

Date: May 30, 2012

Title: School-aged and Adolescent Bone Marrow Transplant (BMT) Recipients: Quality of Life Interventions

Clinical Question:

P (population): Among school-aged children and adolescents undergoing bone marrow transplant

I (intervention): does providing psychosocial interventions

C (comparison): compared to current care practices

O (outcome): improve quality of life

T (time): during the first year post transplant?

Quality of life is multi-dimensional and subjective. The World Health Organization (WHO) defines quality of life as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (WHO, 1997 [5b]). It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient feature of their environment (WHO, 1997 [5b]). Persons who have a bone marrow transplant are impacted in their physical health, psychological state, level of independence, social relationships and personal beliefs. The literature examined various aspects of quality of life following bone marrow transplant in children and adolescents including physical, emotional, and social domains.

Target Population for the Recommendation:

Inclusion criteria: 6-18 year old children and adolescents undergoing bone marrow transplantation, including autologous, and allogeneic, marrow, peripheral blood, and cord blood, as treatment for their underlying malignancy, immune deficiency, bone marrow failure or other congenital disorder.

Exclusion criteria: children younger than age 6 years at time of admission for the bone marrow transplant or older than age 18 years at the time of admission for the bone marrow transplant.

Recommendation:

It is recommended that music therapy, exercise therapy, art therapy and telecommunication be provided to all school-aged and adolescent bone marrow transplant recipients during the first year following transplant to improve quality of life (Burns, D.S., et al, 2009 [2b]; Rosenhagen, A., et al, 2011 [2b]; Robb, S.L., et al, 2008 [2b]; San Juan, A.F., et al, 2008 [3b]; Robb, S. L. & Ebberts, A. G., 2003a [3b]; Robb, S.L. & Ebberts, A.G., 2003b [3b]; Forinder, U., 2008 [4a]; Higuchi, K., et al, 2011 [4b]; Guenter, M. 2000 [5a]).

Note: A single study of massage therapy and humor did not demonstrate improved quality of life for children and teens following bone marrow transplant (Phipps, S., et al, 2010 [2b]).

Discussion/Summary of Evidence Related to the Recommendation:

In the review of literature, the psychosocial interventions that were studied and shown to have a positive effect on quality of life for children and adolescents following bone marrow transplant included music therapy, exercise therapy, art therapy, telecommunication, massage therapy and humor therapy. With one exception, the studies focused on interventions during the initial bone marrow transplant hospitalization. Interventions were directed to improving the quality of life during the most acute phase of the stress of BMT. The target populations were children, teens and young adults between the ages of 4 and 24 years old. Sample sizes were small (under 25) for most of the studies, some of which were conducted as feasibility studies of the interventions. Due in part to the varying nature of the interventions,

there was not a consistent tool utilized to measure the effects of the interventions across the studies. In spite of these limitations in sample size and variable measures, quality of life benefits were demonstrated following the interventions.

Robb and Ebberts (2003a [3b]) conducted an exploratory study of songwriting and digital video production interventions for pediatric bone marrow transplant patients. In their first report, Robb and Ebberts, (2003a [3b]) the digital music video production intervention was found to decrease anxiety, thereby improving quality of life, in 4 of 6 bone marrow transplant patients, ages 8 to 18 years old. In the second article, Robb and Ebberts (2003b [3b]), described the themes of the videos which included independent coping, control, hope, family support and positive mental status. In another study, Robb et al, (2008 [2b]) presented data pertaining to the use of active music interventions for children with cancer who were video-recorded during a single 20 minute session. They found these children showed more engagement and positive facial affect after the active music engagement intervention than the control group who listened to music or audio-books only. Burns and colleagues reported (2009 [2b]) that music video production by adolescents and young adults during bone marrow transplant showed positive trends in decreasing symptom distress, less defensive coping, improved spirituality, quality of life and self-transcendence. These studies provide support for the benefit of music therapy interventions for children with cancer and after BMT in the emotional component of quality of life.

Studies of supervised exercise intervention were implemented at different times in the treatment and recovery period post bone marrow transplant in school-aged children. Rosenhagen et al (2011 [2b]), examined the benefit of structured exercise for twenty-three hospitalized children during the first 30-40 days after transplant. The immediate benefit of exercise at this time was directed toward lessening immobility and resultant risks for pneumonia and muscular atrophy, thus improving the physical health component of quality of life. San Juan et al, (2008 [3b]) examined the benefit of an out-patient exercise for eight patients under a year following bone marrow transplant. The investigators reported patients had improved strength and endurance after the 8 week exercise intervention compared to case controls. Additionally, children receiving the intervention reported more comfort and resilience than the control group children. These studies demonstrate improved quality of life in the physical domain.

The benefit of the art therapy was demonstrated by a single case study report by Guenter (2000 [5a]), of an 8 year-old who had explosive anger outbursts after his bone marrow transplant which interfered with his care. Following his therapy it was reported that he had calmer and more cooperative behaviors.

A telecommunication intervention was studied for feasibility in Japan for fifteen children undergoing bone marrow transplant in laminar air flow isolation, Higuchi, et al (2011 [4b]). The patients were able to utilize the telecommunication system to maintain contact with the hospital school classes and their families during the period of isolation. The use of the telecommunication system did not lessen on days they experienced nausea. This intervention demonstrated improvement in the social domain of quality of life.

A multi-site study of the benefit complementary therapies, specifically humor and massage, provided for children during the first three weeks following bone marrow transplant was conducted by Phipps, et al, (2010 [2b]). They investigated outcomes up to twenty-four weeks following the transplant. They reported no differences between the control group and treatment group in somatic distress or mood disturbance levels.

There were no studies found evaluating the effect of counseling or cognitive behavioral therapy on the quality of life of pediatric bone marrow transplant patients.

Reference List:

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SUPPORTING INFORMATION

Background/Purpose of BEST Development:

BMT is both a life-saving and life-threatening medical intervention for treatment of malignant and non-malignant diseases. Due to the intense nature of the process and prolonged period for complete recovery, many stressors are experienced by the patients and families which impact their mental health for months to years. Forinder (2008 [4a]) reported that adolescents sought psychotherapeutic support from 3 to 12 years post-transplant due to ongoing coping issues. This group of teens reported difficulties in relationships with their parents, and peers as well as anxieties about

their future. A longitudinal study by Felder-Puig, et al (2006 [4a]) identified compromised emotional functioning, a high level of worry and reduced communication during the acute phase of treatment as factors associated with a negative impact on health related quality of life one year after bone marrow transplantation.

Children and adolescents develop coping skills throughout their lives and are, therefore, are even more vulnerable to sub-optimal emotional effects following BMT than adults. In particular, school-aged children and adolescents have a greater awareness of the seriousness of their health condition compared to younger children or infants, but lack the coping skills of adults to moderate the stress of the situation. Developmentally, children are socialized during their school-aged years and adolescence via interactions with their peers, however, in the post bone marrow transplant recovery period the risk for infection necessitates a period of isolation from peers. The lack of normal peer contact can impair the social dimension of quality of life both in the short-term and possibly long-term if the opportunity to develop relationships and social skills is severely restricted.

Applicability Issues:

Several potential barriers influence the applicability of this recommendation including availability of, and cost of providing the music, art, exercise and telecommunication interventions by sufficient numbers of appropriately trained staff, the complex nature of coordination of the timing of multiple types of interventions for the patients during hospitalization or outpatient care, and both physiologic and emotional readiness of the children to engage in the interventions. Nursing care priorities on the acute physical care needs for the patients and the ratio of patients to nurses may impede in part the delivery of nursing care directed toward the psychosocial needs of the patients.

Measures to enhance the applicability of the recommendation include efforts to ensure that the children are not overly sedated to enhance their abilities to engage in the recommended interventions, development of a template for scheduling the activities, establishing a plan for routine and repeat assessments of child preferences, readiness, and improvement in quality of life, and electronic documentation of the assessments and frequency and impact of the interventions.

Outcome or Process Measures:

Child and family assessment – Prociodano’s Perceived Social Support-Family Scale; Family Adaptability and Cohesion Scale II

Health related quality of life – Child Health Questionnaire; Psychosocial Adjustment to Illness Scale; Behavioral, Affective, and Somatic Responses to Pediatric BMT

Anxiety – Spielberger State-Trait Anxiety Inventory

Fatigue – Ped QL fatigue scale

Coping – Self-perception Profile for Children; Child Behavior Checklist; Jalowiec Coping Scale

Readiness assessment for participating in prescribed therapies – Memorial Symptom Assessment Scale

Frequency of use of supportive care therapies with reasons for non-utilization – individualized monitor

Patient experience/satisfaction – departmental/organizational satisfaction survey tools

It is suggested that the initial measures of health related quality of life including anxiety, child activity preferences, coping skills and stressors be assessed shortly before or just after the admission for bone marrow transplant, then fatigue and the readiness assessment are important process measures prior to implementing the interventions. Outcome measures would be repeat assessment of the health related quality of life, anxiety, coping and patient experience/satisfaction that could be assessed every three months for the first year, then every 6 to 12 months thereafter.

Search Strategy:

Databases: Medline, PubMed, CINAHL, Scopus, Psycinfo, Cochrane Library, NACHRI

Search terms included: bone marrow transplant, stem cell transplant, hematopoietic stem cell transplant, child, children, pediatric, adolescent, quality of life, health-related quality of life, coping, interventions, art therapy, music therapy, journaling, exercise, social support, post-traumatic stress disorder, hope, reintegration, depression, anxiety, and cognitive behavior therapy.

Limits included: English language, human, all children, dates between 2000 and 2011.

Literature search was last completed: February 2012.

Relevant CCHMC Evidence-Based Documents: None were found.

Group/Team Members:

Team Leader/Author: Gretchen Vaughn, RN, MSN, CNP, Bone Marrow Transplant/Immunology
Support/Consultant: Mary Ellen Meier, RN, MSN, CPN, EBP Mentor

Conflicts of Interest Declared for each Team Member:

- No financial conflicts of interest were found.
 The following financial conflicts of interest were disclosed:

Note: Full tables of evidence grading system available in separate document

- [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](#)
- [Judging the Strength of a Recommendation](#) (*abbreviated table below, dimensions table above*)

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

Quality level	Definition
1a [†] or 1b [†]	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

[†]a = good quality study; b = lesser quality study

Table of Recommendation Strength (see note above):

Strength	Definition
It is strongly recommended that... It is strongly recommended that... not...	There is high support that benefits clearly outweigh risks and burdens. (or <i>visa-versa</i> for negative recommendations)
It is recommended that... 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...	
<i>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.)</i>	
1. Grade of the Body of Evidence	<input type="checkbox"/> High <input checked="" type="checkbox"/> Moderate <input type="checkbox"/> Low <i>Comments: The majority of the studies had very small samples and were grade level b.</i>
2. Safety/Harm (Side Effects and Risks)	<input checked="" type="checkbox"/> Minimal <input type="checkbox"/> Moderate <input type="checkbox"/> Serious <i>Comments: No harmful effects were noted (Higuchi 2011 [4b], Robb 2003a [3b])</i>
3. Health benefit to patient	<input checked="" type="checkbox"/> Significant <input type="checkbox"/> Moderate <input type="checkbox"/> Minimal <i>Comments: The purpose of the studies was to assess feasibility and benefit (Rosenhagen [2b], San Juan 2008 [3b], Robb 2003b [3b]) Burns 2009[2b]).</i>
4. Burden on patient to adhere to recommendation	<input checked="" type="checkbox"/> Low <input type="checkbox"/> Unable to determine <input type="checkbox"/> High <i>Comments: Percent adherence was 70% or above (Rosenhagen, 2011 [2b], San Juan 2008 [3b])</i>
5. Cost-effectiveness to healthcare system	<input type="checkbox"/> Cost-effective <input checked="" type="checkbox"/> Inconclusive <input type="checkbox"/> Not cost-effective <i>Comments: None of the studies found documented any cost factors.</i>
6. Directness of the evidence for this target population	<input checked="" type="checkbox"/> Directly relates <input type="checkbox"/> Some concern of directness <input type="checkbox"/> Indirectly relates <i>Comments:</i>
7. Impact on morbidity/mortality or quality of life	<input checked="" type="checkbox"/> High <input type="checkbox"/> Medium <input type="checkbox"/> Low <i>Comments: Studies demonstrated a significant improvement on quality of life, (Burns 2009 [2b]; Guenter 2000 [5a]; Higuchi 2011 [4b]; Robb 2008[2b]; Robb 2003a [3b]; Rosenhagen 2011 [2b]; San Juan 2008 [3b]).</i>

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/svc/alpha/h/health-policy/best.htm>

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: Cincinnati Children's Hospital Medical Center: Best Evidence Statement - School-aged and Adolescent Bone Marrow Transplant (BMT) Recipients: Quality of Life Interventions, <http://www.cincinnatichildrens.org/svc/alpha/h/health-policy/best.htm>, BEST 128, pages 1-7, May 30, 2012.

This Best Evidence Statement has been reviewed against quality criteria by 2 independent reviewers from the CCHMC Evidence Collaboration.

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.