who could and should take on the role of a case manager; set out five key responsibilities they would have over and above their normal role; set out the key barriers to establishing such a role in your organization.

• Evaluation and quality assurance: Map out the key objectives you feel a case manager should be aiming to achieve; set five performance indicators you feel would demonstrate if the role was working or not; suggest who should monitor the work of a case manager and why.

• Case conferences: Map out the types of clinical, family or social issues which might require agencies or professionals to come together and discuss an individual case; outline who might attend a case conference and what their roles and responsibilities might be; set out how the discussions in a case conference might be recorded and acted upon.

• Child protection: Outline the types of situations which may trigger an intervention whereby professionals might intervene in the care of a child and over-ride the wishes of parents; map out the ethical and legal difficulties surrounding such an intervention, set out five criteria that might be used to decide whether to intervene or not.

• Managing shifts in goals of care: Describe the process by which the providers caring for a child adapt the child's case management plan to rapid or significant changes in the child’s condition (for example, relapse). Outline the process by which these shifts will take place (such as a communication plan or team meeting) and which staff will be assigned to various tasks. These tasks could include communicating with extended family, assessing new social/financial needs of the family to help them cope acutely, and the like.

5. The participating institutions were also working on the second assignment to map the available psychosocial services for patients and their families. The teams developed a Patient Booklet with comprehensive information about available services in their workplace to better inform patients and their families about the existing psychosocial support as well as about
members of MCM teams and case management approach in general. The example of the Patient Booklet template was attached to the document (Attachment 1).

6. The program website – www.case-management-projecthope.org – was created to facilitate the exchange of experiences and best practices among the local institutions and to promote the pediatric oncology case management method to the rest of the region. The site was created in English and translated into four local languages. The program website includes information on the program approach and principles, contact information of each of the participating MCM Team, program validated and adopted curriculum, case management resources (eg. PAT Psychometrics: Attachment 2) and childhood cancer epidemiology, and links to other professional organizations.
Program Monitoring and Evaluation Plan

Program progress in the attainment of the goals and objectives can be developed and monitored as detailed in below table.

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Indicators</th>
<th>Output/Outcome</th>
<th>Process</th>
<th>Means of Verification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Develop standards in case management for pediatric cancer patients</td>
<td>• Locally adapted and validated Curriculum and the Recommendations</td>
<td>• # Health and social care professionals participating in SenTAG</td>
<td>• Program records</td>
<td></td>
</tr>
<tr>
<td>including creating and publishing a locally adapted and validated</td>
<td>• # hospitals adopting standards in case management for pediatric cancer</td>
<td>• Standards in case management for pediatric cancer patients completed</td>
<td>• Hospital policies</td>
<td></td>
</tr>
<tr>
<td>curriculum for case management training, based on in-country needs</td>
<td>• Satisfaction by the patients and their families with the services provided</td>
<td>• # Copies of Curriculum distributed as a hard copy (also will be included with the final report)</td>
<td>• Surveys conducted among the patients</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• # Copies of Curriculum (with the recommendations as final report)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Program records</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Hospital policies</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Surveys conducted among the patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improve the knowledge and skills of health and psycho-social care</td>
<td>• % health and psycho-social care providers at hospital who show knowledge</td>
<td>• % health and psycho-social care providers at hospital who show knowledge</td>
<td>• Pre and Post tests</td>
<td></td>
</tr>
<tr>
<td>providers in pediatric cancer case management</td>
<td>increase on post tests on pediatric cancer treatment</td>
<td>skills and attitude change in using the case management approach</td>
<td>• Training logs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• % health and psycho-social care providers at hospital who show knowledge</td>
<td>• # health and social care providers trained</td>
<td>• Supervision checklists</td>
<td></td>
</tr>
<tr>
<td></td>
<td>increase on post tests on pediatric cancer treatment</td>
<td>• # Practical sessions/visits held</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Establish a network of health professionals working in health and social</td>
<td>• # health and psycho-social care providers participating in the network</td>
<td>• # Institutions and health and social care providers contacted</td>
<td></td>
<td></td>
</tr>
<tr>
<td>institutions using case management approach in providing treatment and</td>
<td>• # Institutions participating in the network</td>
<td>• Institutions providing services to cancer patients identified during the</td>
<td></td>
<td></td>
</tr>
<tr>
<td>care to children with cancer.</td>
<td>• # Visits/ downloads from the website</td>
<td>mapping of the available services</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• # Referrals among the network</td>
<td>• # Institutions providing services to cancer patients included in the booklet</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• # booklets</td>
<td>• Program records</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Reports from participating institution on the mapping process</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

20
My child’s doctor name is:

Oncology Department
Team Members

The Multidisciplinary Team Members
by name and profession

What is case management?

Case management is “a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual’s health needs through communication and available resources to promote quality cost-effective outcomes”

Case management helps in:

- Assessing the child’s needs
- Developing an individual service plan for accessing and using resources that can meet identified needs
- Linking the child with community services and supports identified in the service plan
- Monitoring the child’s progress as it relates to the child’s service plan at home and community

This booklet was created within

Multidisciplinary Case Management Training Program for the Care and Treatment of Pediatric Cancer in CEE Countries

organized by Project HOPE Foundation
as of part of Bristol-Myers Squibb Foundation’s Bridging Cancer Care initiative in Europe

for more information visit

www.case-management-projecthope.org

Hospital Name
Address
Contact Information

www
Psychological support institutions

List all information about psychosocial services available for the child and its family in your city/province in your language: e.g. Names and contact information such as address, phone, www site, contact person name etc. for the institutions providing psychological support.

Community, primary care and social support institutions

List all information about psychosocial services available for the child and its family in your city/province in your language: e.g. Names and contact information such as address, phone, www site, contact person name etc. for the institutions providing support at the community, primary care level or social services.

Hospice care and Patient advocacy groups or other supportive associations

List all information about psychosocial services available for the child and its family in your city/province in your language: e.g. Names and contact information such as address, phone, www site, contact person name etc. for the institutions providing hospice care and patient advocacy groups or other foundations and associations.
The Psychosocial Assessment Tool (PAT2.0): Psychometric Properties of a Screener for Psychosocial Distress in Families of Children Newly Diagnosed with Cancer

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1Division of Oncology, The Children’s Hospital of Philadelphia, 2Department of Pediatrics, University of Pennsylvania School of Medicine, and 3Department of Biostatistics and Epidemiology, University of Pennsylvania School of Medicine

Purpose Psychometric properties of the Psychosocial Assessment Tool 2.0 (PAT2.0), a brief screener for psychosocial risk in families of children with cancer, are presented. Methods Female (N = 132) and male (N = 72) caregivers of 141 children newly diagnosed with cancer completed the PAT2.0 and measures of child behavior symptoms, anxiety, acute stress, and family functioning to establish validity. Internal consistency and test–retest reliability of the PAT2.0 were also examined. Results Internal consistency and two-week test–retest for the PAT2.0 Total score was strong. Validity for the PAT2.0 was supported by significant correlations between the PAT2.0 subscales and measures of corresponding constructs. PAT2.0 Total scores were correlated with acute stress and child behavior symptoms for both mothers and fathers. Receiver-Operating Characteristic curves provided preliminary support for the proposed cutoffs. Conclusion The PAT2.0 Total score is a useful screening tool for family psychosocial risk in the pediatric oncology population.

Key words assessment; families; parents; pediatric oncology; risk.

The treatment of pediatric cancer involves a demanding medical regimen in which families are confronted with multiple and pervasive stressors including significant medical side effects (Bryant, 2003), considerable changes in daily activities (Woodgate, Degner, & Yanofsky, 2003), disruption of social and family roles (Kazak, Simms, & Rourke, 2002), the burdens of adhering to complicated and often very intense treatment regimens (Crist & Kun, 1991), and the threat of death. Recognizing the impact of such stressors, national and international recommendations for comprehensive cancer care include the provision of psychosocial services to families of children with cancer (American Academy of Pediatrics, 2004).

Unfortunately, clear guidelines have not been established with regard to the delivery of these services. Systematic approaches for assessing psychosocial need and formulating types and levels of intervention for particular patients and families are not available.

Although, collectively, the majority of children with cancer and their families are resilient in the face of cancer diagnosis and treatment (Kazak, 2006), subgroups of children and their families are at risk for or evidence of clinically significant distress and impaired coping (Patenau & Kupst, 2005) and warrant more consistent evidence-based care (Kazak, 2005).

The Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006; See Fig. 1) may be helpful as a framework for conceptualizing psychosocial risk1 and

1“Psychosocial risk is a constellation of individual, family, social, and economic factors that, when considered collectively, increase the likelihood that an individual or their family members will experience difficulties managing the challenges of cancer and its treatment. These difficulties may manifest as psychological symptoms or as diminished academic/professional, social or family functioning of either the patient or a family member”.

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formulating the type and level of interventions required. This model, adapted from the National Institute of Mental Health prevention framework, describes the pediatric health population by conceptualizing families in terms of psychosocial risk (National Institute of Mental Health, 1998). Presented as a pyramid, PPPHM estimates that the majority of families, represented in the base of the pyramid, are transiently and understandably distressed, but resilient (Universal). Another smaller set of families, represented in the middle tier of the pyramid, experience acute distress and the presence of some psychosocial risk factors (Targeted). The remaining set of families, smallest in number, are at the apex of the pyramid, with multiple risk factors indicating intense, persistent and/or escalating distress (Clinical; Kazak et al., 2001, 2003). An evidence-based assessment approach that could reliably classify families by level of psychosocial risk could streamline the delivery and increase specificity in the provision of psychosocial services in health care environments, which have limited resources to meet the needs of children diagnosed with cancer and their families.

The Psychosocial Assessment Tool (PAT) was a screening instrument designed to assess psychosocial risk in families of children newly diagnosed with cancer. The original PAT was a 20-item screening questionnaire that assessed a constellation of risk and resource factors including family structure, family resources, social support, child knowledge, school attendance, child emotional, and behavioral concerns, child maturity for age, marital/family problems, family beliefs, and other stressors (Kazak et al., 2001). In a prospective study of 125 families of children newly diagnosed with cancer, preliminary reliability and validity data for the PAT was established (Kazak et al., 2001, 2003). Higher PAT scores were associated with higher levels of psychosocial risk (Kazak et al., 2003), and PAT scores at time of diagnosis were also significantly related to PAT scores 3–6 months later (p < .01). Although, the PAT was a viable instrument, testing revealed that some items were difficult for respondents to understand and some open ended questions failed to elicit detailed information about child and family psychological symptoms.

Therefore, a data-driven revision of the original PAT was undertaken. The resulting PAT2.0 was modified to improve the clarity of questions, reformatted to be more appealing and user friendly, and expanded in item content based on new knowledge and data from the original PAT study. The PAT2.0 is a two-page self-report measure consisting of 15 item sets. The response format for the items was designed to be brief and simple (e.g., yes/no, categorical responses, Likert-type scales). Completion of the PAT2.0 takes approximately 10 min.

The purpose of the current study is to evaluate the psychometric properties of PAT2.0. First, we evaluate the internal consistency and test–retest reliability of the PAT2.0. In addition, the PAT2.0 scores for mothers and fathers are compared to identify whether there are differences between reporters on the PAT2.0. Next, we
examine the \textit{content validity} of the PAT2.0 subscales, correlating subscale scores with scores on standardized measures designed to measure similar constructs. We hypothesized that higher scores on PAT2.0 subscales would be significantly associated with higher scores on measures that correspond to the content the PAT2.0 subscale is intended to measure (e.g., PAT2.0 Child Behavior Problems subscale and the BASC-2 Behavioral Symptom Index). To assess \textit{criterion-related validity} we test whether PAT2.0 Total Scores are significantly related to more adverse psychosocial outcomes typically associated with family psychosocial risk. We predicted that higher PAT2.0 Total scores would be significantly associated with higher scores on psychosocial outcomes including acute stress, child behavior symptoms, state anxiety, and family conflict and lower scores on family cohesion. The PPPHM categories were also examined to assess \textit{criterion-related validity}. We predicted that families that score in the Clinical category would score higher on measures of psychological distress (i.e., PTSS and anxiety symptoms for parents and behavioral symptoms for children and family conflict) than families that fall in the Targeted or Universal categories. In addition, families in the Targeted category on their PAT2.0 score would score higher on measures of psychological distress and family functioning than those in the Universal category.

Evidence for \textit{convergent validity} is sought through investigation of correlations between PAT2.0 scores and a staff version of the PAT completed by physicians and nurses. Finally, the PAT2.0 does not merely reflect characteristics of the cancer diagnosis or treatment, but rather to capture characteristics and patterns of functioning within the family that put them at risk when confronting cancer diagnosis and treatment. Previous study findings have been mixed, with some showing a relationship between psychological outcomes and medical indicators (Phipps, Long, Hudson, & Rai, 2005) and others not (Alderfer, Cnaan, Annunziato, & Kazak, 2005). Therefore, no relationship between the PAT2.0 Total score and treatment intensity are anticipated (\textit{discriminative validity}). Finally, we predicted that the PAT2.0 scores would discriminate between families that score high on the clinical outcomes [i.e., BASC-2 Behavioral Symptom Index and the Acute Stress Disorder Scale (ASDS)] and those who do not.

\textbf{Method}

\textbf{Participants}

Female ($N = 132$) and male ($N = 72$) caregivers of 141 children newly diagnosed with cancer participated. Inclusion criteria were a confirmed diagnosis of a pediatric malignancy in a child under the age of 18 years without prior chronic or life threatening illness, and fluency in English or Spanish. Six parents completed the PAT2.0 in Spanish (two mothers and four fathers). The majority of families (83.0%, $N = 117$) were two-caregiver households and parents’ average age was in the late 30s and early 40s ($M_{\text{mother age}} = 38.09$, $SD = 7.25$; $M_{\text{father age}} = 41.11$, $SD = 7.03$). Educationally, the sample was diverse, with 23.4% of mothers ($N = 31$) and 16.2% of fathers ($N = 12$) having a high school education or less, 58.3% ($N = 77$) of mothers and 56.7% ($N = 42$) of fathers having college courses or a college degree and 18.2% ($N = 34$) of mothers and 27.0% ($N = 20$) of fathers having some postgraduate education.

The patients ranged in age from 5 weeks to 18 years ($M = 8.2$ years, $SD = 5.6$ years). Sixty percent were male ($N = 84$). Ethnic background was as follows: Caucasian ($N = 111$, 78.7%), African-American ($N = 13$, 9.2%), Hispanic ($N = 7$, 5.0%), Asian ($N = 3$, 2.1%), and bi-racial ($N = 7$, 5%). Cancer diagnoses were: leukemias (ALL, AML, CML; $N = 54$, 38.3%), brain tumors ($N = 31$, 22.0%), and solid tumors (lymphoma, neuroblastoma, sarcomas, Hodgkin’s Disease, germ cell tumors, Wilms’ tumor, and carcinoma; $N = 56$, 39.7%).

Twenty-seven oncologists and 46 nurses were asked to complete the Staff PAT for families in the study. Staff PATs were completed by either the nurse or oncologist for 135 families (95.7% of the total sample) and were completed by both the nurse and oncologist for 80 families. Oncologists were either the attending physician or a fellow assigned to the patient. On average the oncologists had 6.6 ($SD = 8.9$) years experience and spent an average of 11 days ($SD = 12.7$ days) on service with each family prior to completing the measure. Most nurses were the assigned primary nurse. In 27% of the cases, we were unable to identify the primary nurse, and the bedside nurse with most contact with the patient was asked to participate. On average, nurses had 4.4 ($SD = 4.5$) years experience. They spent, on average, five shifts ($SD = 4.3$ shifts) with each family prior to completing the measure.

\textbf{Procedures}

\textbf{Study Procedures}

This study was approved by the Committees for the Protection of Human Subjects of the Institutional Review Board at the hospital where the study was conducted. Newly diagnosed patients were identified when they completed their initial family diagnostic meetings during which a diagnosis of cancer was discussed with parents.
Families were approached for participation during the child’s first inpatient hospitalization or during an outpatient appointment (if the child was not admitted). One hundred and fifty-eight families were approached for participation over a 16-month period between January 2005 and April 2006. Of those, 141 families agreed to participate (89% participation rate) and provided consent. Reasons families gave for declining participation included: feeling overwhelmed (N = 12), not interested in participating (N = 3), already participating in another research study (N = 1), or not wanting to consent to use of data from the medical record (N = 1). Subsequent to providing written informed consent, parents completed self-report measures. Parents completed study measures typically within 2 weeks of the date of diagnosis (Mothers: median = 4.0 days, M = 7.1, SD = 7.2; Fathers: median = 5 days, M = 7.4, SD = 6.8). The majority of staff completed their measures within the first month of diagnosis (Nurses: median = 22.0 days, M = 28.3, SD = 20.9; Physicians: median = 11.0 days, M = 20.8, SD = 22.5). To assess test–retest reliability the first 25 families enrolled in the study with even numbered participant numbers were asked to complete the PAT2.0 a second time two weeks after baseline. A total of 25 mothers and 20 fathers completed the second PAT2.0 an average of 13.5 days (SD = 7 days) after baseline.

Measure Development Procedures: The Psychosocial Assessment Tool 2.0 (PAT2.0)

Prior to enrolling participants for this study, the original PAT measure was revised. Eighteen domains of psychosocial risk were identified based on previous literature and the original PAT study to guide PAT2.0 development. They were as follows: Family Conflict, Family Resources, Family Structure, Social Support, Stress Reactions, Family Substance Use, Family Psychological Problems, Child Internalizing Problems, Child Externalizing Problems, Child Cognitive Problems, Child Social Problems, Child School Enrollment, Child Educational Placement, Patient’s Medical Status, Child Knowledge of Cancer, Family Beliefs, Family Medical Problems, and Sibling Problems. As an initial step in the validation of the PAT2.0, 84 clinical experts in pediatric oncology (21 each—oncologists, nurses, social workers, and psychologists), outside our institution, rated the 18 domains with regard to their level of psychosocial risk using four categories—“no risk”, “low risk”, “medium risk”, or “high risk”. In general, there was strong agreement that the domains were tapping risk factors for ongoing distress. All 18 domains were rated as medium or high risk by at least 65% of the expert raters. Items on the PAT2.0 were developed to correspond with these 18 domains.

The product of this development process was a screening measure for assessing family psychosocial risk in families with a child newly diagnosed with cancer (Fig. 2) which was then administered to caregivers of newly diagnosed patients. A PAT2.0 Total score and seven subscale scores were formed based on theoretical and empirical grounds (Kazak et al., 2001, 2003) and to ensure acceptable preliminary internal consistency (i.e., $\alpha \geq .60$; Ware et al., 1980). The scales are theoretically based on a social ecological perspective on child health (Kazak, 1989; Kazak et al., 2002), reflecting the importance of parent and family functioning, psychosocial resources, social support and illness factors in child outcomes. The family structure and family resources domains were combined to form the Family Structure and Resources Subscale. Likewise, the family problems, family substance use problems, family conflict, and family medical problems domains were collapsed into one subscale with acceptable reliability called Family Problems. The child internalizing, externalizing, cognitive, and social problems domains were collapsed into a Child Problems subscale that mirrors the Sibling Problems subscale. Consistent with the original domains, Social Support, Stress Reactions, Sibling Problems, and Family Beliefs subscales were also developed. There were five items representing four domains (child knowledge of cancer, child school enrollment, child educational placement, and patient’s medical status) that were not included in the PAT2.0 Total score because they were represented by too few items to conduct reliability analyses. They are included on the PAT2.0 because these items assess valuable information for clinicians.

Ultimately, the PAT2.0 was comprised of the following subscales: Family Structure and Resources, Family Social Support, Family Problems, Parent Stress Reactions, Family Beliefs, Child Problems, and Sibling Problems. Each item was dichotomously scored (i.e., risk/no risk), based on the literature and the consensus of our multidisciplinary research group (e.g., respondent indicates that an adult in the child’s home has experienced prolonged sadness or depression). Ranges of possible scores for each of the subscales are in Table 1. To derive the PAT2.0 Total scores, adjusted PAT2.0 subscale scores were calculated by dividing the number of high-risk items endorsed in each domain by the total number of questions in the respective domain. Using this calculation, the adjusted score for each subscale could
Figure 2. The psychosocial assessment tool 2.0.
range from 0.00 to 1.00. These adjusted subscale scores were then summed to create a PAT2.0 Total score for each respondent. Possible PAT2.0 Total scores ranged from 0 to 7.

Validation Measures

Demographic Information
Parents provided information regarding their age, relationship status (married/not married), highest level of education completed, and child’s age and race/ethnicity. Patients were categorized as either Caucasian or non-Caucasian, based on parent-identified race of the child. Parent report of years of education was used to estimate socioeconomic status (SES; Cirino et al., 2002).

The BASC-2 (Reynolds & Kamphaus, 2004) is comprised of 134–160 items (depending on the age of the child), 4-point Likert-type rating scale assessing parental report of child psychosocial competence, standardized for ages 2.5–18 years. Only parents of children over age 2.5 completed the BASC-2. Internal consistencies for the Behavioral Symptoms Index on the current sample ranged from .80 to .94. The Behavioral Symptoms Index was used as a measure of child behavior symptoms.

Acute Stress Disorder Scale
The ASDS (Bryant, Moulds, & Guthrie, 2000) is a 19-item inventory, rated on a 5-point Likert-like scale, designed to serve as a screening instrument to identify acutely traumatized individuals and predict posttraumatic stress disorder. In addition to the Total score, the ASDS consists of four subscales/clusters, Dissociation, Re-experiencing, Avoidance, and Arousal. In the normative sample, internal consistency of the total score was high (α = .96). Two seven-day test–retest correlation coefficients have shown to be strong for the total score (.94; Bryant et al., 2000). The ASDS Total score was used in the current study and the internal consistency for ASDS Total score in our sample was excellent (mothers = .91, fathers = .90).

Family Environment Scale (FES) – Conflict and Cohesion Scales
The FES (Moos & Moos, 1974) is a well-established self-report measure of family functioning. The Conflict and Cohesion subscales are 9-item scales using a True–False format. Higher scores indicate greater conflict and cohesion. Adequate internal consistency has been previously demonstrated for the Conflict (α = .75) and the Cohesion scales (α = .78; Moos & Moos, 1974) along with adequate two- and four-month test–retest reliability (Conflict: r’s = .85 and .66, respectively; Cohesion: r’s = .86 and .72, respectively; Auerbach et al., 2005). Within our sample, alpha was marginal for both the Cohesion (mothers = .55, fathers = .43) and Conflict (mothers = .62, fathers = .63) scales.

### Table I. Descriptive Statistics for PAT2.0 for Female and Male Caregivers

<table>
<thead>
<tr>
<th>PAT2.0 scale (Items)</th>
<th>Female caregivers N = 132</th>
<th>Male caregivers N = 73</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Scale range</td>
<td>Internal</td>
</tr>
<tr>
<td>Total</td>
<td>0–7</td>
<td>.81</td>
</tr>
<tr>
<td>Structure/resources</td>
<td>0–8</td>
<td>.62</td>
</tr>
<tr>
<td>Family problems</td>
<td>0–10</td>
<td>.72</td>
</tr>
<tr>
<td>Social support</td>
<td>0–4</td>
<td>.69</td>
</tr>
<tr>
<td>Stress reaction</td>
<td>0–3</td>
<td>.64</td>
</tr>
<tr>
<td>Family beliefs</td>
<td>0–4</td>
<td>.59</td>
</tr>
<tr>
<td>Child problems</td>
<td>0–15</td>
<td>.81</td>
</tr>
<tr>
<td>Sibling problems</td>
<td>0–15</td>
<td>.73</td>
</tr>
</tbody>
</table>

Note: Mean comparisons between mothers and fathers on PAT2.0 Total and subscale scores (N=64).

*Significant difference between mothers and fathers (p < .05). Internal consistency calculated using Kuder–Richardson-20 and conducted on data provided by the primary caregiver (whether identified as mother or father).
State-Trait Anxiety Inventory (STAI-Y)-State Scale
The STAI-Y (Spielberger, 1983) is a 40-item self-report questionnaire, rated on a 4-point Likert-like scale (1 = not at all, 2 = somewhat, 3 = moderately so, 4 = very much so) that assesses symptoms of current anxiety (state anxiety) and general anxiety (trait anxiety). Only State anxiety was reported in this study as we were interested in measuring current anxiety symptoms rather than dispositional characteristics. Internal consistencies for the State Anxiety scale have ranged from .89 to .96 (Spielberger, 1983). Within our sample, the internal consistency for the state anxiety scale was excellent for both mothers (α = .93) and fathers (α = .94).

Staff Report
Staff PAT
The Staff PAT is a 17-item Likert type rating scale developed by our team that provides a parallel assessment of psychosocial risk from the perspective of the patient’s oncologist (attending or fellow) and nurse (bedside or primary). The items correspond to the PAT2.0 and ask whether a particular risk factor is an area of concern for the family (four point scale ranging from definitely no [0] to definitely yes [3]). A sum score is derived, ranging from 0 to 51. Internal consistency for the Staff PAT in the current sample was α = .88 for oncologists and α = .82 for nurses.

The Intensity of Treatment Rating scale (ITR-2)
The ITR-2 provides a categorization of the intensity of pediatric cancer treatment from least intensive (Level 1) through most intensive (Level 4). Ratings were based on treatment modality (radiation, chemotherapy, surgery) and stage/risk level for the patient. Ratings were made by a pediatric oncologist (A.T.R.), blind to patient identity, and stage/risk level for the patient. Ratings were made by a pediatric oncologist (A.T.R.), blind to patient identity, based on disease and treatment data extracted by chart review. The ITR has been used in prior studies (Hobie et al., 2002; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Kazak et al., 2003) but has been revised recently (Werba et al., 2007). Content validity for the ITR-2 was assessed by examining correlations between the PAT2.0 subscales and measures of the corresponding construct. Specifically, the Family Problems, Family Structure and Resources, and Sibling Problems subscales were correlated with the FES conflict and cohesion scales; the Stress Reaction and Family Beliefs subscales were correlated with the ASDS; the Stress Reaction subscale was correlated with the STAI-State and the Child Problems were correlated with the BASC-2. Due to the marginal reliability of the FES scales, corrected correlations were calculated for all variables correlated with the FES for both mothers and fathers and are reported in Tables III and IV (Spearman, 1904).

Criterion-related validity, the ability of a measure to predict a particular outcome, was examined by correlating the PAT2.0 Total score with measures of parent acute distress and state anxiety, family functioning, child psychological symptoms, and treatment intensity. In cases where there was a clear construct that corresponded to the PAT2.0 subscales and a well-validated measure to test that construct, the content validity was assessed by examining correlations between the PAT2.0 subscales and measures of the corresponding construct. Specifically, the Family Problems, Family Structure and Resources, and Sibling Problems subscales were correlated with the FES conflict and cohesion scales; the Stress Reaction and Family Beliefs subscales were correlated with the ASDS; the Stress Reaction subscale was correlated with the STAI-State and the Child Problems were correlated with the BASC-2. Due to the marginal reliability of the FES scales, corrected correlations were calculated for all variables correlated with the FES for both mothers and fathers and are reported in Tables III and IV (Spearman, 1904).

Overview of Statistical Analyses
Analyses were conducted in four stages. First, descriptive statistics were calculated for all study measures. In the second stage, reliability analyses were conducted for the PAT2.0 Total and Subscale scores including internal consistency, test–retest reliability, and reliability across respondents. Because items were dichotomously scored (i.e., risk/no risk), internal consistencies were calculated using Kuder–Richardson 20 coefficients. Where the internal consistency of the scale was ≥ .60 no items were removed as internal consistency coefficients of ≥ .60 are considered adequate for newly developed scales (Ware et al., 1980). For scales where the internal consistencies were inadequate (<.60) individual items from each scale were examined and removed one at a time until the internal consistency for each scale reached >.60. Test–retest reliability was also calculated for the PAT2.0 Total score. Finally, differences between mothers’ and fathers’ responses on the PAT2.0 total and subscales were compared using paired t-tests.

Second, validation analyses were conducted using Pearson Product Moment Correlation Coefficients. Correlations were calculated between PAT2.0 Total and subscale scores and measures of parent acute distress and state anxiety, family functioning, child psychological symptoms, and treatment intensity. In cases where there was a clear construct that corresponded to the PAT2.0 subscales and a well-validated measure to test that construct, the content validity was assessed by examining correlations between the PAT2.0 subscales and measures of the corresponding construct. Specifically, the Family Problems, Family Structure and Resources, and Sibling Problems subscales were correlated with the FES conflict and cohesion scales; the Stress Reaction and Family Beliefs subscales were correlated with the ASDS; the Stress Reaction subscale was correlated with the STAI-State and the Child Problems were correlated with the BASC-2. Due to the marginal reliability of the FES scales, corrected correlations were calculated for all variables correlated with the FES for both mothers and fathers and are reported in Tables III and IV (Spearman, 1904).
the ability of the PAT2.0 to discriminate those parents that concurrently report clinical levels of child or parent distress.

Results

Descriptive Statistics

Descriptive statistics were calculated for the PAT 2.0 as well as the validating measures. PAT2.0 Total and subscale statistics are reported in Table I. Descriptive statistics for the validating measures are in Table II.

Reliability

Internal consistency for the Total PAT2.0 score was strong (α = .81, Table I). For six of the seven PAT2.0 subscales an alpha coefficient of .60 or above was successfully obtained through removal of items. Due to the multidimensional nature of the Family Beliefs subscale, only four items were analyzed. The internal consistency of these four items were α = .59 but was retained in analyses for theoretical reasons (Kazak et al., 2004).

These items were chosen because they represent a subset of cancer-related beliefs, competence (See Fig. 2; items 15a, 15f, and 15h) and positive growth (item 15c), theoretically measured similar beliefs and demonstrated adequate internal consistency. Pearson Product Moment correlations indicated very good test–retest reliability for the PAT2.0 Total score for mothers (r = .78, p < .001) and fathers (r = .87, p < .001).

Mothers’ and fathers’ scores were compared using paired sample t-tests on the PAT2.0 Subscale and Total scores. There were no significant differences, with one exception. Mothers reported significantly fewer sibling problems than fathers [t (1, 63) = −3.74, p < .01].

Content Validity

The content validity of the PAT2.0 subscales was examined by correlating PAT2.0 subscale scores with measures that theoretically assess the same content. All correlations were conducted independently for mothers and fathers (Table III). Specifically, the Family Structure and Resources, Family Problems, and Sibling Problems subscales were correlated with the FES Cohesion and Conflict Scales; the Family Beliefs and Stress Reaction subscales were correlated with the ASDS; and the Child Problems subscale was correlated with the BASC-2. For mothers, correlations were in the expected directions between the Structure and Resources subscale and FES-Cohesion (p < .05); Family Problems Subscale and the FES-Cohesion (p < .05) and FES-Conflict Scales (p < .05); the Stress Reaction and the ASDS and State anxiety scores, the Family Beliefs subscale and the ASDS (p’s < .05); the Sibling Problems and FES-Conflict (p < .05); and between the Child Problems Subscale and the BASC-2 (p’s < .001). For fathers, significant correlations were observed between the Family Structure and Resources and FES-Cohesion (p < .05), between Family Problems and FES-Conflict (p < .05); the Stress Reaction subscale and the ASDS and State anxiety scale and between Child Problems and the BASC-2.

Criterion-Related Validity

To assess criterion-related validity, PAT2.0 Total scores were correlated with outcome variables indicative of, or associated with, psychosocial risk. Maternal PAT2.0

Table II. Descriptive Statistics for Validation Measures for Female and Male Caregivers

<table>
<thead>
<tr>
<th>Measure</th>
<th>Female caregivers</th>
<th>Male caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>M</td>
</tr>
<tr>
<td>ASDS total</td>
<td>128</td>
<td>50.33</td>
</tr>
<tr>
<td>STAI-state</td>
<td>128</td>
<td>50.57</td>
</tr>
<tr>
<td>BASC-2</td>
<td>100</td>
<td>47.55</td>
</tr>
<tr>
<td>FES-cohesion</td>
<td>128</td>
<td>8.08</td>
</tr>
<tr>
<td>FES-conflict</td>
<td>128</td>
<td>2.30</td>
</tr>
</tbody>
</table>

Note: The N refers to the number of valid cases for a particular measure. N’s vary due to missing data.
scores were significantly correlated in the predicted directions with maternal ASDS, State anxiety, and FES-Conflict and the BASC-2 (all \( p's < .01 \)). Likewise, higher father PAT2.0 scores were significantly correlated with higher paternal ASDS, FES-Conflict, and the BASC-2, as well as lower FES-Cohesion (Table IV). The ITR-2 was not significantly associated with PAT2.0 total scores.

Next, PAT2.0 Total score cutoffs were established to classify families into PPPHM categories. Score cutoffs were determined \textit{a priori} based on the PPPHM theory (Kazak, 2006) and our previous empirical evidence using the original PAT (Kazak et al., 2001). Then the cutoffs were examined to determine where they fell in the distribution of the sample scores. PAT2.0 Total Scores of <1SD above the mean were placed in the Universal category, scores between 1 and 2SD above the mean were classified in the Targeted category and scores >2SD above the mean were classified in the Clinical category. Consistent with what would be predicted by the PPPHM, based upon maternal reports, 55% of the families fell into the Universal category, 32% fell into Targeted, and 13% fell into the Clinical category. For fathers’ reports, 67% of the families fell into Universal, 32% fell into Targeted, and 1% fell into the Clinical range.

To further validate these cutoffs, scores on the ASDS, BASC-2, FES-Conflict scale, and the STAI-Y State scales were compared among the PPPHM categories. Analyses were conducted separately for mothers and fathers. For mothers, omnibus ANOVAs were significant for all measures (\( p's < .05 \)). Follow-up comparisons were conducted using Bonferroni corrections to determine which levels of the PPPHM model differed significantly from one another. Mean differences and effect sizes for each of the comparisons are listed in Table V. ASDS scores were significantly lower for mothers in the Universal versus the Targeted and Clinical groups (\( p's < .05 \)) and those in the Targeted group were significantly lower than the Clinical group. With regard to BASC-2 scores, the Universal and Targeted groups defined by mothers did not differ significantly; however both of these groups had more favorable BASC-2 scores than the Clinical group. Finally,

**Table IV. Correlations Between PAT2.0 Total Score and Validation Instruments: Criterion-Related Validity**

<table>
<thead>
<tr>
<th>Construct</th>
<th>PAT2.0 subscale</th>
<th>Validation instrument</th>
<th>Mothers</th>
<th>Fathers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family psychosocial risk</td>
<td>Total score ASDS</td>
<td>.57*** .30*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>STAI-state</td>
<td>.41** .28*</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BASC-2</td>
<td>.65*** .51***</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>FES-conflict</td>
<td>.40*** .31**</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Disattenuated correlations were calculated for the correlation between the FES-conflict scale and the PAT2.0 Total score (\( r_{\text{matters}} = .56, r_{\text{fathers}} = .44 \)).

Note: *\( p < .05 \), **\( p < .01 \), ***\( p < .001 \).

**Table V. Mean Differences on Outcome Measures Between PPPHM Risk Categories for Mothers and Fathers**

<table>
<thead>
<tr>
<th>Variable</th>
<th>PPPHM categories compared</th>
<th>Mean ( \Delta )</th>
<th>( d )</th>
<th>Mean ( \Delta )</th>
<th>( d )</th>
</tr>
</thead>
<tbody>
<tr>
<td>ASDS</td>
<td>Universal vs. Targeted</td>
<td>F(2, 127) = 25.68, ( p &lt; .001 )</td>
<td></td>
<td>F(1, 69) = 2.92, ( p = .06 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Universal vs. Clinical</td>
<td>6.66* .49</td>
<td></td>
<td>7.06 .47</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Targeted vs. Clinical</td>
<td>26.86*** 1.41</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20.00*** 2.11</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>BASC-2</td>
<td>Universal vs. Targeted</td>
<td>F(2, 99) = 20.09, ( p &lt; .001 )</td>
<td></td>
<td>F(1, 48) = 4.73, ( p = .01 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Universal vs. Clinical</td>
<td>2.99 .02</td>
<td></td>
<td>3.23 .29</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Targeted vs. Clinical</td>
<td>15.02*** 1.25</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>12.02*** 1.43</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>FES-Conflict</td>
<td>Universal vs. Targeted</td>
<td>F(2, 125) = 9.33, ( p &lt; .001 )</td>
<td></td>
<td>F(1, 69) = 2.70, ( p = .07 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Universal vs. Clinical</td>
<td>.46 .31</td>
<td></td>
<td>.55 .48</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Targeted vs. Clinical</td>
<td>2.00*** .90</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1.54** 1.15</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td>State Anxiety</td>
<td>Universal vs. Targeted</td>
<td>F(2, 127) = 14.87, ( p &lt; .001 )</td>
<td></td>
<td>F(1, 69) = 1.86, ( p = .16 )</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Universal vs. Clinical</td>
<td>8.07** .74</td>
<td></td>
<td>5.62 .45</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Targeted vs. Clinical</td>
<td>14.16*** .53</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6.09 1.41</td>
<td></td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>

Note: Cohen’s \( d \) was used as a measure of effect size. Effect sizes were not calculated between the Universal and Clinical and the Targeted and Clinical for fathers because only one father was in the Clinical category based on his PAT2.0 Total Score. Number of participants varies depending on the valid data available for each measure.

*\( p < .05 \), **\( p < .01 \), ***\( p < .001 \).
the STAI-Y State scale was significantly lower for mothers in the Universal group compared to mothers in the Targeted or the Clinical groups. Mothers in the Targeted and Clinical groups did not differ in anxiety scores \((p > .05)\). For fathers, comparisons were only conducted between the Universal and Targeted groups. The Clinical group only included one family, therefore precluding post hoc analyses with this group. No significant differences were observed between the Universal and Targeted groups on the ASDS, BASC-2, FES-Conflict, or the STAI-Y State for fathers.

**Convergent Validity**

Convergent validity, the relationship between two measures purported to measure the same domain, was assessed by calculating correlations between PAT2.0 total scores and Staff PAT scores from nurses and physicians. Maternal PAT2.0 scores were significantly associated in the expected directions with both physician \((r = .45, p < .01)\) and nurse \((r = .38, p < .01)\) staff PAT reports, respectively. For fathers, PAT2.0 scores were significantly correlated with nurse reported Staff PAT \((r = .36, p < .05)\) but not physician reports \((r = .17, p > .05)\).

**Discriminant Validity**

As predicted, the PAT2.0 was not correlated with physician rated treatment intensity for mothers \((r = -.10, p > .05)\) or fathers \((r = -.05; p > .05)\). The sensitivity and specificity of the PAT2.0 to detect clinically significant outcomes was also examined using ROC Curves (McFall & Treat, 1999; Zweig & Campbell, 1993). The ASDS and the BASC-2 were chosen for the ROC analyses as both measures have established clinical or “at-risk” cutoffs, (for the ASDS a Total score of 56 or greater and for the BASC-2 a Behavioral Symptom Index a T-score of 60 or greater). Here, the ROC curves resulted in areas under the curve (AUC) significantly better than .50 (the value when diagnostic performance of a measure is equal to chance) for mothers on both the BASC-2 and the ASDS and for fathers on the BASC-2. For mothers, the AUC for the BASC-2 was .94 \((p < .001)\) and for the ASDS the AUC was .80 \((p < .001)\). Using a PAT2.0 Total score of 1.0 for the cutoff, the PAT2.0 correctly classified 35/47 (75%) of the mothers with scores above the clinical cutoff on the ASDS (sensitivity) and 60/81 (74%) of the mothers who did not have ASDS scores above the clinical cutoff (specificity). Maternal PAT2.0 scores of 1.0 or above correctly classified 8/8 (100%) of the participants with BASC-2 scores over the “at-risk” cutoff and 55/92 (60%) of those scoring below the “at-risk” range. We then examined whether a PAT2.0 Total score of 2.0 or greater discriminated those that scored in the “clinically significant” range on the BASC-2 \((score > 70)\). Indeed, PAT2.0 scores above 2.0 identified 3/3 children with BASC-2 scores above 70 and correctly classified 83/95 (87%) children that did not score in the “clinically significant” range.

For fathers the AUC for the BASC-2 was significant \((AUC = .96, p < .001)\) but not for the ASDS \((AUC = .60, p > .05)\). Further analyses of paternal data on the BASC-2 indicated that a PAT2.0 Total score of 1.0 or greater correctly classified 5/5 (100%) of the participants with BASC-2 scores over the “at-risk” cutoff and 30/45 (67%) of those under the cutoff. There was insufficient data to examine whether a PAT2.0 Total score of 2.0 or greater discriminated children in the “clinically significant” range on the BASC-2 (no fathers reported their child as in the BASC-2 clinically significant range).

**Discussion**

Despite longstanding recognition of the stressors associated with having a child diagnosed with cancer, evidence-based assessment approaches for identifying families at risk have not been available. The PAT2.0 is a standardized, reliable and valid method for medical and allied health providers to objectively and efficiently assess a family’s risk for experiencing clinically significant distress during treatment. The PAT2.0 is a second generation measure that offers a user-friendly screening approach that takes less than 10 min to complete.

Good internal consistency and test–retest reliability were demonstrated for the PAT2.0 Total Scale. Reliability for the Subscale scores were acceptable for a newly developed instrument and suggest that the items within the subscales of the PAT2.0 are relatively homogeneous and measuring aspects of the same construct without being overly redundant. Initial construct and criterion related validity for the PAT2.0 were also demonstrated. Overall, the subscales were associated with corresponding constructs in the expected directions. The PAT2.0 Total Score was also significantly associated with critical child behavioral outcomes in the expected directions. Notably, the PAT2.0 Total score was associated with parent acute distress, child behavior problems, and family conflict for both mothers and fathers. These findings support the PAT2.0 as a useful screening tool for newly diagnosed pediatric oncology patients and their families.
The PAT2.0 is linked to the PPPHM, a model that can be used to guide the development and evaluation of interventions. The data in this study support the use of the PAT2.0 to categorize families based on their level of risk where higher scores are indicative of greater levels of risk. Overall, mothers in the Universal and Targeted groups reported significantly less acute stress symptoms, fewer child problems and less family conflict than their counterparts in the Clinical PPPHM risk group. Mothers in the Universal group also reported less current anxiety than those in the Targeted and Clinical groups. Although trends were in the expected directions for fathers, PPPHM risk group did not distinguish paternal scores on key outcomes. However, sensitivity and specificity analyses support the use of a PAT2.0 Total score of 1.0 to indicate that a particular family may need some type of increased psychosocial services. Due to the limited number of participants with PAT2.0 Total scores higher than 2.0 and BASC-2 scores in the clinical range, future research with larger sample sizes will be needed to determine if the Clinical category cutoff (PAT2.0 Total score of 2.0) is sensitive to differences in degree of clinical need of families assessed with the PAT2.0. Conceivably, this could be due to a lack of power to detect differences between the PPPHM groups as the current sample of fathers was significantly smaller than that of mothers. Alternatively, fathers may respond differently to the PAT2.0 and thus may require the establishment of different cutoffs and norms. Overall, these findings provide preliminary validity for using the PAT2.0 to identify families of newly diagnosed patients most in need of more intensive levels of psychosocial intervention.

Despite the favorable psychometric properties reported in this article, further research is necessary to refine the measure further. First, the PAT2.0 subscales were theoretically derived and empirically tested on a single sample. Although parents in the sample were asked to complete the measures independently we have no way of directly verifying this. A larger multisite sample would increase the diversity if the sample thereby increase the generalizability of the instrument possibly increasing the range of observed scores. Additional higher-level analyses are needed to empirically examine the factor structure of the instrument to determine whether these subscales accurately capture the underlying structure of the measure. Going forward, the sensitivity and specificity of the PAT2.0 needs to be evaluated to fully understand its clinical utility in predicting distress. Such an evaluation should include the examination of both short-term (patients on treatment) and long-term (patients that are posttreatment and long-term survivors) outcomes for patients and families. Although the FES subscales had low internal consistencies, the results held even after correcting for the reliability of the measures. In addition, the sample size for fathers was relatively small, limiting the conclusions that can be drawn about the data from fathers. Some of the constructs likely related to psychosocial risk, such as family beliefs, are difficult to measure and may not necessarily relate consistently to other constructs. For example, items assessing beliefs related to treatment-related suffering and death from the Family Illness Beliefs Inventory (Kazak et al., 2004) included on the PAT2.0 form were not included in the score due to poor reliability, yet these beliefs may be informative about the psychosocial risk level of the family and may be important in interventions.

Although families are under added acute strain at the time of diagnosis, psychosocial risk may be thought of as a moderately stable factor over the course of treatment. That is, pre-existing family stressors (e.g., child behavioral concerns, marital discord) are likely to persist across treatment. Although family structure and resources may shift, in most cases they are not likely to change dramatically. Future research is needed to determine if the PAT2.0 could identify specific areas of risk and directly inform the multidisciplinary treatment teams on targeted psychosocial interventions and care. Eventually, using the PAT2.0 immediately after the diagnostic meeting could allow for quick identification of areas in need of further assessment and subsequently could guide the forms of assistance offered to families such as financial and social services or consultations to prevent child or family difficulties during treatment.

Understanding the ability of the PAT2.0 to predict the “costs” associated with elevated risk is essential. That is, those families at the Clinical and Targeted levels are most likely to have ongoing difficulties that may contribute to a more difficult treatment course (e.g., personal distress of patient and or family members, nonadherence to treatment, difficult relationships with the treatment team, difficulty attending outpatient clinic visits). The previous version of the PAT showed associations between scores on the screener and subsequent utilization of social work services during treatment (Kazak et al., 2003). We expect this to be the case with this revision but will await further data to test the ability of the PAT2.0 to predict the nature and intensity of services provided by social workers, child life specialists and
psychologists, as well as the added care provided by oncologists and nurses in addressing concerns related to psychosocial risk.

The PPPHM asserts that the majority of families with a child with cancer are competent and adaptively organized. However, a proportion of families have pre-existing vulnerabilities or difficulties that may be exacerbated by the diagnosis of cancer and that could result in diminished functioning and increased risk for clinical-levels of distress. In the future, the PPPHM could provide a model to guide interpretation of PAT2.0 scores and subsequently service delivery for all families of children entering the pediatric healthcare system. For example for families in the Universal category services could consist of a family centered care approach by the entire oncology team as well as standard programming that all families have the option to receive. Interventions in the Targeted category would focus on specific or acute problems that the child or family may have (e.g., interventions addressing procedural distress). Finally, interventions for families in the Clinical category would be much more resource intensive and focused, reflecting realistic goals of assuring that medical care is provided safely and that acute distress is reduced, without attempting to “cure” more severe and chronic family problems that may contribute to the presenting problem. For a more detailed description of the intervention suggestions for specific levels of the PPPHM model see Kazak and colleagues (in press). The PAT2.0 may be one tool that can be used to test this model as it provides a standardized and reliable method to identify families that may be at risk. In this way the PAT2.0 could be an essential tool for providing good preventative patient care, as well as an efficient and cost-effective approach to the allocation of psychosocial resources within the health care environment.

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