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Authors

Packman, Wendy

Riano, Nicholas

Kearney, Julia

et al.

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The need to support caregivers during pediatric bone marrow transplantation (BMT): A case report

Christina Mangurian, MD, MAS¹, Wendy Packman, JD, PhD², Nicholas S. Riano, MAS¹, and Julia Kearney, MD^{3,4}

¹University of California, San Francisco, San Francisco, CA.

²Palo Alto University, Palo Alto, CA.

³Memorial Sloan Kettering Cancer Center, New York, NY.

⁴Weill Cornell College of Medicine, New York, NY.

Abstract

Objective: Pediatric bone marrow transplants represent a medically stressful, potentially traumatic, experience for children and caregivers, and psychological support for parental caregivers is paramount to their long-term well-being. However, many medical centers do not have protocols in place to sustain caregiver well-being during these distressing experiences.

Methods: We report on a case of a 10-month infant patient with Wiskott Aldrich Syndrome who was hospitalized for bone marrow transplantation (BMT).

Results: We describe the significant burden that fell upon caregivers during and after a BMT.

Significance of results: This case helped guide our suggestions to improve care for caregivers. Several logistical hurdles could be overcome to alleviate some of these burdens. We suggest a child psychologist or psychiatrist should be on patient care teams and be attentive to parental stress, impairments or impediments to self-care, and signs of emergency of mental illness in this setting of medical trauma. Additionally, promotion of sleep hygiene and linkage to support systems can maximize resiliency. Finally, we believe that hospital administrators should partner with clinicians to facilitate routine support during highly-stressful transitions of care.

Keywords

Bone marrow transplantation; psychosocial support; caregivers; family

INTRODUCTION

Approximately 2,600 children undergo BMT* in the US annually. (*For this article, “BMT” is synonymous with “hematopoietic stem cell transplants.”) The typical length of stay for

Corresponding Author: Dr. Mangurian is the corresponding author. Her address is UCSF/San Francisco General Hospital, Weill Institute for Neurosciences, Department of Psychiatry, 1001 Potrero Ave, Suite 7M, San Francisco, CA 94110. Her phone is 415-206-5925. Her fax is 415-206-8942. christina.mangurian@ucsf.edu.

pediatric BMT is 4–6 weeks. BMT is expensive, with a total median cost of \$302,822 (Majhail et al., 2013).

BMT has a known negative psychological impact on patients and families (Packman et al., 2010; Devine et al., 2016). For patients, BMT is associated with anxiety, depression, post-traumatic stress, and declines in health-related quality of life. Siblings are at risk of developing post-traumatic stress disorder (PTSD), anxiety, and low self-esteem (Pentz et al., 2014); and they also report loneliness, limited comprehension of BMT and lack of parental attention (Packman et al., 1998). There is also significant impact upon parents (Barrera et al., 2012; Lindahl Norberg et al., 2014; Heinze et al., 2015; Manne et al., 2016; Kaziunas et al., 2015), who report emotional concerns (worry, guilt, fear of losing child or of relapse), financial burdens, work-related changes, and logistical concerns (relocating to transplant center, commuting to transplant center, concurrently caring for siblings).

Although parents are key members of the health care team in cooperative care models because they provide individualized care with reduced costs and reduced length of stay, (Schmit-Pokorny et al., 2003), these caregivers also bear the burden of the patient's daily physical and psychosocial needs after hospitalization (Gemmill et al., 2011; Schmit-Pokorny et al., 2003; Von Ah et al., 2016; Myers & Davies, 2009). Children are discharged with the expectation that parents will administer medications throughout the day, monitor hydration status, provide parenteral nutrition or fluids through central lines, and/or draw blood. To our knowledge, there is no standard of care for staff to address the parents' emotional stress of providing these critical nursing services at home.

CASE REPORT

A 10-month old Latino boy with classic Wiskott-Aldrich syndrome was admitted to a pediatric hospital for BMT. He had one prior hospitalization for HSV-1 at 3wks of age, thrombocytopenia, severe eczema and failure to thrive. He received an 11/12 matched cord blood, during a 10-week course complicated by mild skin GVHD.

The boy lived with his 4-year-old sister and parents, who were highly-educated, financially stable professionals. His mother was a psychiatrist on faculty at the hospital and his father was a filmmaker. The parents educated themselves about coping with this “marathon” and talked to various experts (pediatric rheumatology, pediatric BMT, child psychology) about how to proactively minimize the negative impact of transplant on the family. They created a detailed schedule so that they could share overnight duties in the hospital by 24-hour shifts with the highly-involved extended family. To maintain good communication and emotional support in their marriage, the grandmothers were asked to provide two hours of respite care in the hospital most days so the parents could leave for a lunch break together. Family and friends provided in-house support (laundry, food shopping) and help via an on-line support network. This schedule allowed each parent time for daily exercise, sleep at home every other night, weekly psychotherapy, quality time with their healthy daughter, and time together daily as a couple.

Despite this significant support and opportunities for self-care, the family reported disrupted sleep in the hospital and significant challenges with the disposition home (nasogastric tube for feeds, 15 medications with various regimens, central line care). In addition, the parents felt the team missed opportunities to provide emotional support. For example, the staff did not regularly ask about their emotional well-being during the hospitalization, even during very stressful clinical situations. The mother did have her own psychiatrist, a critical part of her coping with transplant, where she felt comfortable expressing her fear about her son dying; anger at insensitive family, friends, and staff; frustration at the disruption of her home life; and vicarious trauma from exposure to other patients who died. This psychiatrist met the mother weekly, learned about BMT from other colleagues so as not to overburden the mother, and recommended titration of Lexapro and Klonopin during particularly stressful periods of the BMT process.

DISCUSSION

Psychosocial care of parents is considered an essential standard in caring for children with cancer, (Kearney 2015), in particular for families of children undergoing BMT (Mangurian & Cowan, 2013; Packman et al., 2010; Gemmill et al., 2011; Devine et al., 2016). However, neither research nor clinical care has addressed the challenge of delivering this support given the unusual circumstance in which the parent is bound to a specific location and has difficulty accessing care (e.g., hospital isolation room, isolation at home) (Mangurian & Cowan, 2013). Although in this case the family had financial means to see a private psychiatrist, many families do not have these resources and might need to receive care at the bedside. Unfortunately, psychiatric care for parents at their children's bedside is complicated by systemic and billing issues, as they are adult outpatients, located in an inpatient pediatric setting.

In one RCT, a bedside cognitive behavioral intervention for parents of children undergoing BMT was helpful for parents with high pre-transplant anxiety (Manne et al., 2016). There is limited evidence about how psychosocial support impacts costs, which compounds the problem since cost-savings drive hospital staff hiring practices. There are additional studies about bedside interventions using problem solving skills for mothers of pediatric patients with cancer, but these have not specifically been applied to the transplant population (Sahler et al., 2013).

This case describes a well-resourced family entering BMT with strong supports (medical training, psychologically sophisticated, social supports,). The efforts to organize and provide resources and respite to the family, and their residual distress despite these seemingly "ideal" supports vividly describes one very resilient family's journey. In our experience, the myriad of needs (e.g., practical, psychological, health-related, parenting) are common to all families going through BMT, usually with a fraction of the resources described above. Below are suggestions for improving care for all caregivers.

Suggestions to Improve Care for Caregivers

1. Screen for mental illness and emotional distress.

Although social workers and child-life specialists serve supportive roles on BMT teams, they do not provide psychiatric assessments. We believe that social workers could implement emotional “check-ins” on patients weekly. This could include screening of caregivers for depression and/or PTSD using validated instruments (*e.g.*, PHQ-9, PCL-5). Through regular check-ins, caregivers will have their stress acknowledged, which in and of itself may relieve distress.

2. Child psychologist or psychiatrist on BMT team.

There is no member of the BMT treatment team that can provide psychiatric treatment of parents. Child psychiatric consult-liaison teams are the most likely to encounter these patients and their families, and they *must* begin to use a family-centered approach (Schor, 2003). Creative systemic solutions are necessary, such as the development of holistic family-centered billing structures, treatment of parents at the bedside by child or adult psychiatrists, provision of respite care, transportation to access local services, or telepsychiatry.

3. Sleep hygiene.

Peer-reviewed publications outline the importance of sleep for mental and physical well-being (Steptoe et al., 2008). Although critically ill children need constant monitoring, hospitals must start protecting the sleep of patients and caregivers by “clustering care” overnight (Ritmala-Castren et al., 2015). Parents should be educated and encouraged to use sleep hygiene techniques (Carter, 2006; Irish et al., 2015). Sound machines, meditation, massage, mindfulness, and/or prescription medications for insomnia should be explored.

4. Family’s quality of life.

The BMT team should help families prepare for hospitalization by working with them to develop a plan for parental self-care, such as: alternating hospital duties between caregivers, getting a full night’s sleep *at home*, prioritizing time with siblings, taking breaks to spend time *together* (as a couple), scheduling time for exercise and psychotherapy, and enlisting friends and family to help with chores. Hospitals could provide respite care for parents and exercise passes to gyms. Further research on how to best support single parent families is needed (Wiener et al., 2015), but clearly respite care is critical when only one parent is involved. Staff should connect families with foundational support, such as “Lotsa Helping Hands” (Lotsa Helping Hands, 2015) and “Be The Match” (National Marrow Donor Program, 2016). It is clearly important that specific strategies be tied to family needs; a combination of these strategies would be important to use.

5. Transition of care to the home.

Parents experience an abrupt change from 24 hours a day multidisciplinary supportive care in hospital to outpatient care after discharge. Research should explore whether home nursing care after discharge could reduce readmission rates due to line infections, medication errors, adherence issues in the post-transplant period. It is imperative that pharmacists and

physicians develop tools to help families manage medication, such as a tool created by the mother in the case for her son after discharge (Table 1).

CONCLUSIONS

Enhanced integration of psychosocial and medical care for families and children undergoing BMT is critical for their psychological well-being, and may improve quality of life. These unmet needs should be systematically addressed in the holistic care of all chronically hospitalized patients and families.

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Table 1:

Sample Medication Management Tool

Time	Medication	Dosage	Sun	Mon	Tues	Wed	Thurs	Fri	Sat
			2/3	2/4	2/5	2/6	2/7	2/8	2/9
7am	Cyclosporine	0.30mL							
	Acyclovir	1.8mL							
	Vitamin D3	1mL							
	Proventil	ii puffs							
	Qvar	ii puffs							
	Bactrim--FSS only	2.5mL F/S/S							
	Probiotic	1/4 tsp							
	Steroid creams	PRN							
9am	TEMPERATURE	Call if >100.4 or 38.0							
1pm	Acyclovir	1.8mL							
	Magnesium	1mL							
	Fluconazole	0.6mL							
	Proventil	ii puffs							
	Qvar	ii puffs							
5pm	FLUSH LINE	Heparin 2cc	Dressing				Caps		
7pm	Cyclosporine	0.30mL				0.25mL	0.25mL	0.25mL	0.25mL
	Acyclovir	1.8mL							
	Bactrim--FSS only	2.5mL F/S/S							
	Steroid creams	PRN							

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