Despite the Institutes of Medicine having recommended in its 2005 From Cancer Patient to Cancer Survivor: Lost in Transition report that survivorship care plans be written for every cancer patient, and despite the Commission on Cancer (CoC) having decided in 2012 to require all accredited cancer centers to prepare survivorship care plans for all cancer patients at the completion of treatment, the latest data find that implementing survivorship care planning is not getting done.

As reported this spring (OT 5/25/14 issue), fewer than five percent of oncologists are actually providing survivorship care plans to their cancer patients, according to a study in the Journal of Clinical Oncology based on data from a national survey of 1,130 oncologists and 1,020 primary care physicians.

What’s Making Survivorship Care Planning So Difficult to Incorporate?

BY SARAH DIGIULIO

Trastuzumab Trial Shows Fewer Cardiac Problems in HER2+ Breast Cancer Patients

BY KURT SAMSON

When administered for up to two years, the monoclonal antibody trastuzumab did not increase heart-related problems in otherwise healthy women with early-stage human epidermal growth factor receptor 2 (HER2)-positive breast cancer after chemotherapy or radiotherapy, according to results from the multinational Herceptin Adjuvant (HERA) trial, published in the Journal of Clinical Oncology (2014;32:2159-2165).

During an eight-year median follow-up period, few adverse cardiac events occurred with trastuzumab, which kills HER-2 cells. Moreover, when cardiac problems did arise, discontinuing treatment reversed them.

The drug was approved in 1998, but the Food and Drug Administration issued a black box label warning of potential cardiac risks, especially left ventricular ejection fraction (LVEF). Since then, however, several large trials have found that the risk may be lower unless women received anthracycline-based chemotherapy.

Metastatic Colorectal Cancer: Therapy Update from Panel at ESMO GI Meeting

BY ROBERT H. CARLSON

Barcelona, Spain—Thirty experts in gastrointestinal cancer pooled their opinions on the best current treatments for metastatic colorectal cancer, the results of which were presented here at the European Society for Medical Oncology’s 16th World Congress on Gastrointestinal Cancer.

“Because medical practice is undergoing very rapid changes in data and environment, and rapidly increasing knowledge, recommendations need frequent updates and refinements,” Congress Co-Chair Eric Van Cutsem, MD, PhD, Professor of Internal Medicine at the University of Leuven and Head of the Digestive Oncology Unit at University Hospital Gasthuisberg in Belgium, said in his introduction of the expert discussion report.

In his recap of the panel’s findings, he said that the discussion was initiated with questions sent in advance to the panel. The answers were analyzed beforehand and discussed again by 20 of those experts during the session at the meeting. The decisions were based on evidence from clinical trials, but in many cases were also influenced by clinical experience, he said.
In addition, according to data published in 2012, only 43 percent of National Cancer Institute-designated cancer centers delivered survivorship care plans to patients with breast or colorectal cancers (CA Cancer J Clin 2012;62:101-117).

The evidence begs the questions: What are the barriers to providing the care plans? And how can they be overcome?

Oncology Nurses Say...

“There seems to be consensus that the idea behind these care plans is well endorsed,” said Jamie Myers, PhD, RN, AOCN, Postdoctoral Scholar at the University of Pittsburgh School of Nursing and Adjunct Professor at the University of Kansas School of Nursing, speaking at this year’s Oncology Nursing Society Annual Congress during a special session called “Are Survivorship Care Plans Meeting Survivors’ Needs?”

“But what’s missing is a consensus of who’s going to prepare the plans, who’s going to deliver them, and when.”

The most significant barrier is time, she noted in a follow-up email after the meeting—and the lack of reimbursement for the time it takes to develop survivorship care plans: “It is very time-consuming to extract—manually in most cases—the pertinent details for each individual survivor’s treatment history and to individualize a plan of care that identifies long-term side effects and appropriate surveillance.”

Also challenging, added Myers—who serves as Coordinator of ONS’s Survivorship, Quality of Life, and Rehabilitation Special Interest Group—is the lack of evidence to define the level of complexity of the information that is appropriate for survivorship care plans (that would be useful and meaningful for the patient and health care provider), as well as the lack of clarity regarding who does what in providing survivors’ follow-up care (i.e., primary care versus the oncology team).

“I’m just totally lost,” Mary Gallagher, RN, an oncology infusion nurse and patient educator at Arrowhead Regional Medical Center in San Bernardino, California, said during the Q&A portion of the session. “My facility is a hospital-based outpatient infusion clinic. And because it’s a county facility and a teaching facility, our patients don’t really have a primary care provider because the residents transfer in and out frequently. I have no idea who to even send a survivorship care plan to.”

Another ONS attendee, Mary Crann, RN, MSN, OCN, a nurse navigator at the Calaway Young Cancer Center at Valley View Hospital in Glenwood Springs, Colorado, explained that nurses there are now completing diagnosis information and treatment summaries as part of the cancer care process. And once the patient finishes treatment, nurses review that treatment summary and survivorship plan, and patients get referred to the survivorship clinic that meets once a week.

“But I think we’re missing the boat with the metastatic patients because they don’t get invited to the survivorship clinic—and I think they may have a larger gap,” she said.

Missing Evidence

A real concern currently is the lack of evidence that giving survivorship care plans is making a difference in the quality of cancer care, explained Deborah K. Mayer, PhD, RN, AOCN, FAAN, Professor in the School of Nursing and Director of Cancer Survivorship at the University of North Carolina Lineberger Comprehensive Cancer Center. In a review of research published between 2006 and 2013 on survivorship care planning for adult cancer patients, Mayer and her colleagues found that 42 studies had been done and only three were randomized controlled trials, according to the findings presented in a poster at the American Cancer Society Cancer Survivorship Research Conference in June (Abstract B-36, the full study of which is in press in the journal Cancer).

Fourteen studies assessed the content of survivorship care plans; 14 assessed dissemination and implementation of survivorship care planning; and 14 focused on the potential influence of survivorship care planning on survivor-, provider-, and system-level outcomes. The analysis showed that:

- Most studies endorsed the concept of survivorship care planning, but found the plans in practice to be not sufficient (survivors wanted more content on health promotion, psychosocial support, and financial and other resources; and providers preferred a streamlined version of survivorship care plans that clearly identified what components of care they were responsible for administering);
- Use of survivorship care planning in cancer programs and among cancer care providers was limited (according to 6 of 14 studies);
- Survivor and primary care provider receipt of survivorship care plans was limited (according to 5 of 14 studies); and
- Studies reported that key barriers to implementing and using survivorship care plans were: insufficient time, staff, training, time to complete templates, and funding.

“I think the biggest real issue is that there’s no evidence that giving the survivorship care plan is making a whole lot of difference yet to the quality of cancer care,” Mayer said in an interview. The research so far has identified how laborious the process is and how time-consuming the plans are to actually put together: “Who’s going to give up an

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‘Has to Be Easier to Do’
A pilot study Mayer led evaluated the implementation of the JourneyForward survivorship care plan for survivors of colon cancer and found that delivery of those plans was well-received, but on average took 49 minutes to complete for a surgery survivorship care plan and 90 minutes for a patient who received both a surgery and chemotherapy plan (Oncol Nurs Forum 2014;41:266-272).

The process of creating survivorship care plans needs to get better in order for them to become the standard of care, Mayer said. “It’s not that people don’t want to use them, or don’t think that they’re necessarily a good idea—but it’s got to be easier to do on a regular basis.”

That study included 28 patients who had stages I, II, or III colon cancer, who had completed treatment and were within one year of diagnosis; 11 had had surgery only and 17 had had surgery and chemotherapy. Oncology certified nurses trained on how to use the JourneyForward survivorship care plan template developed a plan for each patient, and the plans were delivered to the patient by the nurse practitioner for the surgical or medical oncology team. Paper copies of the plan were mailed to the patients’ primary care providers—and follow up was conducted within two weeks via mailed survey.

Additional findings were:
- It took on average 16 minutes to deliver the survivorship care plans for the surgery-only patients, and 26 minutes for delivery for the surgery and chemotherapy patients;
- Nurse practitioners reported not feeling that plan delivery added time to the regular patient visit, but did provide more structure when reviewing the information with the patient;
- 26 patients agreed that the plan was both “easy to understand” and “simple to use”; and
- 14 out of 15 primary care providers said the plans were easy to understand and useful, but too long to use.

Another point was that 18 of the 28 patients reported they would have preferred to receive the survivorship care plan either before the end of treatment or within three months of completing treatment—so timing is important, Mayer noted. “How do you track down patients who are due for receiving a survivorship care plan? Then who’s going to deliver it? Then how do you track all of that? Groups [physician practices and cancer centers] need to decide that. Those questions should be addressed when a program implements survivorship care planning.

“We need to focus more on the communication and coordination of care using the survivorship care plan as a tool to do that with the patient and the primary care provider, and how effectively we are doing that,” she said.

‘Focus Has Been Off’
Asked her opinion, Carrie Stricker, PhD, CRNP, an oncology nurse practitioner at Abramson Cancer Center at the University of Pennsylvania, said that a big problem with implementing survivorship care plans so far has been that people have lost sight of the real purpose of these plans and placed too much emphasis on the time-consuming process of documenting specific treatment details, rather than determining appropriate follow-up care.

“The focus on what the critical elements of a survivorship care plan have are been off,” she said. “The goal of the plans is provide a shared understanding between providers and patients of who should be doing what, what to look for, who to report it to, and when. But, a huge problem has been an overemphasis on the treatment summary portion of the survivorship care plan, versus the actual care plan part.”

Compiling data for the treatment summary component of a survivorship care plan can take hours, Stricker said—on average 60 to 90 minutes per patient, according to her previous research (Journal of Cancer Survivorship 2011;5:358-370).

Carrie Stricker, PhD, CRNP. “A huge problem has been an overemphasis on the treatment summary portion of the survivorship care plan versus the actual care plan part.”

ASCO to Release Streamlined Template

The working group wrote the Survivorship Compendium, published on the ASCO website earlier this year, which includes other resources for care providers to implement new or improve existing survivorship initiatives at their institutions.

Survivorship care plans have suffered—in terms of their utility—because they have tried to do too much, Oeffinger added. “You don’t need to know the details of the cancer treatment to the degree that everybody initially thought. You don’t need chemo doses for every agent a patient receives—you need cumulative doses on the ones that are going to info the screening that gets recommended.

“We need to know the radiation field and the dose to be able to know what screening we would recommend for that area, but we don’t need to know every surgery necessarily—however, we do need to know what organs were affected.”

ASCO’s simplified survivorship care plan template is designed to highlight relevant information. “It’s relatively brief—two pages or so—and it’s very doable,” he continued.

“It has the key information that the patient and the providers—both the primary care provider and the oncologists—need to know. And it doesn’t have a lot of extraneous information.”

The template is modifiable, Oeffinger added—which is important because the document (and the complexity of it) should be dictated by the complexity of the individual patient’s information, the cancer, and the therapy received.

The new version is currently in piloting stages and is expected to be available on the ASCO website (for use by physicians and oncology care providers) by early fall. The template will be available as a Word document that can be adapted for paper or electronic systems, Oeffinger noted.

Kevin Oeffinger, MD, Director of the Cancer Survivorship Center at Memorial Sloan Kettering Cancer Center—who heads the Models of Care working group (part of ASCO’s Survivorship Committee), which has been tasked with revising the template—explained that the new template includes five components:
- Information about the cancer diagnosis;
- Information about the cancer therapy;
- Potential late effects;
- Key recommendations for screening; and
- Whom to contact for questions or problems.

CARRIE STRICKER, PHD, CRNP. “A huge problem has been an overemphasis on the treatment summary portion of the survivorship care plan versus the actual care plan part.”

KEVIN OEFFINGER, MD: “Survivorship care plans have suffered—in terms of their utility—because they have tried to do too much.”

The American Society of Clinical Oncology is taking a step to refocus survivorship care planning efforts by rewriting its survivorship care plan template to be a more streamlined document.

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“So, providers spend all this time pulling together a personalized treatment summary, telling you exactly what the patient got, but then do not spend time creating a personalized plan for follow-up care for the patient—and for supportive care and education,” she noted.

“We need to swing the pendulum back to focus on getting a summary of just the information needed for the multidisciplinary team—including primary care—to provide care to that patient, and to help the patient understand what he or she needs to do for him or herself.”

Getting Health IT Caught Up
Another problem, Stricker said, is that information systems do not currently allow all of the data from a patient’s cancer care trajectory to be easily compiled from across hospitals or health care settings—even from within one institution.

“Traditional electronic medical records systems have focused on generating a record of care for health care providers, she noted. But moving ahead, systems need to focus on leveraging health IT to more efficiently and effectively collect patient data that can help generate support tools—like cancer survivorship care plans—so providers can personalize that care for their patients.”

“A patient of mine may see radiation oncology, medical oncology, surgical oncology, all here at Penn for her breast cancer—but we don’t have discrete data in our electronic medical record with dates and procedures to pull easily into a treatment summary.”

In 2013, to help address some of these gaps, Stricker co-founded a health information technology company, On Q Health—which of which she serves as Chief Clinical Officer—which is investigating platforms to integrate electronic medical record systems and patient-reported symptom data and history data to generate personalized, electronic care plans across the continuum of care, including survivorship care plans.

Another hurdle in implementing survivorship care planning, she added, is determining the best way to efficiently and effectively personalize the care plans. “I do that for my patients in the clinic by asking what symptoms they have and what their top concerns are—and creating a customized plan for how to manage those symptoms, based on their treatment history, and if available, genetic testing results—which is laborious.

“If we could get that information ahead of time, we could facilitate more efficient personalization of care plans for patients that would make this process more feasible.”

Ongoing data from use of the On Q Care Planning System is showing that integrating electronic patient-reported data into care plans is making the developing of those plans more efficient, Stricker said.

Traditional electronic medical records systems have focused on generating a record of care for health care providers, she noted. But moving ahead, systems need to focus on leveraging health IT to more efficiently and effectively collect patient data that can help generate support tools—like cancer survivorship care plans—so providers can personalize that care for their patients.

KELLY BUGOS, MS, NP: “The feature on of our electronic health record allows two variables that we believe are helpful: an abbreviated treatment summary and auto-dating.”

STEPHEN TAPLIN, MD, MPH: “A lot of people expected survivorship care planning to just off. But, now in retrospect it becomes more obvious that there really wasn’t a clear literature base.”

Other tools being investigated include the Oncology History module, a feature of the Epic electronic health record system which is designed to include an abbreviated treatment summary portion of a patient’s survivorship care plan based on that patient’s EHR. Treatment history “events” are auto-categorized by date.

An early clinical review evaluating the effectiveness of the tool at Stanford Cancer Institute was published in conjunction with the most recent ASCO Annual Meeting (Abstract e20609).

Interviewed by telephone for this article, the study’s lead author, Kelly Bugos, MS, NP, Nurse Practitioner and Manager at the Stanford Cancer Survivorship Program, said the initial data on the early experience of using the tool there was positive, showing that though early adoption by physicians was slow, the tool provides organized treatment summary information and was useful in the generation of survivorship care plans.

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**Commission on Cancer Efforts to Address the Challenges**

The most recent data from the American College of Surgeons Commission on Cancer (CoC)—a survey of 1,390 member programs conducted last summer—found that only 40 percent of the programs reported that they were at the time addressing Standard 3.3 requiring the cancer center to develop and implement a process for disseminating a comprehensive care summary and follow-up plan to cancer patients completing treatment (OT 7/10/14 issue).

The survey also found that 37 percent of the respondents reported being completely confident they would be able to be compliant with the standard by the deadline, 47 percent reported feeling somewhat confident that they could meet the deadline, and 16 percent reported feeling not at all confident or unsure.

“The survey was a way for the CoC and our patient-based advocacy member organizations to ‘take the pulse’ of CoC-accredited programs,” said Nina Miller, MSSW, OSW-C, Cancer Liaison Initiatives Manager for the CoC. “The results seem to suggest that of the three Continuum of Care Standards, it was the survivorship care plan standard that was presenting the greatest challenge to programs—thus prompting several initiatives to further explore the challenges and work to address them.”

CoC convened a subcommittee of the Accreditation and Standards Committee earlier this year to determine whether the survivorship care plan standard needed to be clarified or revised prior to the January 2015 implementation deadline—and the conclusions of that discussion are expected to be announced later this month.

In addition, CoC member organizations, including the Livestrong Foundation, the Cancer Support Community, the American Cancer Society, and the National Coalition for Cancer Survivorship (who all collaborated on the aforementioned survey), have been working to more clearly define evidence-based survivorship care models and develop mechanisms for electronic delivery of content for survivorship care plans.

Sarah Arvey, PhD, Livestrong’s Director of Research & Evaluation, noted via email that the Foundation released its “Essential Elements of Survivorship Care” brief in 2012, which outlines best practices and recommendations for how to best incorporate survivorship care into practice (livestrong.org/What-We-Do/Our-Approach/Reports-Findings/Essential-Elements-Brief), and is also funding research to test the feasibility of integrating electronic health records with the Livestrong care plan, which would allow the treatment summary portions of those plans to auto-populate, as well as allowing data to be captured in a registry.

“We don’t have discrete data in our electronic medical record with dates and procedures to pull easily into a treatment summary.”
A more comprehensive listing of oncology-related conferences and courses is available at http://bit.ly/OTMeetings.

**CONFERENCES & COURSES**

**January**
- Jan. 15-17  San Francisco  Gastrointestinal Cancers Symposium  www.gicasym.org

**February**
- February 4-7  Seville, Spain  European Research Organisation on Genital Infection and Neoplasia 2015 International Multidisciplinary Congress  www.eurogin.com/2015/
- February 5-8  San Diego  NRG [combined clinical trials group of NSABP, RTOG, and GOG] Oncology’s Semi-Annual Meeting  www.gog.org/meetinginformation.html
- Feb. 11-15  San Diego  2015 BMT Tandem Meeting  www.asbmt.org
- February 12-14  Nice, France  5th International Conference on Innovative Approaches in Head & Neck Oncology  www.estro.org/congresses-meetings/items/5th-ichno
- February 26-28  Orlando  Genitourinary Cancers Symposium  www.gucasym.org

**March**
- March 5-8  San Diego  The Endocrine Society’s 97th Annual Meeting and Expo  www.endocrine.org/endo-2015
- March 6-7  Torino, Italy  16th European Congress: Perspectives in Lung Cancer  imedex.com/lung-cancer-congress-europe/index.asp
- March 12  Las Vegas  Expert Reviews in Hematology 2015: Highlights from the Annual Hematology Meeting  imedex.com/annual-hematology-meeting-highlights/index.asp
- March 12-14  St. Gallen, Switzerland  Advanced Prostate Cancer Consensus Conference  www.prostatecancerconsensus.org
- March 13-14  Las Vegas  21st Annual Network for Oncology Communication and Research Meeting  imedex.com/annual-noocr-meeting/index.asp

**April**
- April 9-11  Orlando, FL  American Brachytherapy Society Annual Meeting  www.americanbrachytherapy.org/meetings/index.cfm
- April 18-22  Philadelphia  American Association for Cancer Research Annual Meeting  www.aacr.org

**May**
- May 6-9  Phoenix  28th Annual Meeting of the American Society of Pediatric Hematology/Oncology  www.aspho.org/education/2015/workshops.html
- May 29-June 2  Chicago  ASCO Annual Meeting  www.asco.org/asco15/meetings

**June**
- June 6-10  Baltimore  Society of Nuclear Medicine Annual Meeting  www.smnm.org
- June 20-25  Toronto  International Society on Thrombosis and Haemostasis 2015 Congress and 61st Annual Scientific and Standardization Committee Meeting  www.isth.org/page/2015Microsite/
- June 20-23  Florence, Italy  Anticancer Drug Action and Resistance From Cancer Biology to the Clinic  www.ecco.org.eu/Events/EAS2015
- June 25-27  Copenhagen, Denmark  Multinational Association of Supportive Care in Cancer/International Society of Oral Oncology Annual Meeting on Supportive Care in Cancer  www.kenes.com/maco2015

**SURVIVORSHIP CARE PLANS**

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“We are really at the baseline of survivorship care planning, but this feature is a step forward in being able to concisely summarize a patient’s treatment history,” she said.

**NCI Efforts**

To support research, the National Cancer Institute issued a program announcement in 2012—PA-12-274 and PA-12-275—to notify investigators that they can apply for grants evaluating the process of survivorship care and care planning. Either R21 grant funding is available to investigate and evaluate mechanisms and tools for delivering survivorship care planning; and R01 grant funding is available to test interventions and models of care, explained Stephen Taplin, MD, MPH, Branch Chief of the Process of Care Research Branch in NCI’s Behavioral Research Program.

So far there has been one complete cycle of applications and funding since the program announcements were issued, and 30 applications have been received—“a relatively large amount of interest,” Taplin said.

“A lot of people expected survivorship care planning just to take off. But, now in retrospect it becomes more obvious that there really wasn’t a clear literature base for how to do it or what the impact would be. “It took a while to see that things weren’t happening—and that we weren’t addressing the problem that the survivorship care plans were supposed to address.” ✤