

# **Best Evidence Statement (BESt)**

Date: November 28, 2012

Title: Psycho-social interventions for primary caregivers of newly diagnosed pediatric oncology patients

# **Clinical Question:**

P (Population) Among primary caregivers of newly diagnosed pediatric oncology patients,

I (Intervention) do caregiver-focused psycho-social interventions

C (Comparison) compared with current treatment

O (Outcome) lead to improved patient and caregiver adaption to serious illness and

hospitalization

T (*Time*) when started during initial patient treatment?

<u>Definitions</u> for terms marked with \* may be found in the Supporting Information section.

# **Target Population for the Recommendation**

Primary caregivers may include parents, step-parents, grandparents, guardians, and/or foster parents of the pediatric oncology patient.

### Recommendation

It is strongly recommended that primary caregivers of newly diagnosed pediatric oncology patients receive psycho-social interventions of cognitive behavioral therapy or psycho-educational therapy to reduce anxiety, emotional distress, post-traumatic stress symptoms, and negative mood and enhance effective coping skills and adjustment (Meyler, E., et al. 2010 [1b]; Othman, A., et al 2009 [1b]; Pai, A.I., et al. 2006 [1a]; Askins, M.A., et al. 2009 [2a]; Othman, A., et al. 2010 [3a]; McCarthy, P.G., et al. 2011 [4b]).

# Discussion/Synthesis of Evidence Related to the Recommendation

Three meta-analyses reviewing psycho-social intervention in individual studies between 1980 and 2008 found that psycho-social interventions aimed at caregivers demonstrated a reduction in emotional distress, negative mood, stress, anxiety, and post-traumatic stress symptoms while enhancing caregivers' adjustment, constructive coping, and improving family functioning (Meyler, E., et al. 2010 [1b]; Othman, A., et al 2009 [1b]; Pai, A.I., et al. 2006 [1a]). The earliest review examined all psycho-social interventions utilized in connection with an oncology pediatric diagnosis and found that the interventions which had the most significant effect statistically and clinically were the psycho-social interventions aimed at parents (Pai, A.I., et al. 2006 [1a]). Othman, et al.'s 2009 review focused specifically on psychosocial interventions for parents of pediatric oncology patients while Meyler, et al.'s review in 2010 looked at studies with family-based psycho-social interventions (Meyler, E., et al. 2010 [1b]; Othman, A., et al 2009 [1b]). Both studies found that psycho-social interventions designed for caregivers including behavioral and cognitive behavioral therapies demonstrated moderate effects on improving parental adjustment with a corresponding decrease in anxiety, distress, and post-traumatic stress symptoms (Meyler, E., et al. 2010 [1b]; Othman, A., et al 2009 [1b]).

Meyler's review singles out the psycho-social intervention, Surviving Cancer Competently Intervention Program (SCCIP), as a promising intervention as defined by the SPP/Chambless criteria by combining cognitive behavioral therapy and family therapy aimed at caregivers of children with cancer resulting in a statistically and clinically significant decrease in anxiety and post-traumatic stress symptoms (Meyler, E., et al. 2010 [1b]). According to Meyler, et al. (2010[1b]), the SPP/Chambless is a guideline for evaluating the empirical evidence for a psycho-social intervention created by Chambless and modified by the Society of Pediatric Psychology in which an intervention based on supporting evidence could qualify for one of three levels including well-established, probably efficacious, and promising. In order to qualify

as a promising intervention there has to be evidence that the intervention demonstrated a positive effect in more than one study and at least one of those studies must be a well-controlled study (Meyler, E., et al. 2010[1b]).

Four additional studies examining the effects of psycho-social interventions targeted at caregivers report augmented problem solving skills, increased knowledge of cancer and a reduction of anxiety and post-traumatic symptoms (Askins, M.A., et al. 2009 [2a]; Othman, A., et al. 2010 [3a]; McCarthy, P.G., et al. 2011 [4b]). These studies report that augmented problem solving skills and increased knowledge of cancer reduces anxiety and post-traumatic stress symptoms in parents. A randomized control trial examining the Problem-Solving Skills Training (PSST) program, demonstrated benefit to caregivers in improving problem-solving skills and mood while reducing depressive symptoms and post-traumatic symptoms in caregivers over time (Askins et al. 2010 [2a]). The Psycho-educational Program (PeP) with parents of pediatric cancer patients reported a clinically and statistically significant influence on the parents' knowledge of cancer and over time a drop in their anxiety levels and a rise in parent and child interactivity (Othman et al 2010 [3a]). The psycho-social intervention of Therapeutic Scrapbooking was fully explored from theory to practice in a descriptive study. The results of questionnaires filled out by participants after attending four sessions rated it high for meeting other families with children in different stages of treatment and helping them cope by sharing experiences (McCarthy et al. 2011 [4b]). Open-ended questions revealed that the activity was relaxing and fun while aiding caregivers to focus and identify family strengths.

SCCIP-ND, an adaptation of the Surviving Cancer Competently Intervention Program that was designed for parents of newly diagnosed pediatric oncology patients was studied in a randomized control trial (Stehl, M.L., et al. 2009 [2a]). This psycho-social intervention which was implemented very shortly following the cancer diagnosis was unable to show any effect due to high attrition rates in both the treatment and control group. The authors cited the rigidity of randomized control trials as part of the reason for their inability to produce a measureable effect. The inclusion criteria eliminated many who may have benefitted from the intervention due to their inability to enlist a second caregiver to participate. The authors also believed that the study was less effective as a result of the availability of psychosocial care already present which patients and families may utilize on their own terms including child life specialists, social workers and psychologist referrals (Stehl, M.L., et al. 2009 [2a]).

# **Reference List**

- Askins, M. A., Sahler, O. J., Sherman, S. A., Fairclough, D. L., Butler, R. W., Katz, E. R., et al. (2009). Report from a multi-institutional randomized clinical trial examining computer-assisted problem-solving skills training for English- and Spanish-speaking mothers of children with newly diagnosed cancer. Journal of Pediatric Psychology, 34(5), 551-563. [2a]
- McCarthy, P. G., & Sebaugh, J. G. (2011). Therapeutic scrapbooking: A technique to promote positive coping and emotional strength in parents of pediatric oncology patients. Journal of Psychosocial Oncology, 29(2), 215-230. [4b]
- Meyler, E., Guerin, S., Kiernan, G., & Breatnach, F. (2010). Review of family-based psychosocial interventions for childhood cancer. Journal of Pediatric Psychology, 35(10), 1116-1132. [1b]
- Othman, A., & Blunden, S. (2009). Psychological interventions for parents of children who have cancer: A meta-analytic review. Current Pediatric Reviews, 5(2), 118-127. [1b]
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- Pai, A. L., Drotar, D., Zebracki, K., Moore, M., & Youngstrom, E. (2006). A meta-analysis of the effects of psychological interventions in pediatric oncology on outcomes of psychological distress and adjustment. *Journal of Pediatric Psychology*, *31*(9), 978-988. [1a]
- Patino-Fernández, A., Pai, A., Alderfer, M., Hwang, W., Reilly, A., & Kazak, A. E. (2008). Acute stress in parents in children newly diagnosed with cancer. *Pediatric Blood & Cancer*, *50*(2), 289-292. [4a]
- Poder, U., Ljungman, G., & von Essen, L. (2008). Posttraumatic stress disorder among parents of children on cancer treatment: A longitudinal study. *Psycho-Oncology*, *17*(5), 430-437. [4a]

Policy statement. guidelines for pediatric cancer centers.(2004). *Pediatrics, 113*(6), 1833-1835. [5a]
Robinson, K. E., Gerhardt, C. A., Vannatta, K., & Noll, R. B. (2007). Parent and family factors associated with child adjustment to pediatric cancer. *Journal of Pediatric Psychology, 32*(4), 400-410.[4a]

Stehl, M. L., Kazak, A. E., Alderfer, M. A., Rodriguez, A., Hwang, W. T., Pai, A. L., et al. (2009). Conducting a randomized clinical trial of an psychological intervention for parents/caregivers of children with cancer shortly after diagnosis. *Journal of Pediatric Psychology*, 34(8), 803-816.[2a]

# **IMPLEMENTATION**

# **Applicability Issues**

Successful interventions would result from a collaborative effort of psychologist, social worker, and bedside nurse, each working within their scope of practice, so that progress toward individualized collaborative goals established by the patient, caregiver and medical team may continue to be documented during outpatient care. Some training of staff may be required. Interventions which employed education as a facet would probably be easiest for bedside nurses to incorporate into their care as education is already a corner stone of nursing practice.

# **Relevant CCHMC Tools for Implementation**

None were found

## **Outcome or Process Measures**

Every patient and family would have a psycho-social risk assessment completed following diagnosis. Once appropriate referrals are made and interventions decided then all team members will chart on the intervention as appropriate. Outcome measures of the intervention may be assessed using the following tools: Acute Stress Disorder Scale (ASDS) that measures stress, the Impact of Events Scale-Revised (IES-R) that measures adjustment, and the Profile of Mood States (POMS) which identifies primary mood states. These tools could be used to identify individuals who would benefit from a psycho-social intervention. Any or all of these tools could also be used to measure progress when administered before and after an intervention.

# **SUPPORTING INFORMATION**

# **Background/Purpose of BESt Development**

In 2004, The American Academy of Pediatrics published updated guidelines for pediatric cancer centers incorporating changes based on new evidence that emerged since its last update in 1997 (AAP Policy Statement, 2004 [5a]). These guidelines outline the specialists and subspecialists and state of the art facilities and equipment necessary to treat children with cancer. The guideline also states that pediatric cancer centers must provide education and support to the patient's family. To provide children with the best oncology care possible it is necessary to provide care for the caregivers on whom the child depends for support. A study published in 2007 in the Journal of Pediatric Psychology explored the difference(s) between families of children with cancer and a comparison group of families with children not diagnosed with cancer to identify factors which could impact the child's adjustment to cancer (Robinson, K.E., et al. 2007[4a]). What the researchers found was a strong association between the child's level of distress and the parents' level of distress. Children exhibited symptoms of internalizing both their mothers' and fathers' distress. This association was more pronounced between a child and his or her mother's distress. The age and gender of the child influenced the association with the fathers' distress, with younger children being affected more strongly. Another study published in 2008 examined acute stress in parents of pediatric oncology patients and found that for nearly half of the mothers' their anxiety level at the time their child was diagnosed was high enough to qualify, as having an acute stress disorder (Patino-Fernández, AM 2008 [4a]). The anxiety level was just as high for 40% of the fathers. Almost every parent reported symptoms of acute stress including reliving the moment of learning their child's diagnosis, and a desire to avoid the

hospital. This study was also able to show that parents who were anxious by nature were more likely to develop acute stress disorder. That same year another group of researchers published the results of their longitudinal study of post-traumatic stress disorder among parents of pediatric cancer patients from one week after their child's diagnosis up to four months into treatment. They found that at the one week mark one third of the parents qualified as having acute stress disorder and forty-eight percent of that group qualified as having post-traumatic stress disorder at the four month mark (Poder, U., et al. 2008 [4a]). More mothers than fathers qualified as having acute stress disorder or post-traumatic stress symptoms at all three markers.

### **Definitions**

Current treatment is to refer all psycho-social issues or concerns to the social worker. Social workers handle many psycho-social needs of oncology patients and their families and determine when additional referrals are needed. The only exception is if the patient is assessed as being at risk for causing harm to him/herself or others.

Psycho-social intervention refers to any treatment designed to reduce negative symptoms such as anxiety, depression, emotional distress, post-traumatic stress, and/or increase adjustment or coping skills (Meyler, E., et al. 2010 [1b]; Othman, A., et al 2009 [1b]; Pai, A.I., et al. 2006 [1a]).

Cognitive behavioral therapy and psycho-educational therapy are two specific types of psycho-social interventions which have had statistical and clinical significance when provided for caregivers (Meyler, E., et al. 2010 [1b]; Othman, A., et al. 2009 [1b]; Pai, A.I., et al. 2006 [1b]; Askins, M.A., et al. 2009 [2a]; Othman, A., et al. 2010 [2b].

# Search Strategy

Databases searched included Ovid MedLine, Cochrane Library, CINAHL Plus, and PsycInfo.

Search terms included: pediatric oncology, pediatric cancer, pediatric neoplasms, childhood oncology, childhood cancer, childhood neoplasms, psycho-social care, psycho-social interventions, psychological care, psychological interventions, coping, adjustment, mothers, parents, caregivers.

Studies were limited to English language articles.

The search was conducted from January 24, 2012 until July 03, 2012.

# **Relevant CCHMC Evidence-Based Documents**

None were found

# **Group/Team Members**

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# Conflicts of Interest were declared for each team member: ☐ No financial or intellectual conflicts of interest were found. ☐ No external funding was received for development of this BESt. ☐ The following conflicts of interest were disclosed:

**Note:** Full tables of the <u>LEGEND evidence evaluation system</u> are available in separate documents:

- Table of Evidence Levels of Individual Studies by Domain, Study Design, & Quality (abbreviated table below)
- Grading a Body of Evidence to Answer a Clinical Question
- <u>Judging the Strength of a Recommendation</u> (dimensions table below)

# **Table of Evidence Levels** (see note above):

Quality level	Definition
1a <sup>†</sup> or 1b <sup>†</sup>	Systematic review, meta-analysis, or meta-synthesis of multiple studies
2a or 2b	Best study design for domain
3a or 3b	Fair study design for domain
4a or 4b	Weak study design for domain
5a or 5b	General review, expert opinion, case report, consensus report, or guideline
5	Local Consensus

<sup>†</sup>a = good quality study; b = lesser quality study

Table of Language and Definitions for Recommendation Strength (see note above):

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Language for Strength	Definition					
It is strongly recommended that		ions for judging the strength of the evidence are applied,				
It is strongly recommended that not	there is high support that benefits clearly outweigh risks and burdens.					
	(or visa-versa for negative recommendations)					
It is recommended that		ngth of the evidence are applied				
It is recommended that not there is moderate support that benefits are closely balanced with risks and burdens.						
There is insufficient evidence and a lack of consensus to make a recommendation						
Given the dimensions below and that more answers to the left of the scales indicate support for a stronger recommendation, the						
recommendation statement above reflects the strength of the recommendation as judged by the development group.						
(Note that for negative recommendations, the left/right logic may be reversed for one or more dimensions.)						
Rationale for judgment and selection of each dimension:						
1. Grade of the Body of Evidence	High	Moderate	Low			
Rationale:						
2. Safety/Harm (Side Effects and Risks		Minimal	Moderate	Serious		
Rationale:						
3. Health benefit to patient		Significant		Minimal		
Rationale: Stress and anxiety reduction						
4. Burden on patient to adhere to reco	ommendation	Low	Unable to determine	High		
Rationale: None of the articles spoke directly to the burden on patients to adhere to recommendations; however adult patients have the						
right to refuse care. According to Meyler, et al. (2010 [1b]) in the studies with a qualitative component participants expressed positive						
feedback; and Askins, et al. (2009[2a]) stated that participants indicated that they would recommend the intervention. McCarthy, et al.'s						
scrapbooking sessions are held twice a month in two separate locations and all are welcome to attend, but attendance is not mandatory						
(McCarthy, et al. 2011 [4b]).						
5. Cost-effectiveness to healthcare sys	stem	Cost-effective		Not cost-effective		
Rationale:						
6. Directness of the evidence for this target		Directly relates	Some concern of	Indirectly relates		
population			directness			
Rationale: Caregivers of pediatric oncology patients						
7. Impact on morbidity/mortality or q	uality of life	High	Medium	Low		
Rationale: Anxiety, distress, and stress impact the quality of life. Psycho-social interventions reduce anxiety, distress, and stress, while						
boosting general well-being and positive affect (Meyler, E., et al. 2010 [1b]; Othman, A., et al 2009 [1b]; Pai, A.I., et al. 2006 [1a]).						

Copies of this Best Evidence Statement (BESt) and related tools (if applicable, e.g., screening tools, algorithms, etc.) are available online and may be distributed by any organization for the global purpose of improving child health outcomes.

Website address: http://www.cincinnatichildrens.org/service/j/anderson-center/evidence-based-care/bests/

Examples of approved uses of the BESt include the following:

- Copies may be provided to anyone involved in the organization's process for developing and implementing evidence based care;
- Hyperlinks to the CCHMC website may be placed on the organization's website;
- The BESt may be adopted or adapted for use within the organization, provided that CCHMC receives appropriate attribution on all written or electronic documents; and
- Copies may be provided to patients and the clinicians who manage their care.

Notification of CCHMC at EBDMinfo@cchmc.org for any BESt adopted, adapted, implemented, or hyperlinked by the organization is appreciated.

Please cite as: Sparks, A. Cincinnati Children's Hospital Medical Center, Best Evidence Statement: Psycho-social interventions for primary caregivers of newly diagnosed pediatric oncology patients, http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/best.htm, BESt 143, pages 1-6, 11/28/12.

This Best Evidence Statement has been reviewed against quality criteria by two independent reviewers from the CCHMC Evidence Collaboration. Conflict of interest declaration forms are filed with the CCHMC EBDM group.

Once the BESt has been in place for five years, the development team reconvenes to explore the continued validity of the guideline. This phase can be initiated at any point that evidence indicates a critical change is needed. CCHMC EBDM staff perform a quarterly search for new evidence in an horizon scanning process. If new evidence arises related to this BESt, authors are contacted to evaluate and revise, if necessary.

For more information about CCHMC Best Evidence Statements and the development process, contact the Evidence Collaboration at EBDMinfo@cchmc.org.

### Note

This Best Evidence Statement addresses only key points of care for the target population; it is not intended to be a comprehensive practice guideline. These recommendations result from review of literature and practices current at the time of their formulation. This Best Evidence Statement does not preclude using care modalities proven efficacious in studies published subsequent to the current revision of this document. This document is not intended to impose standards of care preventing selective variances from the recommendations to meet the specific and unique requirements of individual patients. Adherence to this Statement is voluntary. The clinician in light of the individual circumstances presented by the patient must make the ultimate judgment regarding the priority of any specific procedure.