Controlling Spiraling Costs of Cancer Called Moral Imperative

BY PEGGY EASTMAN

Holding down costs is both a professional and moral responsibility, said speakers at an Institute of Medicine National Cancer Policy Forum meeting on delivering affordable cancer care while improving quality.

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The Survivorship Care Gap: Psychosocial Care—Making It the Standard

BY SARAH DIGIULIO

Part 2 of a Series

Our series on the shortfalls of cancer survivorship care continues with this analysis of why psychosocial needs of cancer patients often go unmet after treatment.

The first article (9/10/12 issue) covered the system-wide changes needed to transition cancer survivors back to medical care. And now in this article, the experts discuss how to make psychosocial care part of that follow up. Those interviewed say that key to changing the care standard is understanding the needs of distinct subgroups, having more evidence-based follow-up research, and creating more specific guidelines.

Not all health care providers are involved in psychosocial care for their patients—and oncologists and primary care physicians differ in their beliefs about who is responsible on the team to provide such care, as shown in a recent study of health care providers’ perceptions about the psychosocial needs of their cancer patients.

The findings, published in the August 10 issue of the Journal of Clinical Oncology (2012;30:2897-2903), underscore the need for better care coordination to address the issue, the researchers said.

“What was remarkable about the study was that everybody—clinicians, oncologists, and primary care physicians alike—thinks they’re providing the care, but yet we hear survivors tell us, ‘gee, this component of my care is actually the one that’s most neglected,’” said the senior author, Julia Rowland, PhD, Director of the National Cancer Institute’s Office of Cancer Survivorship. “There needs to be doctor-patient communication going on.”

The study surveyed a nationally representative sample of 1,130 oncologists and 1,021 primary care physicians based on data from the Survey of Physician Attitudes Regarding the Care of Cancer Survivors, and found that approximately half of both groups reported broadly treating psychosocial needs, and both also tended to perceive themselves as having responsibility for this care.

“We are happy that some providers are thinking about psychosocial care,” the study’s corresponding author, Laura P. Forsythe, PhD, MPH, a Cancer Prevention Fellow in the NCI’s Office of Cancer Survivorship, said in a phone interview. “But, the study suggests there is also a lot of room for improvement, since many physicians did not perceive that [psychosocial care] to be part of their practice. This has important implications for coordinating care and ensuring a clear delineation of responsibility in survivorship care.”

Studies have shown, since the 1980s, that approximately 20 to 40 percent of newly diagnosed and recurrent cancer patients show significant levels of distress. More current research cites a lower prevalence of “major psychiatric conditions” in cancer patients, but also that not even a third of those patients used mental health services to manage their distress.

The 2007 Institute of Medicine report, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” (OT, 12/10/07) called out the fact that psychosocial care was a missing piece of cancer patient and survivor care. And now, five years later, the gap is still here—specifically in making psychosocial care routine to cancer care—connecting the patients who need treatment with the resources that will actually help and following up to see which models and interventions work best for which patients.

Rowland said, although there are consistent data that the majority of survivors are “remarkably resilient” and don’t need further psychosocial support or care beyond routine screening and services; “the challenge to the clinical community is identifying the 20 to 30 percent of those who are not doing well. And, then in what ways do we need to intervene?”

Putting ‘Teeth in the Issue’

The American Society of Clinical Oncology has included, as part of its Quality Oncology Practice Initiative Quality Measures, emotional well-being assessment and referral to treatment or services as requirements that cancer care practices must meet to be considered to be QOPI-certified (http://qopi.asco.org/program).

And, the Commission on Cancer (CoC) has added providing psychosocial evaluation and services as a quality criterion in their updated “Cancer Program Standards 2012: Ensuring Patient-Centered Care.”

“Put teeth in the issue”

LAURA P. FORSYTHE, PHD, MPH: “The results of our study—showing, for example, that although some primary care physicians are thinking about psychosocial care, there is a lot of room for improvement—have important implications for coordinating care and ensuring a clear delineation of responsibility.”

“If you have a quality standard that clinicians are being expected to meet, we’re going to see more attention to this,” Rowland said. The updated CoC standards and the QOPI certification requirements send the message that this is what standard care should look like: “That’s beginning to put teeth in the issue.”

For a cancer center to be COC accredited according to the updated standards, the program needs to have a policy or procedure to ensure patient access to psychosocial services either on-site or by referral (www.facs.org/cancer/coc/programstandards2012.html). Also, accredited programs are required to have plans in place to support 2015 for routine screening for psychosocial distress, to continued on page 11
be administered at least once per patient at a “pivotal” medical visit (to be determined by the program—which could be at diagnosis, at presurgical or postsurgical visits, during a meeting to discuss chemotherapy, after chemotherapy, during a routine radiology visit, or when transitioning off treatment).

Programs are required to refer patients with distress to psychosocial services on-site or in the community.

Programs will be required to document each patient’s screening, and if applicable, referral or provision of care and follow up as well.

The changes made last year recognize the need to address the outcomes of care and long-term care in cancer survivors, as well as during treatment, CoC Executive Committee Chair Stephen B. Edge, MD, FACS, said in a phone interview.

Making the Mind-Body Connection
Key to closing this gap in care is recognizing that physical health and mental health are inseparable—they travel together, Rowland said. “We’ve always had a delivery system that dichotomizes physical from mental health—so, when we think of cancer survivors in particular, we know that those who are most vulnerable to emotional distress also seem to report more symptoms. … We don’t tend to think: if I’m treating one, I’m helping the other.”

These updates to the CoC standards are an effort to improve patient-centered standards of long-term care beyond the patient management issues that the standards already address, Edge explained. “Cancer requires a multidisciplinary effort—the clinical psychologist, psycho-oncologist, social worker, patient navigator, nurse, and other disciplines.”

“Our results suggest that input from both oncologists and PCPs regarding their respective skills and desires may improve the coordination and delivery of post-treatment psychosocial care.”

As shown in this figure from the Institute of Medicine’s 2007 report “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs” (OT, 12/10/07), the recommended model of delivering psychosocial care heavily stresses patient-provider communication. The model calls for identification of need, linking patients to care, and following up to systematically reevaluate patients to make sure needs are met.

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Putting Systems in Place
But, for cancer programs to meet the new standards there are still hurdles to overcome. “We’ve recognized that you can’t flip a light switch and have all these services in place tomorrow,” Edge continued. “We hope that by having the standard to do this—and to some extent it’s a baby... continued on page 14
Psychosocial Research Highlights from This Year’s MASC/ISOO Symposium

BY SARAH DIGIULIO

This year’s joint symposium of the Multinational Association of Supportive Care in Cancer and the International Society of Oral Oncology featured several relevant abstracts in the area of psychosocial care. Among the highlights were the following:

Individual Meaning-Centered Psychotherapy (IMCP) IMCP—an intervention to help cancer patients and survivors maintain their sense of spiritual well-being—has short-term benefits to lessen spiritual suffering and improve quality of life in patients with advanced cancer, reported William Breitbart, MD, Interim Chairman of the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center, where he is piloting the method.

The study (also now published in the Journal of Clinical Oncology (2012;12:1304-1309)) compared the effectiveness of the IMCP approach with that of therapeutic massage as a method to help patients maintain spiritual well-being through treatment. In 120 patients with stages III or IV cancer, those who underwent IMCP reported significantly greater improvements in spiritual well-being, quality of life, symptom burden, and symptom-related distress than did those who underwent therapeutic massage.

“IMCP is an intervention to help patients with more advanced cancer regain a sense of meaning and hope—a way of dealing with the existential impact of having had cancer and surviving it,” Breitbart explained.

Patient Preferences of Topics for Support Group Discussion What topics do cancer patients and caregivers consider most important to be covered in support group counseling, and what characteristics predict certain preferences over others? Those were the questions Kathleen D. Morse, PhD, LCSW-R, Administrator for Palliative Care & Geriatric Services at South Nassau Communities Hospital in New York, asked in her research. Functional topics (navigating the health system, making decisions about care, cancer treatment choices, and end- of-life care) were ranked by participants as most important, and above the other topics, grouped as physical, spiritual, psychological, and social.

The research surveyed 3,723 cancer patients from the NexCura Cancer Profiler database, who were at least 18 years old and identified as a patient with cancer or a caregiver of someone with cancer.

Post-Allogeneic BMT Support Groups For certain subspecialties of cancer patients (for example, those who have undergone a bone marrow transplant), diagnosis-specific support groups can help meet a mutual need among patients to share their experiences, vent, and find understanding, reported Tammy Weitzman, MSW, LICSW, a social worker for the Stem Cell Transplantation Program at Dana-Farber/Brigham and Women’s Cancer Center.

She led a presentation about a support group specifically for allogeneic BMT patients at Dana-Farber who had undergone the procedure one year previously, with the goal of providing psycho-educational support to meet the patients’ unique needs.

“The feedback that we’ve received has been tremendous,” she said in a follow-up interview. “These patients are very much in the same situation and they all have an understanding of what each has gone through in a way that no else really can. There is an extra level of closeness and understanding these patients have toward each other that makes this program very successful.”

The group of seven patients, all from the Boston area, continued to meet for five years. Topics covered included assimilating back to work and family life, adjustment to being out of isolation, relationships, and medical topics such as living with graft-versus-host disease.

Regaining Control Asked for his opinion for this article, MASC President Steven M. Grunberg, MD, said the bottom line was helping patients regain control of their lives. Some of the most exciting studies at this year’s meeting, he said, looked at the role of spirituality and stress in cancer survivorship.

“The stress of having had cancer is a significant factor,” he said. “People are beginning to think and care about these issues—and realize that even though cure and increased survival are major goals of cancer care, maintaining the quality of life while doing that is important as well.”

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step—it will lead to taking many more steps and putting systems in place to do distress screening so it will become a routine part of care.”

The CoC keeps a Best Practice Repository of tools and resources that accredited programs have contributed that have helped them meet the CoC standards. “We’ll be expecting the Best Practices Repository to be heavily used so we can all learn from each other’s experiences,” Edge said.

The repository includes information on a psychosocial distress screening tool developed and used by a team at City of Hope Cancer Center; a community-based measure tool provided by the Cancer Support Community; patient handouts, evaluations, and interventions developed and used by the Edwards Cancer Center in Illinois; and other recommended support services (http://bit.ly/0Bdppj).

Understanding Need “We need to understand how to tailor treatments to meet individuals’ personal psychosocial needs,” said Carolyn Messner, DSW, LCSW-R, Director of Education and Training at CancerCare. She developed the organization’s teleconference program of workshops that provide supportive psychosocial care and treatment information for patients of all cancer types, which includes a series specifically on survivorship and living with the long-term effects of cancer.

“We have personalized medicine now, which more and more tailors medical care to a patient’s need. Now we have to do the same for psychosocial services,” she said.

Research Gaps In terms of research, there’s a need for more follow-up to assess evidence of what tools work best for which populations, noted the pioneer in this area, Jimmie C. Holland, MD, the Wayne E. Chapman Chair in Psychiatric Oncology at Memorial Sloan-Kettering Cancer Center. And especially needed, she said, are more randomized controlled trials to identify the efficacy of these tools.

Up Next

Part 3 of the series will take a deeper look at why patients struggle in transitioning back to general medical care. Included will be emerging research about the unique burdens of specific survivor populations and what survivors say stops them from taking back control of their health.