

Multidisciplinary Approach to Psychosocial Care: *The Stephen D. Hassenfeld Model*

Eduvigis Cruz-Arrieta, PhD, and Lauryn Weinshank, LCSW

ABSTRACT

Scientific advances that lead to early detection and treatment of childhood illnesses once fatal to most children have contributed to higher survival rates. This article outlines a model used at the Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders for providing outpatient cancer and hematology treatments facilitated and supported by allied health professionals. Coping is sometimes compromised by biopsychosocial factors present in the lives of patients prior to illness. Allied health professionals help patients and families cope by providing a supportive environment for the child with a chronic illness and his or her family. A multidisciplinary team approach is illustrated in this article. The authors describe the process of creating a pathway toward holistic care for all patients, from designing tools that integrate basic information about each patient "in context" to how this is accomplished. Two case examples of collaboration between disciplines are provided. Finally, ideas on the need for research that demonstrates the benefits of psychosocial interventions and the need for dissemination of information about what works within the pediatric, allied health, and mental health professions are offered.

INTRODUCTION

The Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders (SDHCC) of New York University Langone Medical Center functions both as a day hospital and an outpatient

Needs Assessment: This article aims to educate others who are less familiar with the psychosocial care needs of pediatric hematology/oncology populations. The article provides a description of multidisciplinary collaborations within the same program in contrast to services accessible to this population via outside referrals.

Learning Objectives:

- List issues that arise for children with chronic illness.
- Understand the steps required for organizing a multidisciplinary approach to psychosocial care.
- Ask questions about how children and families can be best served in outpatient clinics.

Target Audience: Primary care physicians and psychiatrists.

CME Accreditation Statement: This activity has been planned and implemented in accordance with the Essentials and Standards of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of the Mount Sinai School of Medicine and MBL Communications, Inc. The Mount Sinai School of Medicine is accredited by the ACCME to provide continuing medical education for physicians.

Credit Designation: The Mount Sinai School of Medicine designates this educational activity for a maximum of 3 *AMA PRA Category 1 Credit(s)*[™]. Physicians should only claim credit commensurate with the extent of their participation in the activity.

Faculty Disclosure Policy Statement: It is the policy of the Mount Sinai School of Medicine to ensure objectivity, balance, independence, transparency, and scientific rigor in all CME-sponsored educational activities. All faculty participating in the planning or implementation of a sponsored activity are expected to disclose to the audience any relevant financial relationships and to assist in resolving any conflict of interest that may arise from the relationship. Presenters must also make a meaningful disclosure to the audience of their discussions of unlabeled or unapproved drugs or devices. This information will be available as part of the course material.

This activity has been peer-reviewed and approved by Eric Hollander, MD, chair and professor of psychiatry at the Mount Sinai School of Medicine, and Norman Sussman, MD, editor of *Primary Psychiatry* and professor of psychiatry at New York University School of Medicine. Review Date: June 4, 2008.

Drs. Hollander and Sussman report no affiliation with or financial interest in any organization that may pose a conflict of interest.

To receive credit for this activity: Read this article and the two CME-designated accompanying articles, reflect on the information presented, and then complete the CME posttest and evaluation found on page 84. To obtain credits, you should score 70% or better. Early submission of this posttest is encouraged; please submit this posttest by July 1, 2010 to be eligible for credit. Release date: July 1, 2008. Termination date: July 31, 2010. The estimated time to complete all three articles and the posttest is 3 hours.

Dr. Cruz-Arrieta is senior psychologist and clinical assistant professor in both the Departments of Child & Adolescent Psychiatry and Pediatrics at the New York University (NYU) School of Medicine in New York City. Ms. Weinshank is licensed clinical social worker in the Social Work Department at NYU Langone Medical Center.

Disclosure: The authors report no affiliation with or financial interest in any organization that might pose a conflict of interest.

Please direct all correspondence to: Eduvigis Cruz-Arrieta, PhD, Stephen D. Hassenfeld Children's Center for Cancer and Blood Disorders, 160 E 32nd St, Second Floor, New York, NY 10016; Tel: 212-263-9925; Fax: 212-263-8410; E-mail: Eduvigis.cruz-arrieta@nyumc.org.

medical facility for children with cancer and blood disorders. It provides modern medical treatments facilitated and supported by allied health professionals. The last 30 years have witnessed scientific advances that led to earlier detection and treatment of childhood illnesses once fatal for most children. For example, the 5-year survival rate in pediatric cancer is approximately 80%, resulting in a continuously growing population of childhood cancer survivors. Data collected in the last 10 years shows $\geq 270,000$ survivors of childhood cancer in the United States. One in 1,000 individuals is a childhood cancer survivor. Demographics of the childhood cancer survivors in the US show that while 33% of these survivors are <20 years of age, 46% are 20–40 years of age, and an additional 18% are >40 years of age.¹

Children affected with blood disorders such as sickle cell anemia are transitioning into longer, productive lives with significantly less impairment than before thanks to transfusion and oral medication therapies. However, despite the development of promising future cures through procedures such as bone marrow transplants and gene therapies, inadequate attention to psychological, social, and interpersonal functioning is still present.² Along with these changes, the need for supportive services (ie, nursing and medical teams) for children, families, and caregivers coping with a chronic, life-threatening illness have evolved in specialized ways to further them.³ In the 1990s, changes in health care led to a reduction of available psychosocial services because they were perceived as expensive and “less essential than other evaluations and interventions.”⁴

Most people who experience a chronic and/or life-threatening disease cope adequately with the stressors it brings. However, this is not an easy task. For a smaller number of patients and families, their coping is compromised by biopsychosocial factors present in their lives prior to the illness (eg, financial difficulties, psychological disorders). Child life, creative arts therapies, family health librarian, pastoral care, psychology, recreation and rehabilitation therapies, and social work, along with the newly integrated complementary therapies, including mind/body techniques such as aromatherapy, acupuncture/acupressure, dance-movement therapies, herbalism, hypnotherapy, therapy massage, music, Reiki, and yoga, now offer tools and support focused on the needs of ill children and survivors of childhood diseases. These therapeutic activities provide children with age-appropriate ways to identify and discuss numerous feelings associated with treatment.⁴

The SDHCC's allied health professional staff, comprised by the disciplines outlined above, is dedicated to providing a positive, nurturing, and supportive environment for children with a chronic illness and their families. This psychosocial team focuses on helping children gain and maintain developmental skills during their illness, hospitalization,

and treatment.⁴ At the SDHCC, the family health librarian is a member of the psychosocial team that participates in clinical discussions. This is anchored in the understanding of these professionals' contribution to the therapeutic needs of patients and families via their input, selection, and recommendations of bibliotherapy resources. Similarly, pastoral care services that address the spiritual and religious needs of patients and families are a core component of the group's work (S. Harding, personal communication, August 2007).

Both the quality of patients and parents' perception of the support received and their individual reactions at the time of diagnosis determines the experience at different stages of medical treatment. It colors their transition out of treatment. The authors believe that a multidisciplinary team approach^{3,5-7} is essential, as they describe the process of creating a pathway toward holistic care for all patients from the designing of tools that integrate basic information about each patient “in context” to how they accomplish this. Two examples of collaboration between disciplines are offered. The authors hope that these practices lead to well-adjusted survivors of childhood cancer.⁴

PATHWAY

In an effort to fine-tune the available therapeutic offerings, as well as keep a finger on the pulse of the team's professional interests and potential contributions, periodic meetings focusing on program planning were organized with administrative leadership. A survey that combined feedback from parents and staff was designed and conducted, and its results were compiled by a social work trainee. The results were incorporated into an in-service presentation for all staff to assist with program planning. How patients and their families moved from the point of diagnosis to participation in active treatment was reviewed.

ASSESSMENT

The SDHCC's social workers obtained various tools already in use in similar local hospital settings. One model was selected and adapted for the author's purposes in a series of multidisciplinary reviews. The authors examined its ease of use, whether it built-in basic relevant information regarding each child, its cultural relevancy, and the inclusion of all professionals needed for child-in-context services. The clinic's manager consulted with hospital administration concerning the viability of the document draft and the protocol for approval.

THE PROCESS OF MEETING NEW PATIENTS

The tool adaptation was followed with a review of communication pathways, starting from the moment patients enter the medical center's system to their first visit to the clinic (Table 1).

The psychosocial rounds forum is a meeting in which high-risk issues are identified from the initial interview and impressions and concerns are articulated. The main objectives are to design a multidisciplinary care plan for patients and caregivers, discuss in greater detail relevant psychosocial/behavioral health issues, prepare to follow up with those issues by presenting them at our Interdisciplinary Medical Rounds, and address urgent issues or emergencies. In addition, this meeting serves as a forum for program planning and administrative problem-solving related to services provided to patients.

The standard procedure for case discussions begins with soliciting patients' names and topics from all medical/psychosocial staff in advance to generate a list for discussion. Urgent issues are addressed first, followed by newly diagnosed patients and a review of ongoing cases. For new patients, a care plan is designed. For existing patients, the care plan is periodically reviewed.

A summary of the discussion is shared with all faculty and staff in medical rounds. The patient's chart, psychosocial assessment form (excerpted in Table 2), and psychosocial treatment planning form (excerpted in Table 3) are used to guide the psychosocial discussion.

This form is completed by the social workers after completing three meetings with a new patient and his or her family. Table 2 contains examples of basic psychosocial information

TABLE 1
MEETING NEW PATIENTS

- Patients may be referred from ER directly to inpatient unit at our medical center; or from a pediatrician's office to ER to inpatient unit/or Hassenfeld Center
- When a patient is hospitalized, the team is notified during weekly rounds of his or her newly diagnosed status
- When a patient comes from another facility or from home, team is notified by treating MD/NP on the day of appointment, or as early as possible
- Patient/family meets with social worker for initial psychosocial assessment
- Member of allied health professionals' team takes family on a tour/introduces them to all staff on their first to third visit
- Patient's psychosocial plan is designed during weekly team meeting
- Coordination of patient care is discussed with entire medical team

ER=emergency room; MD=medical doctor; NP=nurse practitioner.

Cruz-Arrieta E, Weinshank L. *Primary Psychiatry*. Vol 15. No 7. 2008.

included in the form. The information collected is shared with the team. When a patient is referred to other disciplines, this is noted in the "professional collaboration" section. The form is stored in the patients' medical record. From there on, all pertinent allied healthcare providers document psychosocial interventions in the progress notes section of the medical record.

Table 3 shows a section of the treatment planning form used to organize the psychosocial care plan. Not shown are the list of all disciplines available to work with each child and the short- as well as long-term goals section. This form is brought to the psychosocial rounds and used as part of the treatment planning for the patient. After the initial psychosocial assessment is discussed, the patient is referred to other disciplines if not previously done. The date of the referral is noted, and the form is filed in the patients' medical record. As each team member meets with the patient or after interventions are completed, these are noted and dated in the form. A full progress note is then added to medical record explaining the intervention.

Patients' care can be brought up by any staff member whenever issues arise. The following cases, concerning Linnea and Beth, provide a general view of how these routine procedures work.

CASE EXAMPLES

Case 1: Linnea

Linnea, a 7-year-old female recently diagnosed with medulloblastoma, was left visually impaired after having emergency brain surgery prior to beginning treatment. Her vision loss was not discovered until after she began her chemotherapy and radiation protocol. Linnea presented as a shy, quiet child who did not interact much with psychosocial or medical staff. Her mother was constantly tearful but was not forthcoming in discussing these feelings with staff. The psychosocial team was introduced to Linnea and her mother with the goal of ameliorating the crisis of a diagnosis of pediatric brain cancer and the medical crisis of losing part of her vision. Linnea responded well to social work and art therapy staff. Ongoing sessions were arranged where Linnea could produce artwork that helped her express her feelings regarding her diagnosis. Linnea also used imaginative play therapy to cope with painful medical procedures and long hours of receiving chemotherapy. (A general description of these interventions can be found elsewhere.)⁸

Linnea's mother met with the psychologist who assisted her in understanding how to help her daughter and other members of the family during this difficult time. In addition, the psychologist helped her figure out the extent of Linnea's vision difficulties prior to her diagnosis. Linnea's mother had

expressed some guilt about whether there had been signs no one had noticed. Linnea's decreased appetite and weight loss were also discussed, and her participation in creating a simple, palatable menu was encouraged. Various members of the team also worked with Linnea's 8-year-old brother, Mike, who has a love of theatre and music. The music therapist succeeded in introducing music as the modality in which he could express his feelings surrounding his sister's illness. This shows how easily psychosocial care extends to the whole family unit when the patient's treatment is provided in context and services are available to address the different needs of its members.

Midway through Linnea's treatment, eating issues became a concern. The psychosocial team was consulted again. The psychologist met with her mother to assess the reasons for Linnea's appetite issues and to monitor possible mood changes secondary to her medical conditions. Consultations with the inpatient unit team and a consultation/liason pediatric psychiatrist followed. Linnea's social worker began to engage her in an age-appropriate manner in order to better understand why she was not eating. A plan to restructure Linnea's meal times with parental assistance was devised and, in this way, the placement of a feeding tube was avoided. This was a temporary solution as the team is still trying to find out the best way to help her. The medical and psychosocial teams continue to collaborate to support this family through their battle with pediatric cancer.

Case 2: Beth

Beth is 8 years of age and was recently diagnosed with acute lymphocytic leukemia. Beth lives with her parents in a New York suburb. Her grandmother, who was her primary care-

giver, also lives near the family. There were initial identified issues, including conflict within the family regarding caregiving and Beth's anxiety toward medical procedures. Beth's social worker spent time speaking with both the parents and the grandmother reviewing caregiving details. Beth's mother had previously worked long hours and the grandmother had cared for her. Since diagnosis, the mother had stopped working and began to care for Beth full time. Role changes are often seen in families due to a medical diagnosis, as priorities change for all members of the family when faced with life-threatening circumstances. The mother expressed guilt over her not being able to spend time with Beth prior to her diagnosis. The grandmother felt distant from the family now that the mother was increasingly active with Beth's daily care.

Team members directly working with the family assisted with creating a schedule for Beth's care with which all members felt comfortable. They addressed the mother's feelings of guilt and helped the grandmother feel comfortable with the new limitations on her caregiving role. The psychologist worked with them on basic parenting strategies such as relaxation techniques to decrease Beth's anxieties. In addition, the expertise of Beth's nurse for identifying medication strategies was incorporated to help the patient manage her anxieties before spinal taps in the event that non-pharmacologic strategies were not enough.

Both the music and art therapists contributed to Beth's care by providing a multimodal intervention to calm her medical procedures anxieties. Family issues that are still impacting Beth's treatment experience in the clinic continued to be addressed with the help of the team's psychologist on an "as-needed" basis.

TABLE 2
PSYCHOSOCIAL ASSESSMENT FORM EXCERPT

Living Situation

- Parent(s) _____
- Relative(s) _____
- Foster Care _____
- Homeless shelter _____
- Can articulate needs
- Family friends
- Stable housing

Religion _____
Language _____
Ethnicity _____

Support System

- Two-parent family
- Single-parent family
- Divorced/separated parents
- Significant other
- Number of children _____
- Other _____
- Adequate resources
- Adequate supports
- Adherent with treatment/follow-up
- Extended family
- Understanding illness

Notes _____

CONCLUSION

Psychosocial issues related to the treatment of pediatric illness have been given more attention in recent years.^{5,9-11} The authors believe that their interdisciplinary team model allows for the most comprehensive psychosocial care of patients and their families. They attempt to identify issues at an early stage and coordinate psychosocial care in a manner that alleviates some of the stressors associated with pediatric illnesses. Their team aims to enhance the quality of life of all patients and families treated at SDHCC.

Future directions of this effort include conducting research to demonstrate the benefits of psychosocial interventions. More information is needed on the existing benefits of the services provided formally and informally at the facility. Who benefits from what? Which interventions are prioritized by the families? Requesting and incorporating feedback from each family on how they and their child benefited from various psychosocial interventions will help refine the work.

The authors intend to compile a psychosocial care manual based on the practice model as well as that of other centers in the US and abroad. Its goal is to provide a map to make the provision of modern medical treatments facilitated and supported by allied health professionals an essential part of any center's mission. Such models have been designed before³ but are not readily available; others require updated information on how to provide services that fit the needs of families living in complex social contexts with cultural, financial, political, educational, and spiritual¹² challenges that are part of living with cancer and other chronic childhood diseases. This manual will offer basic principles of psychosocial care, as well

as general interventions that can be implemented by different disciplines either collaboratively or individually. It will also include specialized modules for patients and families at higher risk of having more difficulties with the experience of diagnosis and treatment. Dissemination of information about what works for the authors within the pediatric, allied health, and mental health professions will follow. The poet Maya Angelou said, "Children's talent to endure stems from their ignorance of alternatives."¹³ Primary care physicians can help them endure less and cope more successfully by their knowing what works and creating better alternatives. **PP**

REFERENCES

- Bhatia S. Cancer survivorship—pediatric issues. *Hematology Am Soc Hematol Educ Program*. 2005;507-515.
- Edwards CL, Scales MT, Loughlin C, et al. A brief review of the pathophysiology, associated pain, and psychosocial issues in sickle cell disease. *Int J Behav Med*. 2005;12(3):171-179.
- Kusch M, Labouvie H, Ladisch V, Fleischhack G, Bode U. Structuring psychosocial care in pediatric oncology. *Patient Educ Couns*. 2000;40(3):231-245.
- Kazak AE, Cant MC, Jensen MM, et al. Identifying psychosocial risk indicative of subsequent resource use in families of newly diagnosed pediatric oncology patients. *J Clin Oncol*. 2003;21(17):3220-3225.
- Hicks MD, Lavender R. Psychosocial practice trends in pediatric oncology. *J Pediatr Oncol Nurs*. 2001;18(4):143-153.
- Creagan ET. Psychosocial issues in oncologic practice. *Mayo Clin Proc*. 1993;68(2):161-167.
- Kaufman KL, Harbeck C, Olson R, Nitschke R. The availability of psychosocial interventions to children with cancer and their families. *Child Health Care*. 1992;21(1):21-25.
- Nesbitt LL, Tabatt-Haussmann K. The role of the creative arts therapies in the treatment of pediatric hematology and oncology patients. *Primary Psychiatry*. 2008;15(7):56-58,61-62.
- Mitchell W, Clarke S, Sloper P. Survey of psychosocial support provided by UK paediatric oncology centres. *Arch Dis Child*. 2005;90(8):796-800.
- Waters EB, Wake MA, Hesketh KD, Ashley DM, Smibert E. Health-related quality of life of children with acute lymphoblastic leukaemia: comparisons and correlations between parent and clinician reports. *Int J Cancer*. 2003;103(4):514-518.
- Ljungman G, McGrath PJ, Cooper E, et al. Psychosocial needs of families with a child with cancer. *J Pediatr Hematol Oncol*. 2003;25(3):223-231.
- Harrison MO, Edwards CL, Koenig HG, Bosworth HB, Decastro L, Wood M. Religiosity/spirituality and pain in patients with sickle cell disease. *J Nerv Ment Dis*. 2005;193(4):250-257.
- Angelou M. *I Know Why the Caged Bird Sings*. 1st ed. New York, NY: Random House; 1969.

TABLE 3
PSYCHOSOCIAL TREATMENT PLANNING FORM EXCERPT

<u>Psychotherapeutic Services</u>	<u>Date Referred</u>	<u>Began On</u>	<u>Reviewed On</u>
Case consultation			
Crisis intervention			
Cognitive rehabilitation			
Counseling: individual/parent/marital/family/sibling/group/pastoral			
Complementary therapies (eg, horticulture/massage/reiki/yoga)			
Medical play/music therapy/recreation therapy/art therapy			
Onsite educational tutoring			
Patient/family health education			

Cruz-Arrieta E, Weinshank L. *Primary Psychiatry*. Vol 15. No 7. 2008.

Copyright of Primary Psychiatry is the property of MBL Communications and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.