

Touchpoints

A newsletter of the Kenneth B. Schwartz Center

*Dedicated to
strengthening the
relationship between
patients and
caregivers*

Narrative medicine: Reflections of caregivers

On the first and third Wednesday of every month, a group of oncology unit caregivers meet in a room at Columbia-Presbyterian Hospital in New York City. As they take their seats, they spread out a few pages in front of them – some are handwritten, some typed. One young woman volunteers to begin. She reads,

*I look at you in the bed, a child,
you think you are a man.
You are fading away,
now only your eyes seem to enlarge.
You ask when you can go home,
go back to your life.
This is your life now.
Your family members stand
mute awaiting answers
that are not there.*

I will stay the course with you.

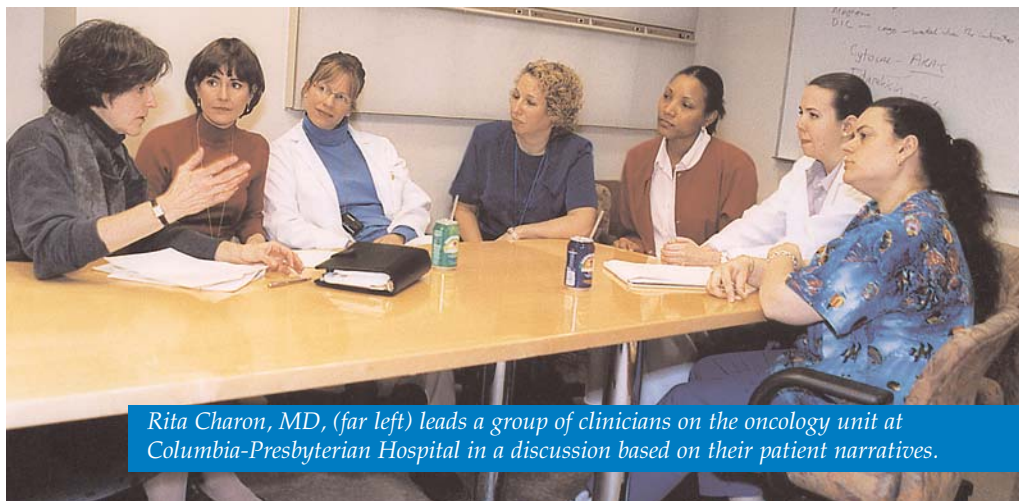
If you are surprised to find poetry instead of long list of clinical terms, you are reading a piece from Drs. Gwen Nichols and Rita Charon's narrative oncology project funded by the Schwartz Center. Dr. Nichols, Director of the Hematologic

Malignancies Program at Columbia University, began developing the project several years ago while seeing patients on the oncology inpatient unit. One day she noticed the absence of an intern treating a pregnant cancer patient struggling to stay alive to bring her child to term. "The intern was so upset over the case, she just couldn't come in to work that day," she recalls. Dr. Nichols recognized a profound need to address the sadness and distress of oncology physicians, nurses and social workers. She asked her colleague, Dr. Rita Charon, Director of the Program in Narrative Medicine at Columbia University, to collaborate in the design of a reflective writing seminar. Their goals: to increase the staff's capacity for empathy; to boost morale, communication and collegiality on the unit; and to reduce the rate of burn-out this group faces from the emotional intensity of caring for cancer patients.

In this innovative, one-of-a-kind program, staff clinicians keep "parallel charts" in which they write about their patients in "ordinary language." (Continued on page 2)

SAVE THE DATE

Save the Date for the eighth Schwartz Center annual dinner on October 23, 2003 at the Westin Hotel in Copley Place. The winner of the fifth annual Compassionate Caregiver of the Year Award will be announced.



Rita Charon, MD, (far left) leads a group of clinicians on the oncology unit at Columbia-Presbyterian Hospital in a discussion based on their patient narratives.

— *Narrative medicine: Reflections of caregivers*

(Continued from page 1)

In their bi-monthly meetings, they volunteer to read their work aloud. What Drs. Nichols and Charon hear is far from ordinary: astonishing prose and introspective poems in which moving descriptions of suffering and testimonials to patients' courage in the face of serious illness are coupled with questions about the role of a caregiver's emotions in the treatment of cancer patients. Each reading is followed with a discussion of the piece's form, content, mood, and voice. The dialogue among the attendees tends to focus on the challenges, frustrations, pain and joy of the patient-caregiver relationship depicted in the piece as well as in daily life. After reading a poem written in the voice of a woman who was too sedated to speak herself, one nurse said, "I really got to know her, and I know this is what she would have said if she could." Heard among the comments was admiration for the nurse's commitment to her patient, but also concern that she had become too close, and that she was risking emotional burnout.

In today's health care world, professional caregivers have precious little time to address their own emotions, and even less time to discuss them in an open, nurturing environment. Writing, says Dr. Nichols, "provides a freedom and, at the same time, forces you to think about your words." Dr. Charon, who is widely known for writing at length about the relationship between literature and medicine, believes the act of writing can increase a caregiver's ability to understand what he or she can offer a patient both medically and emotionally. She explains that writing about a difficult experience can help caregivers make better sense of their feelings. "Effective medical care springs from engagement, rather than detachment," Dr. Charon has written. In gaining self-awareness, a caregiver can administer the kind of compassionate care a patient deserves

while continuing to take care of his or her own emotions.

One staff member wrote about the transformation of a patient's facial expression from one of pain and suffering back to "his placid, accepting, calm, controlled face – a face I had initially found hard to fathom, but had learned to believe was his way of facing the unfaceable."

Drs. Charon and Nichols agree that the literary form and interactive discussion allows all caregivers to meet on "an equal playing field." Those who participate are given the opportunity to take pride in their own work, as both clinicians and writers. In addition, they feel less isolated, communicate better, have a greater sense of team, and become more supportive and caring of each other and their patients and patients' families. The group is intense and emotional, as caregivers explore some of the most painful and darkest places in their minds and hearts, but always, these moments move the attendees to positive and constructive actions.

In the past year, 30 clinicians in the oncology unit at Columbia-Presbyterian have participated in at least one session, and the quality of the writing has improved both in skill and depth. "I have a new respect not only for my colleague's intelligence but also for their resolve to remain in oncology," says Dr. Nichols. "It becomes their mission, not just their job."

Drs. Nichols and Charon plan an in-depth outcome study, but both physicians are already seeing incredible enthusiasm among the staff for the project. Those who do not consider themselves writers are eager to write, read and listen, and word of the group is fast spreading throughout the unit, and the health care community in New York City. The Schwartz Center recently funded the program for a second year, enabling Drs. Nichols and Charon to add sessions to accommodate more clinicians and offer similar sessions to patients and their families.

"With Schwartz Center support, we have begun to more fully understand the plights of our patients," Dr. Charon says. "At each session we share hard feelings, laughter, and every time, tears."

CELEBRATION OF WOMEN IN HEALTH CARE THURSDAY, MAY 29

The Schwartz Center is holding a special gathering to recognize the leadership, strength and investment of women in the health care system. A diverse group of women is expected to attend this networking/fundraiser reception including physicians, nurses, social workers, health educators as well as hospital executives, insurers, health care attorneys and representatives of the biotech and pharmaceutical industries.

The Schwartz Center is especially pleased that Jeanne Blake has agreed to be the featured speaker. She is a television medical reporter and President of Family Health Production, Inc., and host of "About Health," a nationally syndicated television talk show.

The event will be held on Thursday, May 29, 5:15 to 7:30 pm. The Schwartz Center is grateful to the law firm of Goulston & Storrs for hosting the gathering at its office on Boston's harborside and for providing refreshments. Goulston & Storrs has been a loyal supporter of the Schwartz Center since its inception.

To purchase tickets for \$40 each, please call (617) 724-4746.

OUR HEALTH CARE WORLD

When the Schwartz Center began giving grants in 1997, it became clear that the cultural competency of health care providers was an important issue in the delivery of compassionate health care. Building a relationship between patients and caregivers can be greatly challenged by perceptions around race, ethnicity, culture, and religion. Between 1997 and 2002, 25 percent of the grants we awarded were devoted to cultural competency training programs or other related efforts.

An important Institute of Medicine (IOM) report released late last year on the interrelationship between cultural competency and disparities in health care caught our attention. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* documents the existence of major disparities in the process and quality of health care for racial and ethnic minorities in the United States.

John Rich, MD, Medical Director of the Boston Public Health Commission and a Schwartz Center Board member, is working on Boston's efforts to reduce racial disparities. In a recent talk, he cited the following points from the IOM report:

- Disparities are consistently found across a wide range of disease areas and clinical services;
- Disparities are found even when clinical factors such as stage of disease, co-morbidities, and age are taken into account;
- Disparities are found across a range of clinical settings; and
- Disparities in care are associated with higher mortality among minorities.

The data is stark as these examples demonstrate:

Black and White Differences in Specialty Procedure Utilization among Medicare Beneficiaries Age 65 and Older, 1993

	Black	White	Black-to-White Ratio
Angioplasty (procedures per 1000 beneficiaries per year)	2.5	5.4	0.46
Mammography (procedures per 100 women per yr)	17.1	26.0	0.66
Amputation of All or Part of Limb (procedures per 1000 per yr)	6.7	1.9	3.64

The report summarizes three key sources of disparities of care:

- *Health systems factors* – such as financing, structure of care, cultural, and linguistic barriers;
- *Patient factors* – such as poor adherence and biological differences; and
- *The clinical encounter* – during clinical encounters health care disparities may be due to: bias (or prejudice) against minorities; greater clinical uncertainty when interacting with minority patients; and beliefs (or stereotypes) about the behavior or health of minorities. The bias may exist in overt, explicit forms, as represented by traditional bigotry. Or, because biases arise from virtually universal social categorization processes, they may also exist, often unconsciously, among people who strongly endorse egalitarian principles and truly believe that they are not prejudiced. In addition, workplace conditions – time pressure, medical complexities, and pressures on cost containment – appear to enhance the likelihood that care is unequal.

The potential sources of disparities in health care that result from the provider interaction with the patient brings us directly back to the Schwartz Center mission – improving the relationship between patients and caregivers. The IOM report succinctly summarizes my concluding thoughts: “The challenge in transforming the practice of medicine to more effectively meet the needs of ethnically diverse patients will include the generation of racial and ethnic-neutral social norms regarding patient expectations and judgments of physician conduct, as well as *the establishment of medical practice norms that value communication skills, interpersonal sensitivity, and cultural competence.*”

References: For more information on the IOM Report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, visit www.nap.edu. To learn more about Schwartz Center cultural competency grants, visit www.theschwartzcenter.org.

Cultural Competency is loosely defined as a set of academic and interpersonal skills that allow clinicians to increase their understanding of and interaction with patients of different cultural, racial, ethnic, religious, and socio-economic backgrounds. *Joseph R. Betancourt, MD, et al, Integrating Social Factors into Cross-cultural Medical Education, Academic Medicine. 2002; 77:193-197*



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Touchpoints

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4

Touchpoints

WHAT'S HAPPENING

In March approximately 90 nursing and other allied health students and faculty attended the first session of **"Difficult Conversations: Schwartz Center Educational Rounds"** at the **Institute of Health Professions (IHP)** in Boston. These sessions are similar in format to the Schwartz Center Rounds but are aimed at clinicians in training. "Difficult Conversations" was so successful that the Schwartz Center plans to replicate the forum



"Difficult Conversations" Group: (Seated in front) Melissa Vecchio, IHP student presenter; (back row from left to right) Emily Chandler and Carol Picard, IHP; Marjorie Stanzler, Schwartz Center; Sandra Berkman, IHP; and IHP student presenters Sheila Dwyer and Jessica Forsyth.

in other educational settings. With a grant from the Center, Northwestern University Medical School initiated "Difficult Conversations" for third-year medical students last summer ... On March 25 the Schwartz Center organized a **reception for health care attorneys** hosted by **Ropes & Gray**. Board

member **Steve Weiner, Esq.**, updated the 70 attendees on the Center's programs, and **James Mongan, MD**, President and CEO, Partners HealthCare System, spoke about health care costs and the importance of advocating for fair Medicare and Medicaid funding. Ropes & Gray continues to support the Schwartz Center in many ways.

RECENT SCHWARTZ CENTER GRANTS

The Albert Schweitzer Fellowship Program, Boston - to engage Boston fellows in reflective learning about how to establish effective, compassionate relationships with patients across cultural and other differences

American Academy on Physician and Patient (AAPP) - to design programs to assist U.S. residency programs in meeting the new Accreditation Council on Graduate Medical Education (ACGME) standards

Cambridge College, Cambridge, MA - for 10 scholarships to its Medical Interpreter Training Program for low-income students from the bilingual immigrant community in greater Boston

Columbia University, College of Physicians and Surgeons, New York City - to continue for a second year the oncology inpatient unit's narrative medicine project (*see lead story*)

Northwestern Memorial Hospital, Chicago - to develop and produce an original drama based on health care workers' own stories of their relationships with patients

Lidia Schapira, MD, and Rev. Mary Martha Thiel, Boston - to support a monthly study group for physicians to allow for collective learning, sharing of stories and intergenerational learning

St. Joseph Manor Health Care, Brockton - to conduct communication training workshops for certified nursing assistants

SUNY at Stony Brook, New York - to support a pilot program for its medical school curriculum where residents would serve as co-facilitators with faculty in teaching compassionate, humanistic medicine

Tufts University, Medford, MA - to teach compassionate care to third-year medical students using a patient as educator model

CALENDAR OF EVENTS FOR 2003

April 28 - Schwartz Center Speaker Series - Ann Webster, PhD, "Hurry Up and Relax"

May 29 - Celebration of Women in Health Care (*see page 2 for details*)

July 16 - End-of-life conference sponsored by the Schwartz Center, Mass Hospital Association and the Hospice Federation

October 23 - Schwartz Center annual dinner

For details on these events, call the Schwartz Center at (617) 724-4746 or visit www.theschwartzcenter.org