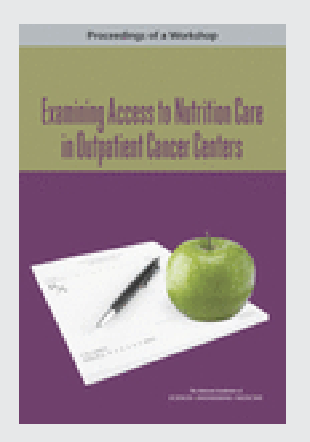

Examining Access to Nutrition Care in Outpatient Cancer Centers: Proceedings of a Workshop

DETAILS

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Examining Access to Nutrition Care in Outpatient Cancer Centers

Proceedings of a Workshop

Leslie Pray and Ann L. Yaktine, *Rapporteurs*

Food and Nutrition Board

Health and Medicine Division

The National Academies of
SCIENCES · ENGINEERING · MEDICINE

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PLANNING COMMITTEE ON ASSESSING RELATIONSHIPS BETWEEN ACCESS TO STANDARDIZED CARE AND HEALTH OUTCOMES AND COST-EFFECTIVENESS OF CARE IN OUTPATIENT CANCER CENTERS[1]

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[1] The National Academies of Sciences, Engineering, and Medicine's planning committees are solely responsible for organizing the workshop, identifying topics, and choosing speakers. The responsibility for the published Proceedings of a Workshop rests with the workshop rapporteurs and the institution.

Reviewers

This Proceedings of a Workshop has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published Proceedings of a Workshop as sound as possible and to ensure that the Proceedings of a Workshop meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this Proceedings of a Workshop:

Nancy J. Emenaker, National Cancer Institute
Kelly Kelleher, Nationwide Children's Hospital
Colleen Spees, The Ohio State University College of Medicine
Cynthia Thomson, University of Arizona Cancer Center and Mel & Enid Zuckerman College of Public Health

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the Proceedings of a Workshop before its release. The review of this Proceedings of a Workshop was overseen by **Nancy E. Adler,** University of California, San Francisco. She was responsible for making certain that an independent examination of this Proceedings of a Workshop was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this Proceedings of a Workshop rests entirely with the rapporteurs and the institution.

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APPENDIXES

Acronyms and Abbreviations

ACCC	Association of Community Cancer Centers
ACO	accountable care organization
ACS	American Cancer Society
AICR	American Institute for Cancer Research
AND	Academy of Nutrition and Dietetics
ANDHII	Academy of Nutrition and Dietetics Health Informatics Infrastructure
ASCO	American Society for Clinical Oncology
ASTRO	American Society for Radiation Oncology
BMI	body mass index
CDHP	consumer-driven health plan
CDR	Commission on Dietetic Registration
CMMI	Center for Medicare & Medicaid Innovation
CMS	Centers for Medicare & Medicaid Services
CoC	American College of Surgeon’s Commission on Cancer
COE	center of excellence
COPD	chronic obstructive pulmonary disease
COSA	Clinical Oncology Society of Australia
CPT	Current Procedural Terminology
CSO	Board Certified Specialist in Oncology Nutrition
DIANA-5	Diet and Androgens-5 study
DSHEA	Dietary Supplement Health and Education Act of 1994

EAL	Evidence Analysis Library
ENERGY	Exercise and Nutrition to Enhance Recovery and Good Health for You Trial
FDA	U.S. Food and Drug Administration
FNCE	Food and Nutrition Conference Expo
FTE	full-time equivalent
GI	gastrointestinal
GP	General Practitioner
ICD	*International Classification of Diseases*
IEN	immune-enhancing nutrition
IOM	Institute of Medicine
NBGH	National Business Group on Health
NCCCP	National Comprehensive Cancer Control Program
NCCN	National Cooperative Cancer Network
NCI	National Cancer Institute
NEL	U.S. Department of Agriculture's Nutrition Evidence Library
NIH	National Institutes of Health
NIS	nutrition impact symptom
ONDPG	Oncology Nutrition Dietetic Practice Group
PEG	percutaneous endoscopic gastrostomy
PG-SGA	Patient Generated Subjective Global Assessment
PIVOT	Prostate Cancer Intervention Versus Observation Trial
RCT	randomized controlled trial
RD	registered dietitian
RDN	registered dietitian nutritionist
RENEW	Reach Out to ENhancE Wellness in Older Survivors
SNAQ	Short Nutritional Assessment Questionnaire
WCRF	World Cancer Research Fund International
WHEL	Women's Healthy Eating and Living Study
YMCA	Young Men's Christian Association

1

Introduction

An estimated 90 percent of oncology patients in the United States receive treatment in outpatient cancer centers and clinics (Halpern and Yabroff, 2008). This change from the older model of inpatient care has important implications for overall quality of care for oncology patients and nutritional care in particular. Amidst growing concern about access to oncology nutrition services, combined with growing recognition of the importance of providing nutritional care to optimize oncology treatment outcomes and maximize quality of life among both patients and survivors of cancer, an ad hoc planning committee of the National Academies of Sciences, Engineering, and Medicine's Food and Nutrition Board[1] convened a 1-day public workshop in Washington, DC, on March 14, 2016, titled "Examining Access to Nutrition Care in Outpatient Cancer Centers," to explore evolving interactions between nutritional care, cancer, and health outcomes.

Specifically, as per the statement of task (see Box 1-1), participants explored how health outcomes and survival of cancer patients in outpatient cancer centers are affected by current standards for nutritional services, nutritional interventions, and benefits associated with oncology patient access to medical nutrition therapy. Workshop speakers and discussants also

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[1] The planning committee's role was limited to planning the workshop, and the Proceedings of a Workshop has been prepared by the rapporteurs as a factual account of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and have not been endorsed or verified by the National Academies of Sciences, Engineering, and Medicine. They should not be construed as reflecting any group consensus.

BOX 1-1
Statement of Task

An ad hoc planning committee will plan a 1-day public workshop exploring the evolving interactions between nutritional care, cancer, and health outcomes. Specifically, workshop participants will explore how the following parameters affect the health outcomes and survival of cancer patients in outpatient cancer centers: current standards for nutritional services, the role of nutritional intervention in nutritional status and morbidity and mortality in oncology patients, and benefits associated with access of oncology patients to medical nutrition therapy. The workshop will also explore nutritional interventions and cost of outpatient care. The workshop discussants will take into account a range of analytical approaches, including use of aggregate data from electronic medical records, to assess cost–benefit relationships between oncology nutrition services and health outcomes and survival. The committee will plan and organize the workshop, select and invite speakers and discussants, and moderate the discussions. An individually authored summary of the presentations and discussions at the workshop will be prepared by a designated rapporteur in accordance with institutional guidelines.

explored the cost of outpatient nutritional care and assessed cost–benefit relationships between oncology nutrition services and health outcomes and survival. The specific workshop objectives are outlined in Box 1-2.

Importantly, this Proceedings of a Workshop summarizes information presented and discussed at the workshop and is not intended to serve as a comprehensive overview of the topic. Nor are the references cited throughout this summary intended to serve as comprehensive sets of references for any

BOX 1-2
Workshop Objectives

- Describe the current status of nutritional care for oncology outpatients, including the availability of data during treatment and long-term survivorship.
- Describe the ideal care setting, including models of care within and outside the United States.
- Describe the potential benefits of outpatient nutritional care on morbidity, mortality, and long-term survival.
- Describes the issues relating to cost–benefit assessment for both recent diagnosis and post-treatment care.
- Describe the barriers to achieving an ideal care setting and the information resources available to patients.

topics; only references cited on speaker slides or in the workshop briefing notebook are cited in the text. Additional references used by the planning committee to help develop the workshop agenda are included in Appendix C. Also of note, while the material presented and discussed over the course of the workshop touched on all of the components outlined in the statement of task (see Box 1-1) and met all of the workshop objectives (see Box 1-2), some issues drew more attention than others. For example, compared to other bullet points listed in Box 1-2, there was more extensive discussion of barriers to access to nutritional care (i.e., the last bullet point). Finally, the information and suggestions for future action included here reflect the knowledge and opinions of individual workshop participants and should not be construed as consensus.

ORGANIZATION OF THIS PROCEEDINGS OF A WORKSHOP

The organization of this Proceedings of a Workshop parallels the organization of the workshop (see Appendix A for an outline of the workshop agenda), with summaries of the keynote presentation and sponsor panel (i.e., panel of representatives from all sponsors who donated at least $10,000) included in this first chapter.

Chapter 2 “Current Knowledge and Status of Nutrition Practices in Oncology Outpatient Care” summarizes Session 1 presentations and discussion, with a focus on current evidence on the role of nutrition in cancer prevention, treatment, and survivorship and the current status of nutrition practices in oncology outpatient care. Chapter 3 “Models of Care: National and International Perspectives” summarizes Session 2 presentations and discussion. Session 2 speakers described several models of nutrition care in outpatient oncology from around the world, including here in the United States, as well as in Australia, Europe, and Canada. Chapter 4 “Benefits and Costs of Care” summarizes presentations and discussion from Session 3, which focused on the economic benefits and costs of nutrition care in outpatient oncology. Chapter 5 “Dissemination and Implementation: Reaching the Ideal” summarizes the Session 4 presentations and discussion on the dissemination and implementation of nutritional care evidence. Finally, Chapter 6 “Evidence on Nutrition Care in Outpatient Oncology: Closing Discussion” summarizes the closing facilitated discussion.

KEYNOTE PRESENTATION[2]

Pulling together different interests relating to nutrition care access in outpatient cancer centers was “a long time coming,” Steven Clinton began.

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[2] This section summarizes information and opinions presented by Steven K. Clinton, M.D., Ph.D., The Ohio State University, Columbus, Ohio.

He recalled that the "war on cancer" began when President Richard Nixon signed into law the National Cancer Act of 1971. Since then, according to Clinton, the emergence of more than 40 comprehensive cancer centers and the development of cooperative groups to conduct phase III randomized trials has led to the more efficient translation of basic science into clinical care for the benefit of millions of people with cancer. These comprehensive cancer centers also serve as a framework for training and for bringing expert care into communities. "Although those of us working in the field may never feel it's enough," Clinton said, "we see that the cancer incidence rates, after decades of increase, have plateaued and are beginning to maybe decline." Additionally, cancer mortality rates among both women and men have changed significantly and are clearly declining.

However, these same positive trends have created new challenges, Clinton continued. The number of cancer survivors is increasing dramatically, from about 4 million in 1975 to 14 million today and potentially 24 million by 2024. Because of these improved survival rates, coupled with the aging U.S. population, the actual burden of cancer is increasing, with 1.6 million new cancer cases in 2016 alone. Added to the increasing number of cancer survivors is the rising cost of cancer care which, according to Clinton, is expanding at a rate that exceeds virtually every other area of medicine. An estimated $124 billion was spent in 2010, a figure expected to rise to $158 billion by 2020. "I'm astounded at the cost of the drugs that we use to treat patients in my clinic," he said.

With respect to the role of diet, nutrition, and physical activity in the war on cancer, the scientific evidence has expanded tremendously over the past few decades, Clinton observed. Systematic reviews conducted by the American Institute for Cancer Research (AICR), the World Cancer Research Fund International (WCRF), and other organizations have supplied evidence-based reports that make these data not only useful for researchers but also applicable to public health policy and to governmental food, nutrition, and agricultural programs around the world. Data have emerged showing how dietary and nutritional strategies integrated into patient care plans not only enhance therapeutic efficacy and reduce complications of therapy but also promote healthy survivorship in terms of both reducing risk of recurrence and improving overall health (i.e., with regard to other chronic disease outcomes). Additionally, integrating nutrition into both prevention and clinical care could enormously impact health care expenditures for cancer. However, in Clinton's opinion, while this growth in scientific evidence regarding diet, nutrition, and physical activity has created enormous potential to reduce the cancer burden, this potential has yet to be fully reached.

Implementation of Research Findings: Barriers in the Medical Model

Clinton's frustration, he said, is not only with insufficient funding for nutrition and cancer research but more so with the fact that all the knowledge that has accumulated over the past several decades is not being implemented. He recognized the enormous amount of research conducted with regards to diet, nutrition, exercise, and cancer risk and etiology that has been reviewed and organized by AICR and WCRF and the public health guidelines put forth based on that review. Without elaborating, Clinton remarked that the greatest challenge to implementation is political. He focused the remainder of his talk on barriers in the medical model, that is, barriers to actually taking care of individuals.

Regarding how to integrate diet and nutrition into medical care, Clinton observed that many experts feel that the failure lies with practitioners (e.g., physicians, nurses, nurse practitioners, physician assistants) who are not adequately trained in nutrition. In recent years, however, he has taken a different view. He mentioned attending a recent meeting where someone discussed how their institution was increasing the number of lectures on nutrition and dietary guidelines and providing first-year medical students with hands-on cooking demonstrations, and so on. He suspected that the main outcome of these entertaining demonstrations is socialization with one's peers and perhaps an impact on the diet of the student. Given what it takes to train a physician, including 4 years of medical school, and in his case, 3 years of an internal medicine internship and residency and another 3 years of medical oncology, Clinton asked, "Do you really think those two or three lectures during your first year of medical school mean anything? Absolutely not."

He suggested increasing awareness of nutrition in subsequent clinical training, particularly during residency and fellowship. Additionally, he suggested changing the biochemistry course most first-year medical students take to "Nutrition and Metabolism." But, most important in Clinton's opinion, physicians need to be taught how to use the talent pool at hand in the hospital environment. That pool is and will continue to be the registered dietitians (RDs)/registered dietitian nutritionists (RDNs). "It amazes me," he said, "that we think that the physician needs to be the nutritionist." When medical oncologists need radiation therapy for a patient, they do not do it themselves. They get the radiation therapists to collaborate. Likewise, with physical therapists. So, he asked, why not do the same with nutrition education? Physicians are not trained to provide nutrition education to their patients. Clinton called for more people to be trained as dietitians and nutritionists. Additionally, he called for more grants to be awarded to institutions with the infrastructure to offer combined degree training programs, particularly RDs/Ph.D.s, which he predicted will be at the forefront of bringing nutrition expertise to the bedside.

Perhaps the greatest barrier to implementation, one that Clinton highlighted, is lack of reimbursement for RD/RDN services, given that hospitals and other institutions will not invest in a service unless they can see a tangible return on investment. But the financial challenges, he said, are "really deep." In spite of the positive effects the 2010 Affordable Care Act, which has greatly improved access to medical services for many who were previously uninsured, the cost of healthcare in the United States is increasingly being shifted to the patient, with insurance costs, co-pays, and annual deductibles rising every year. Clinton mentioned treating a patient with terminal cancer whose monthly co-pay for pain medications jumped from $15 in December to $500 on January 1. In this kind of health care system with patients paying that much for critical items such as pain medications, Clinton asked, "How are we going to achieve payment for nutritional services?" Compounding the challenge are growing social and economic disparities that make it even more difficult to meet the rising cost of healthcare. So the financial challenges are an "enormous obstacle," Clinton summarized.

Another major barrier to implementation is the need for standards of care regarding evidence-based nutritional support. Recognizing that many organizations have worked on developing standards of cancer care in various ways, Clinton suggested that these same organizations work together to develop peer-reviewed standards of care for nutrition support services in cancer centers. He pointed to the National Comprehensive Cancer Network (NCCN) guidelines for cancer therapy as an outstanding example that profoundly impacts the quality of cancer care in the United States. Perhaps it is time to revisit the integration of nutritional services into specific components of the NCCN guidelines. With both head and neck and oral cancers, where surgical procedures coupled with chemotherapy and radiation make it difficult for patients to consume an adequate diet, there is very clear and strong evidence that nutritional support can greatly improve the ability to receive a full complement of effective therapy on time and at the most impactful dose. Based on this evidence, the NCCN guidelines include suggestions for nutrition interventions that help to promote optimal outcomes for patients with head and neck and oral cancer. But all cancer types need to undergo this type of review, Clinton opined, and the information needs to be made readily available to all practitioners.

In addition to education and training translational investigators, we also need a greater number of RDs/RDNs in the cancer center to meet demands. For Clinton, who is privileged to work at one of the National Cancer Institute's (NCI's) comprehensive cancer centers, when he calls a dietitian to consult on an outpatient, he often finds the RD to be covering five different buildings that have 4,000 outpatient patient clinic visits a day. Most cancer centers are similarly understaffed in outpatient settings, which increasingly account for the vast majority of cancer care.

Another barrier to implementation, in Clinton's opinion, is the lack of infrastructure. For Clinton, when he calls an RD who is covering five different buildings and 4,000 patients per day, the question is not only when can the RD get to the clinic, but also where is the space? Dietitians need dedicated space. Additionally, Clinton observed, all data relevant to nutrition care need to be integrated into the electronic medical records system so the data are readily available to everyone on the health care team.

In Clinton's opinion, the supplement industry set up a barrier to the integration of evidence-based nutritional support into cancer care. He called for enhancing the U.S. Food and Drug Administration (FDA) oversight and empowering the Office of Dietary Supplements to do more to provide education for cancer patients. Many patients, when they complete active care, whether that has been chemotherapy, surgery, or radiation, reach a point in time when their clinician says, "Well, congratulations. We'll see you in 3 months." Suddenly, all that intense care and interaction with caregivers is severed. That is when many patients step back and realize they want to step up and do something for themselves. Unfortunately, in Clinton's opinion, that is when a high school student working at one's local health food store becomes the provider of advice and guidance for cancer survivorship. He added, "There's much worse than that." The supplement industry, in Clinton's opinion, is one of the biggest challenges for cancer survivors.

To close, Clinton emphasized that the time is now to take greater action in this arena. In his opinion, all professional organizations related to nutrition need to be made aware of the potential for this field to contribute significantly in the war on cancer. There is no doubt, he said, "We can have a very dramatic and significant impact. So learn today, speak up, and act."

SPONSOR PANEL

Representatives from the six sponsors who contributed more than $10,000 to support this workshop described their institutions' interests in the workshop topic.

First, Deirdre McGinley-Gieser, Senior Vice President for Programs at AICR, described AICR as a national nonprofit organization based in Washington, DC, with a focus on the link between nutrition, physical activity, and weight management to the risk of cancer. The workshop agenda "goes to the heart" of AICR's mission, she said. AICR's evidence has shown for many years that diet and nutrition play a crucial role in not only cancer prevention, but also treatment and survivorship. Moreover, patients and families recognize this and are receptive to making healthy changes. The challenge is lack of access to the experts, the oncology dietitians. Oncology dietitians help patients to manage side effects and other difficulties during treatment and to adopt lifelong healthy eating habits after treatment. AICR wants to see improved access to nutrition services. "It's part of who we are and what we do," McGinley-Gieser said. The organization will continue to support the work that emerges from this workshop.

Next, Elaine Trujillo of the Nutrition Science Research Group at the National Institutes of Health's (NIH's) NCI echoed Clinton's opening remarks about how this workshop was "a long time coming." According to Trujillo, there are 69 NCI-designated cancer centers across the United States providing diagnosis and treatment to more than one-quarter of a million people. Because these centers provide the best quality of care, they attract people from around the world, she noted. But there is only 1 dietitian for every 2,600 of these patients. She asked, "How is it possible, with this wonderful treatment, that nutrition, which is so basic, so fundamental, so essential for life—how is it that a patient can go from diagnosis to survivorship and not receive routine nutrition care?" In Trujillo's opinion, this workshop represented an opportunity to begin talking about next steps so every cancer facility that offers treatment is equipped with nutritional services.

Evidence indicates, Trujillo continued, that scientific data continue to be inadequately applied to clinical practice and that this is certainly the case for nutritional science. She wondered whether, without access to nutritional services, advances in nutritional science research are even "trickling down" to patients. Historically, when thinking about the nutritional status of patients with cancer, the focus was on cachexia and anorexia. But today, obesity is a growing problem in the cancer population, among both patients and survivors. There is good evidence, according to Trujillo, showing that cancer survivors respond well to weight loss treatments. Yet there are very few weight loss treatment opportunities available for cancer patients and survivors, although she noted a 2014 report issued by the American Society of Clinical Oncology emphasizing the oncology community's commitment to look for ways to implement nutrition weight loss programs for cancer survivors. A group at particularly high nutritional risk and one often missed as being at high risk is patients with sarcopenic obesity. Sarcopenia in cancer patients is associated with poor functional status, shorter survival, and a higher incidence of dose-limiting toxicity. As would several speakers throughout the day, Trujillo emphasized the need for standards of nutritional care for cancer patients and survivors and remarked that implementation of such standards would help to identify these and other nutritionally high-risk patients.

Also as did several other speakers, Trujillo highlighted the need to address reimbursement of nutritional services and called for more data to make the case for such reimbursement. Although poor nutritional status has been associated with increased hospital cost, very few studies have examined the cost-effectiveness of nutritional interventions. "We need to think about what type of data is best to capture the cost savings," she said.

Trujillo also mentioned dietary supplements and noted that the NIH Office of Dietary Supplements is interested in understanding the current use of dietary supplements in cancer patients, which is a lot higher than use of dietary supplements in the general American population and often underreported. Although some supplements may be beneficial, Trujillo continued, others may cause serious side effects and interfere with cancer treatment. She noted that the NCI's Division of Cancer Prevention has sponsored large clinical trials of dietary supplements and, according to Trujillo, has found them to be harmful. She suggested that RDs who can talk with patients about the safety and efficacy of supplements need to be part of multidisciplinary cancer care teams.

Next, Russell Clayton, chief medical officer of Alcresta, Inc., explained that in November 2015 FDA approved an Alcresta product for use in adults to hydrolyze fats in enteral formula. This product is a device designed to be used with enteral nutrition ("feed tubing") for a particular subgroup of patients, that is, patients who cannot hydrolyze fats. This includes patients with pancreatic cancer. Clayton expressed surprise at some of the responses he received when talking with dietitians and oncologists about potential use of the products. While some folks were enthusiastic, others were not. They told Clayton they do not use enteral nutrition in patients with pancreatic cancer. Given that, according to Clayton, 65 to 85 percent of these patients have malnutrition, he was puzzled as to why this is the case. One answer he received was that enteral nutrition is not reimbursed by health care insurers or that reimbursement requires that certain criteria be met. Another was lack of resources, that is, that there were not enough staff to help manage patients on enteral nutrition. Yet another answer, which Clayton found the most troubling, was that many patients with pancreatic cancer are incurable and that placing a feeding tube confuses end-of-life issues. In his opinion, whether fighting for survivorship or fighting to make the last days of life as dignified and comfortable as possible, malnutrition during the last days of life should not be part of the problem. His goal at this workshop was to better understand what Alcresta can do to help remove some of these barriers so patients who need enteral nutrition can get it.

Representing the American Cancer Society (ACS), Colleen Doyle, managing director of nutrition and physical activity, mentioned having attended an Institute of Medicine meeting a few years ago and talking about the concept of this workshop. She echoed other speakers' excitement and gratitude that this workshop was finally happening. Providing nutrition and physical activity support to cancer patients and survivors is critical to the ACS's mission to help save more lives from cancer. On behalf of the ACS, Doyle said "we are thrilled" to be part of this meeting and "excited" to help expand nutrition services for cancer patients and create healthy environments for cancer patients where barriers to eating well and being active are reduced. Additionally, she echoed Clinton's sentiment about the critical importance of reimbursement.

Next, representing the Academy of Nutrition and Dietetics (AND) and the AND Foundation, Alison Steiber, chief science officer, remarked that while the Academy's more than 100,000 credentialed practitioners clearly do not meet the need for practitioners described earlier by Clinton, nonetheless it is a very large workforce. Founded in Cleveland, Ohio, in 1917, the AND serves many purposes, including advocacy, the provision of professional resources, education, and research. One of the biggest member benefits with respect to research, Steiber observed, is the Academy's Evidence Analysis Library (EAL), which is focused on creating evidence-based systematic reviews that pull together nutrition information from studies in humans and that can be used to develop practice guidelines. In 2013, the EAL released an updated *Oncology Evidence-Based Nutrition Practice Guideline* (AND, 2013), which Steiber described as a "huge undertaking." It includes five nutrition screening recommendations, six nutrition assessment recommendations, one nutrition diagnosis recommendation, eight nutrition intervention recommendations, two monitoring and evaluation recommendations, and one outcomes management recommendation.

But creating guidelines, Steiber said, is not enough. To help fine-tune and improve the guidelines, she emphasized the importance of not just collecting outcome data from practitioners, but of generating new outcome data as well. To help with this effort, the AND recently created a Web-based program, the Academy of Nutrition and Dietetics Health Informatics Infrastructure (ANDHII), that allows clinicians to enter outcome data. Based on the data already collected, Steiber and colleagues submitted an abstract to the 2016 Food and Nutrition Conference Expo (FNCE).[3]

Finally, Katrina Claghorn, an outpatient oncology dietitian at the University of Pennsylvania, spoke on behalf of the Oncology Nutrition Dietetic Practice Group (ONDPG) of the AND. She echoed other remarks about the lead-up to this workshop, calling it a "historic day." Outpatient oncology nutrition has evolved into its own field of practice over the past 20 years, especially with the shift to outpatient care, with 90 percent of cancer care now being provided in the outpatient clinic (see Box 1-3). Yet, Claghorn said, while witnessing the growth of outpatient cancer centers, she has been troubled by not seeing a corresponding increase in dietitians in these facilities. She remarked that she frequently receives calls from dietitians who are new to outpatient oncology seeking advice on guidelines for care and

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[3] The 2016 FNCE will be held in Boston, Massachusetts, in October 2016.

BOX 1-3
How Prevalent Is Outpatient Cancer Care?

According to sponsor panelist Katrina Claghorn, a member of the Oncology Nutrition Dietetic Practice Group of the Academy of Nutrition and Dietetics, an estimated 90 percent of cancer patients in the United States are treated in outpatient settings.

how to screen and triage patients. She finds it frustrating that she cannot provide concrete answers.

Claghorn's hope was that this workshop would help to validate the integral role that nutrition therapy plays in cancer care. "There is perhaps no other area of medicine where the risk of malnutrition is greater," she said. The diseases most affected by malnutrition, in order of risk, are pancreatic cancer, lung cancer, head and neck cancer, and gastrointestinal cancer, followed by stroke and chronic obstructive pulmonary disease. So the top four diseases are cancers. Claghorn remarked that many workshop attendees had likely witnessed how, among cancer patients, medical nutrition therapy delivered by dietitians can help to prevent delays in treatment, prevent unplanned hospitalizations, avoid reactionary nutrition support, improve outcomes in patient satisfaction, and reduce the cost of care. Additionally, registered dietitians serve an important role in helping cancer survivors with the long-term side effects of treatment, one of the most challenging being obesity. Registered dietitians also serve as intermediaries between conventional and complementary medical practitioners. In closing, she reiterated the need for practice guidelines and standards of care to move the field forward. In her opinion, this workshop could not have been more timely in galvanizing action and providing future direction to ensure that dietitians "will have a seat at the table."

To end the sponsor panel, moderator Cheryl Rock recognized additional sponsors of the workshop who were in attendance: Susan Bratton from Savor Health, Ann Fonfa from The Annie Appleseed Project, and Noreen Luszcz from OptionCare.

2

Current Knowledge and Status of Nutrition Practices in Oncology Outpatient Care[1]

OVERVIEW

In Session 1, moderated by Cheryl Rock, speakers provided an overview of nutrition issues that individuals face during cancer treatment and as cancer survivors. First, Mary Platek discussed nutrition issues facing individuals in early oncology treatment. Early oncology care includes patients undergoing active treatment and patients recovering from treatment. Platek highlighted challenges created by nonstandardized screening for cancer patients at nutritional risk and the lack of available nutrition services in outpatient settings; provided an overview of the effects of cancer on nutritional status, the effects of treatment on nutritional status, and the effects of nutritional status on treatment and clinical outcomes; and discussed her search of the scientific literature for evidence of nutritional intervention in early oncology care. She concluded that overall findings indicate important roles for both nutritional counseling and nutritional support in improving clinical outcomes.

Rock addressed many of the same nutrition issues that Platek discussed, but in the context of long-term oncology care among cancer survivors. Because of the aging U.S. population and other factors, the past 30 years have seen a remarkable increase in the number of cancer survivors living post-treatment. The largest group of cancer survivors is breast cancer survivors (22 percent), followed by prostate cancer (20 percent). Rock discussed

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[1] The title of this chapter, as well as those of remaining chapters, is the same as the title of the workshop session being summarized (i.e., for this chapter, Session 1).

evidence linking diet and nutritional factors, obesity, and comorbidities (e.g., diabetes) to recurrence and survival; elaborated on several treatment-related nutritional problems that develop during the early phase of care and that sometimes continue and are endured throughout survivorship, such as changes in body composition, vasomotor symptoms in breast cancer survivors, and psychosocial problems; and described findings from nutrition intervention research in breast and prostate cancer survivors. The evidence she reviewed suggests that nutritional care may reduce the risk for cancer recurrence and progression. Rock cautioned, however, that while cancer survivors are an appropriate target for intervention because of their ability to make behavioral changes, they also present with special issues and concerns. Interventions used for the general population may be ineffective.

This chapter provides detailed summaries of both presentations and the discussion that followed.

NUTRITIONAL INTERVENTIONS AND ISSUES IN EARLY ONCOLOGY TREATMENT[2]

With 35 years of practice as a registered dietitian and a focus on head and neck cancer patients, Mary Platek expressed gratitude for the efforts that led to this workshop and passion for the topic of discussion. Back when she began practicing and was seeing patients in the intensive care unit, she always wondered how her patients did after sending them off. Then she became involved with conducting studies on outpatients at a comprehensive cancer center but still with a focus on early oncology care and, specifically, nutritional status of the outpatient. She noted that while much of what she would talk about relates to pediatric oncology, the focus would be on adult oncology patients, including adult patients undergoing radiation or chemotherapy; patients who have had surgery; patients who have been sent home and are being followed up in the clinic; and any combination of these situations. The patients who are at increased need of professional nutrition intervention, in her opinion, are those receiving multi-modal therapy.

Nutritional Status in the Outpatient

Nutritional status reflects how well a person's physiological nutrition needs are actually being met. Adequate nutritional status results from a balance between what an individual is taking in and what his or her requirements are, with many factors at play (e.g., digestion, absorption, excretion). With cancer, if an individual's needs are not being met, their nutritional

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[2] This section summarizes information and opinions presented by Mary Platek, Ph.D., M.S., RD, Roswell Park Cancer Institute, Buffalo, New York.

status is sometimes referred to as *malnutrition*, sometimes *under-nutrition*, and sometimes *cachexia*. Platek referred to Elaine Trujillo's earlier remarks on obesity and the number of patients with cancer who are obese. (See Chapter 1 for a summary of Trujillo's remarks.) Obesity in cancer is a difficult challenge to manage, Platek emphasized, especially when so many of those patients are experiencing sarcopenia (loss of muscle mass).

Registered dietitians use what is known as the Nutrition Care Process to identify nutritional status in the clinic. The first part of the process, Platek explained, is screening to identify patients at risk for a nutrition problem. Because people present in so many different ways, some patients may already have malnutrition. But for those who do not, if symptomology can be captured and dealt with early on, "We're really ahead of the ball game," Platek said, and the patient may never enter the realm of malnutrition or cachexia. One screening tool that has been well validated in the outpatient oncology setting is Patient Generated Subjective Global Assessment (PG-SGA) (Ottery, 1996; Vigano et al., 2014), which Platek explained involves a physical exam (conducted by a professional) and four boxes of questions (answered by the patient and then scored) to triage people into intervention. The questions pertain to nutritional intake, unintentional weight loss, and symptomology.

Screening initiates a nutritional assessment, Platek continued, which involves enlisting the help of a dietitian, collecting more information, and determining an intervention. The goal of the nutrition intervention is to remedy the nutrition problem, not the etiology. Nutritional interventions include everything from individualized nutrition counseling to finding out whether patients have enough food to eat when they go home to coordinating nutrition care within the hospital setting (i.e., among patients who are readmitted).

Until recently, Platek observed, much of the challenge to identifying nutritional status in the clinic was lack of consensus on definition. It is difficult to screen and identify something for which there is no consensus. Today, operational definitions exist for inadequate nutritional status in cancer patients, cancer-related malnutrition, and cancer cachexia. Today, the greater challenge in the outpatient cancer setting is nonstandardized screening. Screening is either not happening, according to Platek, or different tools, including tools that have not been validated, are being used. The lack of nonstandardized screening tools make for difficult comparative efforts and a lack of evidence-based nutrition care paths. An even greater challenge, in Platek's experience, is the lack of available nutrition services in the outpatient setting. In a 2012 survey of what were then 40 comprehensive cancer centers, Platek and colleagues found that the majority of respondents used referral or consult-based services (Platek et al., 2014). That can work very well, she said, when outpatient dietitians are available to meet the call. But when dietitians are not part of a multidisciplinary service and patients are referred instead, there is no assurance that patients actually receive that particular service.

Effect of Cancer on Nutritional Status

Cancer often results in some sort of nutrition imbalance at some point during treatment, recovery from treatment, and possibly beyond, Platek continued. The effects are either from the tumor itself, host response to the tumor, or other factors (e.g., stress, anxiety, or depression that make it difficult for people to focus on eating). The intensity of the nutrition consequence varies depending on the stage of cancer, where the cancer is and, importantly, according to the literature, whether treatment is multimodal (Dewys et al., 1980; Capra et al., 2001; Ravasco et al., 2003; Platek et al., 2011). Patients receiving surgery followed by radiation and chemotherapy are at very high risk, with up to 80 percent of patients receiving multimodal therapy experiencing unintentional weight loss and malnutrition. The majority of these patients, according to Platek, have head and neck, gastrointestinal (GI), lung, or any advanced cancer.

Platek emphasized the need to stage people correctly and to intervene before they reach cancer cachexia, a metabolic syndrome driven by a continuous decrease in food intake and abnormal metabolism and characterized by ongoing loss of skeletal muscle (Fearon et al., 2011). An estimated 50 to 80 percent of cancer patients are cachectic at some point during the continuum of care, according to Platek, and about 20 percent of the cancer patient population dies not from cancer but cachexia (Ryan et al., 2016).

Effect of Treatment on Nutritional Status

Now that improved definitive treatments are available and more people are surviving cancer, in addition to considering the effects of cancer itself on nutritional status, Platek considered the effects of cancer treatment on nutritional status. While surgery can increase the body's need for calories so the extra work necessary for healing can be done, it can also cause anorexia, poor appetite, delayed gastric emptying, early satiety, and other GI discomforts (e.g., nausea, vomiting, and diarrhea). Platek and colleagues advise patients, surgeons, and other members of health care teams that patients who have had surgery need to eat more calories and protein in particular. But it is difficult to target patients who need this advice, Platek observed, when there is no systemic protocol in place for nutrition interventions.

Treatment effects of radiation and chemotherapy can be "astronomical," Platek continued, with effects from radiation differing depending on where the radiation is focused. In her work with head and neck cancer patients, she deals with people with extreme mucositis, dry mouth, and poor appetite. Effects of chemotherapy include nausea, vomiting, taste changes, and food aversions, with patients often eliminating foods they need because of taste changes and aversions.

Compounding the challenge are the facts that not everyone who begins treatment is well nourished and that both cancer and treatment for cancer can aggravate preexisting nutrition problems. Many patients who have ignored their symptomology have already experienced a 10 percent or more unintentional weight loss. Platek remarked that patients often say their eating is fine and that it has not changed when really they have adapted to a new level of eating (e.g., soup becomes the "new normal," when before it was a full plate of all kinds of foods). In a survey of 1,200 outpatients at seven comprehensive cancer centers, with patients having been diagnosed with all types of different cancers at an average of about 9 months before the survey, Platek and colleagues found that most patients experienced some sort of symptomology and that fatigue was at the top of the list of symptoms (Coa et al., 2015) (see Figure 2-1). The most interesting finding, in Platek's opinion, was that symptoms were most likely to be reported among people who were losing weight unintentionally.

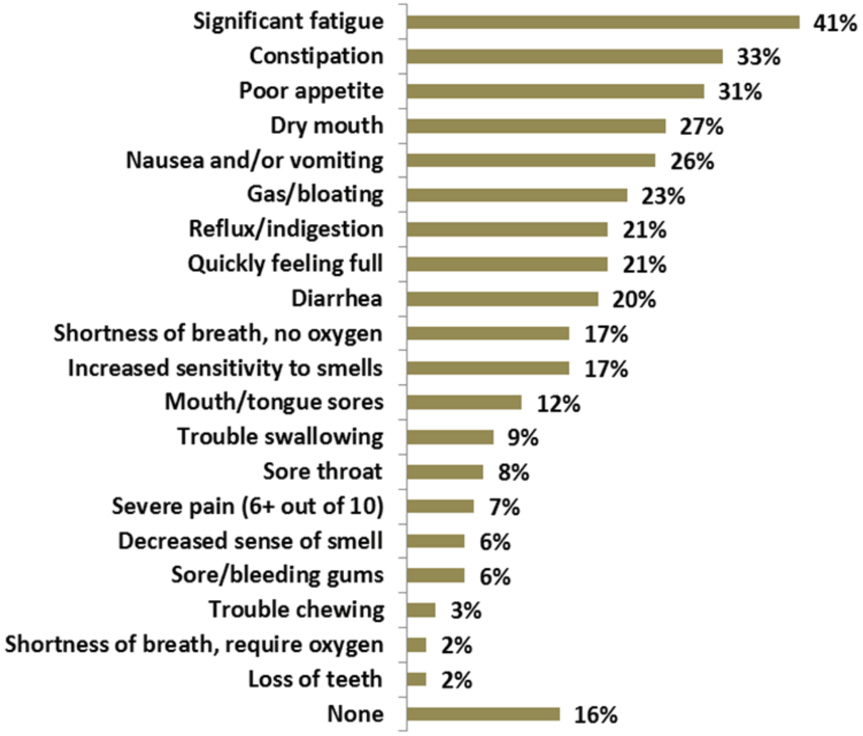
Effect of Nutritional Status on Treatment and Clinical Outcomes

Added to the effects of cancer and treatment on nutritional status are the effects of poor nutritional status on treatment. Poor nutritional status can have major effects on treatment. Platek listed several. They include decreased treatment response, increased treatment complications, and increased treatment toxicity (both with respect to the number of people experiencing toxicity and the intensity of toxicity). Altering or interrupting the treatment schedule or de-escalating the dose because of these effects has been associated with recurrence, increased hospital admissions or readmissions (because of infections), increased length of hospital stays, poor quality of life, and early mortality.

Malnutrition also affects drug metabolism. Patients who are malnourished have low albumin levels, which can make drugs more potent by increasing their availability to tissues. Platek explained that lower doses are often recommended for persons with low albumin to avoid poor seizure control, hemorrhage, and other side effects.

Nutrition Interventions in Early Oncology Care

Evidence for nutrition interventions in early oncology care is available from many resources, including the Academy of Nutrition and Dietetics' (AND's) Evidence Analysis Library (EAL) and *Oncology Evidence-Based Nutrition Practice Guideline* (AND, 2013), which Platek noted was based



Symptoms are most likely to occur among those …

- ☐ Losing weight unintentionally
- ☐ Consuming less food and beverages since beginning treatment
- ☐ Avoiding foods during treatment

FIGURE 2-1 Symptoms experienced by cancer patients during early treatment, based on a study of 1,200 outpatients at 7 comprehensive cancer centers.
SOURCES: Presented by Mary Platek on March 14, 2016; Coa et al., 2015.

on a systematic review and grading of the literature by a team of 45 professionals, as well as PubMed and Embase. Using these resources, Platek searched the literature as far back as 1980, which is when, she said, "We started talking about the skeleton in the closet." She found it very interesting to go that far back and trace the path forward and noticed a lot more randomized controlled trials (RCTs) and interventions in the more recent literature. She found a total of 653 papers published from 1980 to 2016, but reported during this workshop on overall results from only 36 of these plus 2 additional systematic reviews (all published between 2010 and 2016).

The majority of evidence in the 38 papers that Platek reviewed concerns patients with either upper or lower GI cancers or head and neck cancers, which in Platek's opinion, is the cancer population at highest risk for nutritional problems. Among the RCTs she examined, the comparisons were between interventions and controls. Among the prospective studies, the comparisons were between cohorts where an intervention was started versus cohorts where what was done before was still being done. In the retrospective studies, researchers either compared a population in a certain time period to an older population prior to an intervention change or compared results to what had been reported in the literature.

Of these 38 papers, 4 RCTs and 1 prospective study related to systematic individualized nutrition counseling. Overall, systematic individualized nutrition counseling was associated with improved weight, improved quality of life, improved nutritional intake, improved nutritional status and, with radiation therapy in particular, decreased toxicity (both reports and intensity of toxicity). Additionally, one of the systematic reviews (of head and neck cancer studies conducted up through January 2012) identified 4 of 10 RCTs that examined the effects of nutrition counseling versus either no counseling at all or counseling by a nurse (Langius et al., 2013). All four studies showed a positive association on nutritional status among those who received nutrition counseling. Three of the four demonstrated decreased weight loss among those who received nutrition counseling, and three demonstrated decreased incidence of malnutrition. Two of the four studies also assessed quality of life and showed a decline in global score (using the measurement of quality life) with nutritional counseling. Thus, Platek concluded, nutrition counseling is important.

But so is nutrition support, she continued. Nutrition support includes oral nutrition supplementation, enteral feeding, parenteral feeding, and other modes. Of the 38 papers she reviewed, 11 RCTs, 4 prospective studies, and 6 retrospective studies concerned nutrition support. Overall, the studies show that early nutrition support, that is, nutrition support that is provided before a patient reaches criteria for malnutrition, is associated with improved nutritional status, GI recovery, enhanced immune response (as reflected by biomarkers), improved quality of life, decreased length of hospital stay, decreased incidence of surgical complications, and decreased readmissions to the hospital.

When nutrition counseling and support are combined, as they were in one RCT, one prospective study, and two retrospective reviews (again, all from 2010-2016), overall effects included improved weight status, improved functional walking (improved performance status), improved recovery from surgery, improved quality of life, improved treatment tolerance, decreased postoperative complications, and decreased treatment toxicity to chemoradiation.

In addition to nutrition counseling and support, the literature on immune-enhancing nutrition (IEN) support is increasing as well, according to Platek, although she emphasized the importance of clearly defining what is meant by IEN. She defined IEN as formulas having at least two of the following: arginine, omega-3 fatty acids, glutamine, and ribonucleic acid. Of the 38 reviewed papers, she found 4 RCTs and 2 prospective studies on IEN support. Her review of these studies showed improved body weight and lean body mass, as well as improved performance status, with use of IEN support. These same studies also showed decreased inflammation, decreased length of hospital stay, decreased postoperative complications, and decreased incidence of infections. In a meta-analysis of 27 RCTs on the effects of different IEN support regimes among patients who underwent surgery for resectable GI malignancies, Song et al. (2015) found a decreased risk for infectious complications in all settings (i.e., preoperative, perioperative, postoperative), a decreased risk of non-infectious complications in the perioperative setting, and a decreased length of both perioperative and postoperative hospitalization. According to Platek, Song et al. (2015) concluded that IEN is a promising alternative to standard enteral care and that IEN is optimal for managing perioperative care. In addition to these studies, Platek continued, the EAL provides strong evidence (i.e., from 24 studies) for fish oil being associated with preservation of weight and lean body mass.

Summary

In summary, Platek emphasized that there is an established role for individualized dietary counseling. She said, “I don’t think we need to look at this again.” Likewise, although it is difficult to conduct RCTs on nutrition support, it is established that there is a role for nutrition support as well. Now, she said, “We need to have people do this.” She made a call for the use of nutrition support accompanied by education and counseling. Additionally, evidence is growing that supplements containing immune enhancers, such as fish oil, may play a role in certain settings.

Intervention is especially needed, Platek urged, when treatment is multimodal; the earlier the intervention, the better. She noted evidence in the EAL (from 20 studies) providing strong evidence for improvement of treatment outcomes in patients undergoing outpatient chemotherapy and/or radiation treatment with medical nutrition therapy.

Finally, she emphasized that registered dietitians are an integral part of the outpatient multidisciplinary healthcare team and that administrative support is needed to make this happen. She encouraged the development of validated screening and assessment tools; more follow-up after clinical nutrition interventions; continued use of predictive modeling; and development of evidence-based nutrition protocols.

NUTRITIONAL INTERVENTIONS AND ISSUES IN LONG-TERM ONCOLOGY CARE[3]

Cheryl Rock addressed many of the same nutrition care issues that Platek discussed, but in the context of long-term oncology care. In the United States, the most frequently diagnosed cancer in men is prostate cancer (29 percent in 2012, according to the American Cancer Society [ACS]), followed by lung cancer (14 percent), then colon and rectal cancer (9 percent). In women, the most frequently diagnosed type of cancer is breast cancer (29 percent in 2012), followed by lung cancer (14 percent), then colon and rectal cancer (9 percent). For both men and women, all cancers, even the less common types, can have significant nutritional effects, Rock noted.

Among cancer survivors, the largest percentage are women who have been diagnosed with breast cancer (22 percent), followed by men who have been diagnosed with prostate cancer (20 percent), then persons diagnosed with colorectal cancer (9 percent) (Mariotto et al., 2011) (see Figure 2-2). That the largest percentage of cancer survivors are women who have survived breast cancer explains, Rock said, why so much of the evidence for the cancer survivor population is based on breast cancer patients.

The past 30 years have seen a remarkable increase in the number of cancer survivors who are living post-treatment (Mariotto et al., 2011) (see Figure 2-3). Rock listed several reasons for this trend. First is the aging U.S. population. Given that cancer is very much a disease of aging, with a cancer diagnosis becoming more likely as one ages, the number of people in the United States who are potential cancer diagnosis cases has increased. It has been predicted that, by 2020, two-thirds of cancer survivors in the United States will be over the age of 65 years (Parry et al., 2011). Another reason for the growing number of cancer survivors is the availability of better screening approaches. The earlier a cancer is detected, the greater the likelihood of surviving treatment and becoming a long-term survivor. Although cancer screening is still not "great," Rock said, with many organizations supporting this workshop actively involved in promoting better cancer screening, screening has improved. A third factor is the availability of better initial treatments. It wasn't too long ago, Rock recalled, that many women with breast cancer were not diagnosed until their cancer was advanced and the only treatments available were surgery or cytotoxic chemotherapy. That is no longer the case, Rock said, "thanks to the war on cancer."

Today, more than 14.5 million persons in the United States are cancer survivors, Rock observed. Owing to early detection and treatment, 65 percent of Americans diagnosed with cancer now live more than 5 years. For

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[3] This section summarizes information and opinions presented by Cheryl Rock, Ph.D., RD, University of California, San Diego.

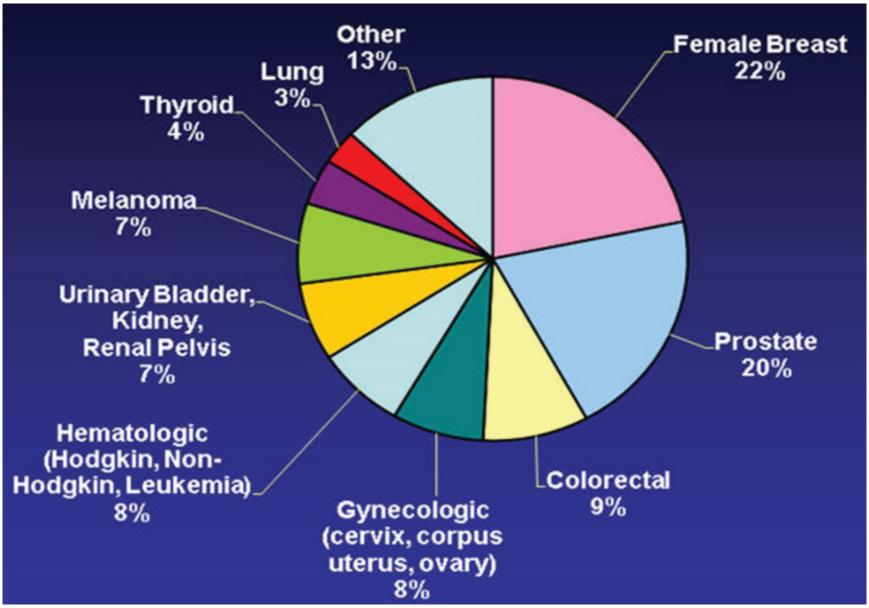

FIGURE 2-2 Persons alive in the United States who were diagnosed with cancer, distributed by site.
SOURCE: Presented by Cheryl Rock, on March 14, 2016 (adapted and reprinted with permission from de Moor et al., 2013).

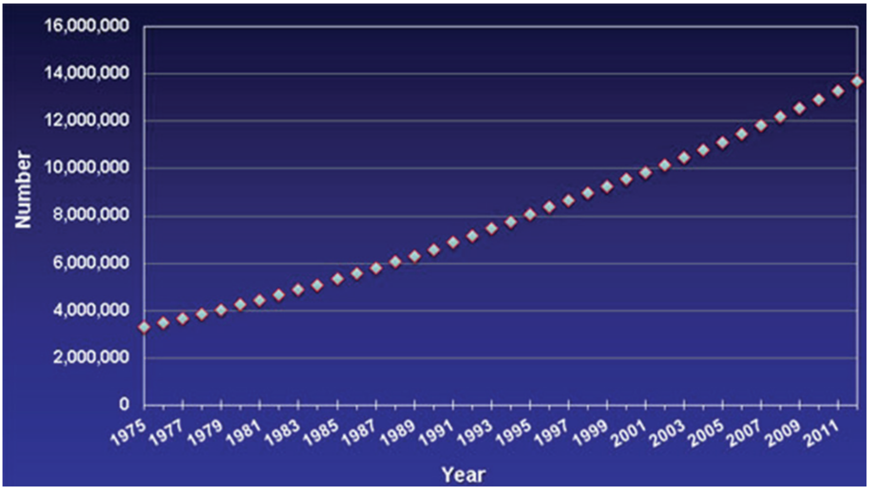

FIGURE 2-3 Estimated number of cancer survivors in the United States, 1975-2012.
SOURCE: Cheryl Rock, March 14, 2016 (modified from Parry et al., 2011).

lower-stage cancers, the percentages are even higher, with close to a 98 percent 5-year survival rate for early-stage breast cancer. Rock remarked that many younger people do not realize how common cancer is and how many people around them who appear to be living wonderfully healthy lives are in fact cancer survivors. Again, of those 14.5 million, a large percentage are over the age of 65 years, with breast cancer survivors being the largest group, followed by prostate cancer survivors and colorectal cancer survivors. Among all survivors, over 4.7 million received their diagnosis 10 or more years earlier.

Rock reiterated Platek's emphasis on the critical amount of evidence calling for early oncology nutrition care, but she explained that she would be focusing on long-term disease-free living. The ACS has delineated in its guidelines two goals for long-term disease-free living: (1) reduce the risk of cancer recurrence and progression, and (2) prevent and manage comorbidities. Because long-term cancer survivors are still at risk of dying from recurrent cancer or a second cancer, Rock identified palliative care as another important component of long-term care.

Diet, Recurrence, and Survival: The Evidence

Regarding available evidence indicating that diet and nutritional factors are related to recurrence and survival, first and, in Rock's opinion, of "critical" importance, very strong biological evidence from the laboratory setting suggests that nutritional factors are likely to influence cancer progression. In fact, she explained, cell culture studies by their very nature are more reflective of cancer progression than they are of risk. To make cells grow in culture, those cells have to be transformed. Otherwise, they would die. Thus, much of what scientists have learned about nutritional factors is highly relevant to cancer progression simply because of the nature of the cell culture model.

In addition to this biological evidence, epidemiological studies conducted over the past 2 decades suggest that many of the nutritional factors associated with risk for primary cancer also seem to affect survival after diagnosis. While this epidemiological evidence is cruder than what has been seen in the lab, it is consistent, Rock remarked.

Third, at least for breast cancer, studies have been conducted to determine whether diet interventions can actually modify recurrence and survival. Rock was aware of at least two other ongoing studies.[4]

Finally, evidence from observational studies is fairly consistent. That is, a healthy dietary pattern, which Rock described as one that provides

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[4] Rock discussed these studies toward the end of her talk; see the section titled "Nutrition Intervention Research in the Long-Term Oncology Population: Current Evidence."

vegetables, low-fat dairy foods, whole grains, tree nuts, olive oil, and fish and poultry rather than red meat, has been associated with lower risk for the most common cancers (i.e., breast, prostate, colon) and greater likelihood of survival after diagnosis. However, Rock pointed out, observational studies are confounded, which means that it might be that people who eat that way have had better treatment, for example, or there may be subtle differences in social support or demographic characteristics that explain the association. In Rock's opinion, although results from observational studies do not provide definitive evidence, they are good for generating hypotheses.

Obesity and Cancer

It has been known for many years, Rock continued, that obesity is related to risks for disease like diabetes and cardiovascular disease. Only over the past 15 years or so has evidence begun to emerge suggesting that obesity is probably the strongest nutritional factor related to not only cancer diagnosis, but also survival after diagnosis. An estimated 14 percent of all deaths from cancer in men and 20 percent of deaths from cancer in women are related to obesity. While it was expected that hormone-related cancers, namely breast and prostate cancer, would be related to obesity, because adipose tissue is basically an extra-gonadal source of hormones, the surprise, Rock said, was that mortality from many other types of cancers are also associated with obesity. Obesity and overweight have been associated with increased mortality from cancers of the esophagus, colon and rectum, liver, gallbladder, pancreas, kidney, and stomach, as well as non-Hodgkin's lymphoma and multiple myeloma.

In addition to its effects on survival after diagnosis, being lean and physically active appears to also be associated with fewer treatment-related problems during the initial treatment period (e.g., lymphedema with breast cancer, incontinence with prostate cancer, physical function with all cancers).

Thus, the effect of obesity begins during early treatment and extends through long-term survival. In a meta-analysis of more than 40 studies, while accounting for other influencing factors such as physical activity, demographic characteristics, and type of treatment, Protani et al. (2010) found that obesity was inversely associated with about a 30 percent increase in breast cancer–specific survival and also in overall survival among breast cancer survivors. This observed effect was apart from the fact that many women, about two-thirds, gain weight when they go through breast cancer treatment, according to Rock. The studies in the analysis were based on obesity (and body mass index [BMI] generally) at the moment of diagnosis.

Comorbidities

Comorbidities are a critical priority with respect to what needs to be accomplished with providing nutritional care to long-term cancer survivors, Rock continued. Again, cancer is a disease associated with aging, and over 80 percent of older adults have at least one comorbid condition, such as diabetes, cardiovascular disease, or hypertension, at the time of their cancer diagnosis, and 50 percent of older adults have more than two comorbidities at the time of diagnosis. With breast cancer in particular, more than 40 percent of survivors have other chronic comorbid conditions at the time of their cancer diagnosis, and developing new conditions post-diagnosis is common.

Comorbidities contribute to poorer long-term survival and increased overall mortality. Rock recalled studies she has been involved with where women who had diabetes when they were diagnosed with breast cancer were more likely to have an early death during the course of the study regardless of treatment. Also worth pointing out, Rock noted, post-menopausal breast cancer patients are far more likely to die from cardiovascular disease than from the effects of breast cancer. Additionally, having comorbidities while going through concomitant cancer treatments and dealing with the anxiety and stress of the treatments has been associated with poor physical and mental quality of life.

Treatment-Related Nutrition Problems

Rock discussed in detail several treatment-related nutrition problems that develop during the early phase of care and that sometimes continue and are endured throughout the entire cancer survivorship. First is evidence that treatment for cancer is associated with changes in body composition and metabolic consequences. Rock explained that when an active population suddenly becomes less active because they are ill or because they are going through treatment, which is especially true of older adults, the loss of physical activity that occurs during this period of time means that body composition changes. Changes in body composition include loss of lean body mass (i.e., sarcopenia) during initial treatments which, in the long run, have a big effect on energy balance. This is probably why certain groups of cancer survivors gain weight after they have gone through the initial treatment, Rock said. She explained that lean body mass is the primary determinant of resting energy expenditure which, in turn, is the main source of calorie expenditure. So a woman who might have a resting energy expenditure of 2,000 calories per day on the day of her diagnosis will have a substantially lower resting energy requirement after treatment because she will have lost so much lean muscle mass. Yet, she will probably have gained some adipose tissue during that time and, thus, weigh the same.

With less lean muscle mass and more adipose tissue, the ability to maintain weight by eating 2,000 calories per day becomes much more challenging. This change in body composition, Rock continued, is attributed mainly to reduced physical activity and, among pre-menopausal women, treatment-related ovarian failure. As a result of these changes, post-treatment weight gain is common in this population.

Another treatment-related problem with important nutrition implications is chemotherapy-induced peripheral neuropathy, which affects physical activity and function. This is particularly problematic for older adults who already have some gait instability.

Yet another treatment-related problem, one that has become a greater problem over the past decade or so, according to Rock, because of changes in cancer treatment, are bone health issues, especially for breast and prostate cancer patients. Many breast and prostate cancer patients are prescribed and benefit from either aromatase inhibitors or androgen deprivation therapy, respectively, both of which have effects on bone. Cytotoxic chemotherapy can also have direct effects on bone resorption and formation.

Several treatment-related problems are specific to the breast cancer population. One is vasomotor symptoms, which Rock described as hot flashes that develop as a result of hormonal therapies and the effects of treatment on ovarian function. They occur in 65 to 95 percent of patients and are much more severe than in the general population. She noted that, over her years of leading weight management interventions for breast cancer survivors, always at least half the women in the group sessions will have to fan themselves or open a window. Vasomotor symptoms are the type of thing that can affect not only quality of life, but also the ability to continue physical activity and make good diet choices. They are very disruptive, Rock said. They are not minor concerns.

In addition to vasomotor symptoms, another breast cancer treatment-related problem is lymphedema, which occurs in about 15 to 20 percent of breast cancer survivors. Rock noted that it is less common now than in the past because of differential diagnosis and sentinel lymph node biopsies, but it is still very common. A high BMI may increase the risk for lymphedema. Again, the physical discomfort can limit physical activity. Limited physical activity, in turn, affects energy balance, body composition and adiposity, and eventually recurrence.

Finally, arthralgias and myalgias, that is, joint and muscle pain, occur in more than 40 percent of women with breast cancer who are treated with chemotherapy and in up to 50 percent of women who are treated with aromatase inhibitors. According to Rock, these problems are more common in obese women and can contribute to reduced physical activity.

In addition to these numerous physical problems that can persist well beyond initial treatments, a substantial proportion of cancer survivors (20 to 30 percent) experience dysphoria, with depression and fatigue being the most common problems. Different studies define fatigue differently, with estimates of the prevalence of fatigue among cancer survivors ranging from 15 to 90 percent. Several mechanisms have been proposed to explain cancer-related fatigue, including neurotoxicity of the cancer treatments, chronic stress, inflammatory responses, and hormonal change. Rock noted that younger cancer survivors report greater psychosocial distress than older survivors.

Additionally, because cancer patients are a group for whom there has been a major life change, that is, the diagnosis of a life-threatening medical condition, many cancer survivors have a heightened awareness and concerns about foods. Because of these heightened concerns, Rock said, “You can’t just take [a nutrition intervention] that has some success in the general population and throw it into this population, this target group, and expect that it would be successful.”

Childhood cancer survivors represent a newly burgeoning population of long-term cancer survivors, with 5-year survival rates among this population now more than 80 percent. Yet, despite these fantastic 5-year survival rates, Rock remarked, survivors of acute lymphoblastic leukemia, the most common cancer diagnosed in children, have a life expectancy of only 54.7 years. All childhood cancer survivors are at increased risk of cardiovascular disease and are 10 times more likely to develop cardiovascular disease and 8 times more likely to die of heart failure during their first 30 years post-diagnosis. These long-term consequences of childhood cancer indicate potential benefit for nutrition intervention, in Rock’s opinion. There is a fair amount of evidence from observational studies that diet, low physical activity, and obesity all contribute to the very short life expectancy in this population compared to the general population.

GI and head and neck cancer patients represent another special population for whom nutrition intervention likely has potential benefit, given the enduring effects of surgery among these patients on dietary intake and nutrient absorption. Finally, cancer patients undergoing palliative care represent yet another special group for whom nutritional support and counseling may help patients to live as actively as possible and improve quality of life.

Rock ended her overview of nutritional issues related to long-term cancer care with a few remarks on dietary supplements. Evidence from a number of studies indicates that 64 to 81 percent of cancer survivors use dietary supplements. While the evidence further suggests that perhaps some supplements may be appropriate for patients with inadequate dietary intake, in the long run, if anything, supplements are unlikely to improve prognosis or overall survival and may actually increase mortality. There is also a potential risk for interactions between dietary supplements and prescription medications.

Nutrition Intervention Research in the Long-Term Oncology Population: Current Evidence

Rock was aware of only two completed randomized clinical trials on dietary intervention in breast cancer survivors. First, the Women's Intervention Nutrition Study enrolled approximately 2,500 postmenopausal women who had been diagnosed and treated for early stage (i.e., I, II, III) cancer (Chlebowski et al., 2006). The women were followed for 5 years, on average. The diet intervention aimed to reduce percent energy from fat to 15 percent, although the researchers went into the study expecting to be doing well if they were able to get people to consume less than 20 percent of their calories from fat. It was a complicated study, Rock explained, because the primary analysis indicated only a borderline significant effect on recurrence and no significant effect on survival. However, a secondary analysis among women with estrogen receptor (ER)-negative cancer, which was a little over one-third of the women, showed a significant benefit. The study was further complicated by the fact that the group targeted with the low-fat dietary intervention actually showed greater weight loss, which means that some of the benefits may have been due to weight loss, not the dietary intervention itself.

The second study, the Women's Healthy Eating and Living (WHEL) Study (Pierce et al., 2007), was not as complicated to interpret, Rock said. The study enrolled both premenopausal and postmenopausal women who had been diagnosed and treated for early-stage breast cancer and followed the women for about 7 years. The dietary intervention was not a weight loss intervention. In fact, the women were encouraged to maintain weight because weight change was viewed as a potentially confounding factor. The intervention emphasized a plant-based diet, with, on a daily basis, five vegetable servings plus 16 ounces of vegetable juice or equivalent, three fruit servings, 30 grams of fiber, and again a reduction in dietary fat intake (15 to 20 percent energy from fat). The dietary biomarkers that were measured in the study indicated very good adherence. The study revealed no differences in breast cancer recurrence or survival. Though, again, in a secondary analysis, which Rock noted is problematic from a scientific standpoint, but nonetheless interesting, the researchers found that women without hot flashes at enrollment (indicative of higher circulating estrogens) experienced a substantial reduction in their risk of breast cancer events (i.e., either recurrence or new primary breast cancer). Rock explained that a lot of dietary fiber in the diet can increase the gastrointestinal loss of estrogens, which may explain why this intervention was beneficial for that subgroup in particular. Higher estrogens in the blood are associated with a greater risk for breast cancer and greater likelihood of death from breast cancer. While not as difficult to interpret as the previous study, one notable complication is that women when enrolled in the study were already eating over seven servings of vegetables and fruits daily.

In addition to these two completed studies Rock mentioned two ongoing studies of effects of lifestyle (i.e., weight loss, diet, physical activity) on breast cancer outcomes: the SUCCESS C trial in Germany and the DIANA-5 study in Italy.

Numerous other studies, at least more numerous than in other areas of research in nutrition and cancer, have examined the effect of weight loss interventions on weight and selected biomarkers in overweight and obese breast cancer survivors. Upon reviewing the literature, Rock identified 13 RCTs that have done so and an additional five single-arm or other design studies. Rock recalled unease 20 years ago about recommending weight loss interventions in cancer survivors. These studies have shown overwhelmingly that achieving weight loss is not only feasible, but safe. The majority of the 13 RCTs identified by Rock showed greater than 5 percent weight loss as a result of the intervention.

The largest weight loss intervention study to date, according to Rock, is the ENERGY trial, a multi-state RCT of both pre- and post-menopausal women who were overweight or obese and who were diagnosed with stage I-III breast cancer between 6 months and 5 years earlier (i.e., women who had completed their initial treatments) (Rock et al., 2015). The intervention was an intensive 1 year of group cognitive behavioral therapy, supported by telephone or email contacts and newsletters. At 12 months, the average weight loss across all sites was 6 percent in the intervention group, compared to 1.5 percent in the control group (see Figure 2-4). The second year of the study involved very little contact with participants, so not unexpectedly, there was some recidivism, with many women regaining the weight they had lost during the first year. However, even at 24 months, many more women in the intervention group achieved clinically significant weight loss (i.e., 5-10 percent) compared to women in the control group (see Figure 2-4). There were also favorable effects of the intervention on physical activity and blood pressure.

There have also been a fair number of studies of interventions targeting prostate cancer survivors, Rock noted. She identified 12 small randomized controlled diet intervention studies among prostate cancer survivors that have examined various biochemical and quality-of-life outcomes. Additionally, she identified two larger studies that included not only prostate cancer survivors, but also either breast cancer survivors or breast cancer and colon cancer survivors. The first of these, the FRESH START study, enrolled more than 500 prostate and breast cancer survivors with early-stage disease (Demark-Wahnefried et al., 2003, 2007). Participants were randomized to having either tailored or standardized print material aimed at increasing exercise, increasing fruit and vegetable servings, decreasing saturated fat

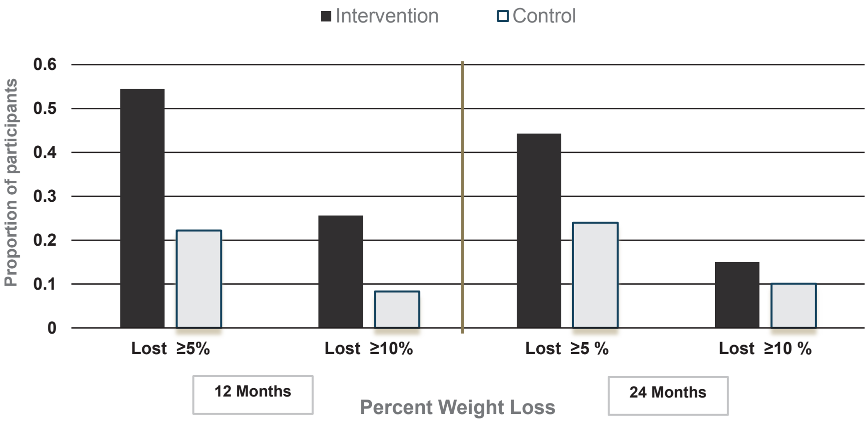

FIGURE 2-4 Proportion of study participants achieving a weight loss of more than 5 percent and more than 10 percent of initial weight at 12 and 24 months.
SOURCE: Presented by Cheryl Rock on March 14, 2016. Reprinted with permission. © 2016 American Society of Clinical Oncology. All rights reserved.

intakes, and maintaining a BMI less than 25. Results indicated that the intervention resulted in increased fruit and vegetable servings and decreased saturated fat intakes, compared to the control group. The second study, the Reach Out to ENhancE Wellness in Older Survivors (RENEW) study, enrolled 641 prostate, colorectal, or breast cancer survivors, most over the age of 65 years. The intervention was an 18-month mailed material/telephone counseling program. Results indicated an association between the intervention and improved physical functioning, improved strength and endurance, improved diet quality, and a modest reduction in BMI (Morey et al., 2009).

Rock found only one dietary intervention weight loss study among childhood cancer survivors (Huang et al., 2014), but she did find several physical activity intervention studies that have either been completed or are underway. The goal of these physical activity interventions is to stop sedentary behavior before it becomes habituated. Overall, the results have been modest, Rock said.

Conclusions, Considerations, and Challenges

In closing, first, Rock repeated that cancer survivors present with special issues and concerns. She cautioned against using interventions developed for the general population. Not only would doing so be inappropriate, but the interventions probably would not be effective. Involvement of an oncology nutrition dietitian who is knowledgeable about the special issues and concerns of cancer survivors greatly increases the likelihood of provision of appropriate care. Rock emphasized her choice of the word *involvement*. She said that the person knowledgeable about the nutritional needs of cancer survivors does not necessarily have to be the person who provides the care, but he or she should play an important role in overseeing and monitoring these particular interventions. Second, Rock emphasized how the evidence suggests that nutritional care may reduce the risk for cancer recurrence and progression and should help prevent and manage comorbidities. Finally, she remarked that studies conducted to date suggest that cancer survivors are an appropriate target for interventions because they are able to make behavioral changes.

PANEL DISCUSSION WITH SPEAKERS: DATA GAPS IN CURRENT NUTRITION PRACTICE IN ONCOLOGY OUTPATIENT CARE

Following Rock's presentation, she, Platek, and Clinton answered questions from the audience on a wide range of topics related to the current knowledge and status of nutrition practices in oncology outpatient care (see Chapter 1 for a summary of Clinton's keynote presentation). This section summarizes the discussion that took place.

Educating Oncology Clinicians About Cancer-Related Nutrition Issues

Ann Fonfa mentioned having attended the American Society for Clinical Oncology (ASCO) meeting on survivorship in January 2016 and heard *nutrition* mentioned only three times, twice by board members of her organization while asking questions and once by a speaker. "We need to involve the actual practitioners in this," she said. Later during the discussion, Suzanne Dixon added that she had experienced something similar at an obesity workshop at ASCO. "I think we have our work cut out for us in that regard," she said.

Clinton was disappointed to hear of Fonfa's experience, but remarked that at least ASCO has a survivorship program and clinicians are participating in it. In his opinion, part of why there is not more nutrition representation in ASCO, a professional organization that represents clinical oncology, is that very few medical oncologists are actually trained in nutrition. He expressed hope that, with time, ASCO's new involvement in survivorship will bring more nutrition expertise into play. He mentioned that the society had recently issued an announcement that anyone who wanted to serve on a committee could volunteer. He himself has volunteered and said he was looking forward to helping.

Rock agreed that very few oncologists are trained in nutrition. Rather, their extensive specialist knowledge is in drugs, treatment complications, and related issues. She suggested that oncology nutrition specialists help to educate oncologists about nutrition problems. She mentioned the number of women who have participated in her interventions and research projects and then go back to their clinicians and mention having experienced a little bit of leg pain because they have been walking 4 miles every day. But their oncologists immediately think the pain is related to the cancer. Or, participants in weight loss interventions go back to their physician having lost 20 pounds, and the physicians "freak out" because they cannot imagine it was voluntary, not involuntary, weight loss, and they order more scans, which triggers anxiety in the patients, which makes it difficult for the patients to maintain the behavior changes that enabled them to lose the weight. It is not just the oncologists, but families too, Rock said, that react to a survivor's weight loss or change in behavior. Too often they think, "Oh, no, the cancer's back." It used to be that unexplained weight loss was one of the "seven signs of cancer." That mentality has persisted, Rock said. She remarked that, while nutrition education at the undergraduate level has expanded, nutrition education efforts should also be targeting the clinical setting.

"Everything always starts with education," Platek agreed. The more you know, the better your decisions will be, and the better care your patient will receive. She reiterated the importance of registered dietitians having conversations with medical and radiation oncologists and others so that the clinicians know what to be concerned about and also what to not be concerned about (e.g., weight loss through survivorship). But in order for the oncologists to gain this knowledge, the registered dietitian, Platek said, needs to be "brought to the table."

There was a brief discussion about how, among physicians, sometimes a little bit of nutrition knowledge goes a long way, but, as Rock said, often the wrong way. The discussion was prompted by a question from an audience member about all the "hype" in the media about soy and breast cancer and the controversy around the relation between soy and breast cancer. Rock found it interesting that this controversy exists given the overwhelming evidence indicating that there is no reason to be concerned with soy. In fact, she said, epidemiological evidence suggests that, if anything, soy is helpful. Another source of the problem, Rock continued, is physicians knowing too little. She noted that the next batch of ACS guidelines for survivors would be addressing soy to a greater extent than in the past.

Educating the Public About Cancer-Related Nutrition Issues

An audience member who identified herself as an oncology dietitian working "in the trenches" has been trying to encourage women who are diagnosed with breast cancer to meet with her before surgery. Many of these women are overweight, the audience member said. Moreover, many come to see her once but then never return even though she offers a free service (e.g., to help them lose weight to prevent recurrence). She asked, "Why are these women not coming to see a dietitian when it's even a free service?" Rock responded that, again, the challenge is education, in this case, education of the public. She credited organizations such as the ACS for communicating to the public about the importance of nutrition, diet, and weight control for cancer patients.

Fonfa, speaking as both an advocate and patient, suggested that weight loss not be presented as weight loss. Rather, it should be presented as nutrition. The focus is on health, not weight loss. That opens the door, she said, without "attack" and in a way that will not trigger a reaction during what is a very sensitive time. Additionally, Fonfa suggested that, in the beginning, rather than one-on-one education, the focus should be on group discussions.

Rock agreed that the message should be "healthy lifestyle," not "weight loss." However, in response to Fonfa's suggestion that initial education efforts be group discussions, Rock said she finds the one-on-one visits with patients very empowering. There are so many things about cancer that you cannot do anything about, but lifestyle is something that is modifiable, she stated.

Clinton identified a need for research on how to optimally integrate patient education about nutrition into the process of cancer care. While it is easy to wonder why women are not taking advantage of such a wonderful opportunity, he said, "You have to look at what is going on in many of these people's lives." These women are often working, taking care of their families, and doing all sorts of other things that do not immediately get turned off when they get their diagnosis. It is very difficult for someone to look ahead when she is worried about how she is going to get through the next few weeks of chemotherapy, hormone therapy, radiation, and surgery. He encouraged more thinking about the optimal time to intervene. "We may all think it should be day 1," he said, "but that may not always be the most practical point." In his opinion, the most important time for long-term nutrition intervention is when the really intense therapy begins to wind down.

Another audience member, self-described as an "in-the-trenches" outpatient oncology dietitian of 33 years, suggested that dietitians be part of the survivorship plans that the Commission on Cancer is beginning to implement. In her experience, many patients are so overwhelmed at the onset that they are just grappling with "the C word" and trying to get through treatment. She agreed with Clinton that the perfect time for intervention might be when they are done with treatment and are asking, "Now what?"

Suzanne Dixon brought the discussion back to education of the clinician. She suggested that providers mentioning to their patients the importance of nutrition and physical activity to survivorship would go a long way toward motivating patients to take care of themselves. Though providers would need to be trained on how to approach their patients with that information, she added.

Data Gaps

Toward the end of her presentation, Platek had emphasized the need to implement what has been learned from research already conducted rather than conduct more research. Recognizing that need, an audience member asked what research gaps still exist. Platek called for more work on standardized nutrition screening, at least in head and neck cancers, which she noted was her area of expertise. She also called for more validation of prognostic indicators and entering of that information into predictive modeling so a person's risk can be determined. Cancers have definitive treatments—everyone knows the stage, the site, and the comorbidities. In her opinion, the same work needs to be done with nutrition so particular treatments can be applied to prevent poor nutritional status and better outcomes. Risk needs to be modeled and nutrition care paths developed and compared.

Immune-Enhancing Nutrition Support

Also during her presentation, Platek had reviewed evidence on the effects of immune-enhancing nutrition (IEN) support. A webcast participant asked for a better definition of IEN. Platek explained that, in the studies she reviewed, IEN was defined as such if it contained at least two of following items: arginine, omega-3 fatty acid, ribonucleic acid, or glutamine. Clinton remarked that he does not like the term. It is too vague and nonspecific, in his opinion. The immune system and its role in cancer is complex. He asked, "What does *immune enhancing* mean when it is many components working in concert and beautifully orchestrated?" He called for more careful and precise use of language and encouraged consumers to be very conscious about products being marketed with such a vague and nonspecific name. An omega-3 supplement is omega-3. An arginine supplement is arginine. Marian Neuhauser agreed with Clinton and suggested being more specific about which supplements and doses were tested when communicating findings from those studies. Clinton added that the problem begins when vague terminology enters the literature early on—it becomes self-perpetuating. He compared the use of "immune-enhancing nutrition support" to the struggle with "anti-oxidant." "What are we talking about, and what does it mean?" he asked. Platek concurred with Clinton and reiterated that the way she presented the information is the way it is presented in the literature.

3

Models of Care: National and International Perspectives

OVERVIEW

Moderated by Kim Robien, Session 2 panelists discussed several models of care in oncology nutrition from around the world. First, Rhone Levin focused on U.S. models of care, with one of the most common ways for cancer patients to access oncology nutrition services being via a hospital inpatient registered dietitian or nutritionist (RD/RDN). Given that inpatient dietitians are often assigned multiple floors and working on very tight schedules, "pulling" them to help with outpatient care creates what Levin described as a "very negative situation" for everyone involved—the dietitians, doctors, and patients. Other hospital-based models of care being implemented in the United States include referrals to outpatient dietitians, outpatient services with dedicated nutrition staff, and outpatient clinics with embedded nutritionists. Levin discussed the challenges associated with each of these models of care and several other, non-hospital-based models of care.

More generally, Levin also discussed the goals of oncology nutrition, with a major goal being to increase patients' tolerance of their prescribed treatments; described evidence showing the value of nutrition services for oncology outpatients; and called for the need to develop what she called a "culture of nutrition" among all cancer care staff.

Liz Isenring shifted the focus of discussion to international models of care and described several different, mostly hospital-based care pathways being implemented in Australia, one example from Europe, and one example from Canada. She emphasized nutrition screening as a key component of any outpatient oncology nutrition care pathways. For her, a key message from this workshop was the importance of evidence-based, validated nutrition screening tools. Such tools can be used not only to identify oncology patients at high risk who would benefit from nutrition treatment but also for monitoring. Isenring also emphasized the important role of evidence in the development of care pathways and stated that the first step to developing a model of care is to conduct a thorough literature search. "Being aware of the evidence is always the first step," she said. But it is not the only step. The next step is collaborative critique of the evidence, with all stakeholders involved. Based on her experience, when the entire care team feels responsible for developing a care pathway, then the entire team is likely to ensure the pathway is implemented and that nutrition is on the agenda.

Following these two presentations, Diana Dyer provided a personal perspective on oncology nutrition care based on her experience as both a provider and a patient. This chapter summarizes both presentations, Dyer's perspective, and the brief panel discussion that occurred after Dyer spoke.

MODELS OF NUTRITION CARE IN OUTPATIENT ONCOLOGY IN THE UNITED STATES AND BARRIERS TO ACHIEVING IDEAL CARE[1]

When she began her oncology practice, Rhone Levin recalled, a common paradigm was that malnutrition was an inevitable consequence of having cancer and going through cancer treatment. But based on evidence collected since then, such as that included in the Academy of Nutrition and Dietetics' (AND's) Evidence Analysis Library (EAL), Levin said, "we know now that that is an outdated paradigm." It is time to move past that way of thinking, in her opinion, and find what works for patients more effectively. That being the case, Levin said, "Malnutrition happens." While it happens more frequently in certain diagnoses, notably gastrointestinal (GI) tract, pancreatic, and head and neck cancers, it also happens in patients with late stage diseases of other cancer diagnoses (Kubrak et al., 2010).

The Goals of Oncology Nutrition

Whereas mild and moderate nutritional deficiencies in cancer patients are potentially reversible, severe nutritional deficiencies are often not (Van Cutsem and Arends, 2005). Thus, malnutrition in cancer patients needs to be addressed before it progresses, Levin emphasized. The conversation needs to happen not just with oncology staff but also with patients. It is not uncommon, Levin observed, for an oncology dietitian to meet with a

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[1] This section summarizes information and opinions presented by Rhone Levin, M.Ed., RD, CSO, LD, Dell Children's Medical Center, Austin, Texas.

patient who is new to oncology treatment and experiencing a decline in their nutritional status and who expresses to the physician what Levin said she could "almost describe as joy" that they are losing weight. Even many clinicians do not understand that weight loss in high-risk cancer patients can create an irreversible situation.

Malnourished patients may not be able to tolerate treatment, which means they may not be able to receive treatment. And while it may be difficult to stratify nutrition with respect to how it affects outcomes, including mortality from cancer treatment, it is easy to show that people who receive less treatment are less likely to be cured of their cancer or have their cancer controlled, according to Levin (Lammersfield et al., 2003; Fearon et al., 2006). In fact, any treatment hold or break potentially affects a patient's ability to control or cure his or her cancer. According to Levin, some literature suggests that every day of treatment hold for head and neck cancer treatment decreases the effectiveness of the treatment by about 1 percent. So losing 1 week of treatment, for example, potentially decreases someone's chance of cure or control by more than 5 percent. Given that many head and neck cancer patients start with only a 15 percent chance of cure or control, that loss is significant. With chemotherapy, guidelines suggest that patients need about 85 percent of their original prescribed dosages to achieve the best control. Thus, the overarching goal of oncology nutrition is to tolerate prescribed treatment, or, as Levin put it, "no break, no delays, no dose reductions."

Levin identified several specific goals: early identification of pre-cachexia or cachexia states, early identification of involuntary weight loss, early identification of etiology-based malnutrition characteristics, and aggressive responses to nutrition impact symptoms to protect both quality of life and the treatment plan.

Data collected from the Cancer Nutrition Research Consortium on the incidence of nutrition impact symptoms in 2012 reveal a lengthy list of symptoms:

- fatigue (41 percent),
- constipation (33 percent),
- anorexia (31-80 percent),
- xerostomia (15-25 percent),
- nausea (26 percent),
- emesis (35 percent),
- gas/bloating (13 percent),
- reflux/indigestion (21 percent),
- early satiety (21 percent),
- diarrhea (14 percent),
- shortness of breath (17 percent),

- bothered by smells (48 percent),
- taste alteration (62 percent),
- mucositis (22-75 percent),
- dysphagia/swallowing (6 percent),
- dysphagia/chewing (3 percent),
- severe pain (7 percent), and
- decreased smell (6 percent).

Levin emphasized that not only do multiple symptoms often occur at the same time, but they also present in complex ways. One of the examples she likes to share with staff members who are training is that a natural instinct for managing diarrhea is to stop eating and to only drink clear liquids for a day or two, believing that decreasing stimulation to the GI tract will settle it down. But what do you do with a cancer patient who experiences 5 weeks of diarrhea? Managing these symptoms, she said, is "something beyond which a usual experience or a usual life experience would prepare you for."

U.S. Recognition of the Role of Nutrition Services in Oncology Treatment

Several U.S. agencies recognize the role of nutrition in oncology treatment, including the the American Cancer Society (ACS), American College of Surgeons' Commission on Cancer, American Society of Clinical Oncology (limited to certain diagnoses and survivorship), American Society of Parenteral and Enteral Nutrition, the AND, Association of Community of Cancer Centers, National Cancer Institute (NCI), National Comprehensive Cancer Network, National Institute for Health and Care Excellence, and Oncology Nursing Society. However, while widely recognized as being an important part of treatment, the specific role of nutrition in treatment remains very ambiguous, Levin observed.

A key difference between the United States and several other countries is the lack of U.S. guidelines that either require or recommend a frequency of interaction with or even access to oncology nutrition services. Levin remarked that it is very much up to individual facilities to decide what and how often patients have access to dietitians.

Updated Evidence from the Field of Oncology Nutrition

Having served on the EAL oncology nutrition 2013 update group, Levin explained that the workgroup was instructed to answer or update only 11 of what had been around 80 to 90 questions or topics in the 2007 library. Being restricted to 11 questions created a flurry of discussion, with different opinions about how to prioritize the topics. They ended up choosing their questions based on which information or evidence would best demonstrate the value of oncology nutrition service. The majority of evidence in the 2007 library was rated as Grade III ("limited number of studies"), compared to the majority of evidence in the 2013 library being rated as Grade I ("good—the evidence consists of results from studies of strong design for answering the question addressed").

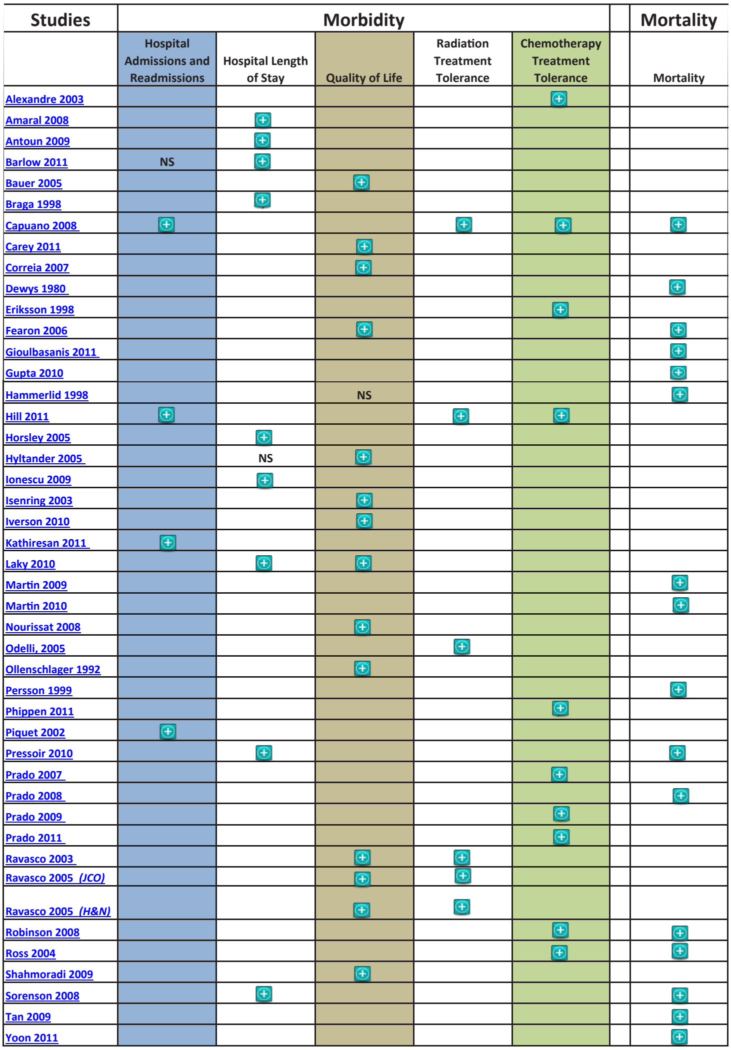
To help formulate their answers, the workforce put together a chart of nutrition outcomes data based on 45 studies demonstrating the effectiveness of medical nutrition therapy in reducing or preventing hospital admissions and readmissions, reducing hospital length of stay, improving quality of life, improving radiation treatment tolerance, improving chemotherapy treatment tolerance, and reducing mortality (see Figure 3-1). While the chart was created for use by the workgroup, Levin suggested that it might also be useful after this workshop to move the discussion forward with people outside the nutrition world.

Models of Care in the United States

One of the most common ways for cancer patients in the United States to access oncology nutrition services, Levin continued, is via a hospital inpatient RD/RDN who often is assigned multiple floors and working on a very tight schedule. Inpatient staff members are often "pulled" to cover outpatient oncology needs on an ad hoc basis, creating a negative cycle where the physician knows it is difficult to pull the dietitian and will therefore wait until they are sure they need one. But by that point, patients are often severely malnourished and in acute or crisis situations. Thus, a dietitian who is already short on time is faced with what Levin described as a "crash-and-burn consult," which is not only time consuming for the dietitian but often not effective or not as effective as it would have been earlier in the process. From the patient perspective, again, severe malnutrition may be irreversible. In sum, Levin said, "The patient is losing, the facility is losing, the physician is losing, the dietitian is losing. It's just a very negative situation."

A second option is referral to a hospital-based outpatient registered dietitian. The challenge with this model, according to Levin, is that patients often see the outpatient dietitian only once. Moreover, most patients who see outpatient dietitians or nutritionists are self-selected patients with the ability to pay. Medicare does not cover oncology nutrition outpatient services, and many insurance plans either do not cover or only partially cover such services.

A third and "better" option, based on Levin's experience, is for hospital outpatient oncology services to have a dedicated nutrition staff. The problem with this level of care, Levin explained, is that it is often limited



Studies	**Morbidity**					**Mortality**
	Hospital Admissions and Readmissions	Hospital Length of Stay	Quality of Life	Radiation Treatment Tolerance	Chemotherapy Treatment Tolerance	Mortality
Alexandre 2003					⊕	
Amaral 2008		⊕				
Antoun 2009		⊕				
Barlow 2011	NS	⊕				
Bauer 2005			⊕			
Braga 1998		⊕				
Capuano 2008	⊕			⊕	⊕	⊕
Carey 2011			⊕			
Correia 2007			⊕			
Dewys 1980						⊕
Eriksson 1998					⊕	
Fearon 2006			⊕			⊕
Gioulbasanis 2011						⊕
Gupta 2010						⊕
Hammerlid 1998			NS			⊕
Hill 2011	⊕			⊕	⊕	
Horsley 2005		⊕				
Hyltander 2005		NS	⊕			
Ionescu 2009		⊕				
Isenring 2003			⊕			
Iverson 2010			⊕			
Kathiresan 2011	⊕					
Laky 2010		⊕	⊕			
Martin 2009						⊕
Martin 2010						⊕
Nourissat 2008			⊕			
Odelli, 2005				⊕		
Ollenschlager 1992			⊕			
Persson 1999						⊕
Phippen 2011					⊕	
Piquet 2002	⊕					
Pressoir 2010		⊕				⊕
Prado 2007					⊕	
Prado 2008						⊕
Prado 2009					⊕	
Prado 2011					⊕	
Ravasco 2003			⊕	⊕		
Ravasco 2005 *(JCO)*			⊕	⊕		
Ravasco 2005 *(H&N)*			⊕	⊕		
Robinson 2008					⊕	⊕
Ross 2004					⊕	⊕
Shahmoradi 2009			⊕			
Sorenson 2008		⊕				⊕
Tan 2009						⊕
Yoon 2011						⊕

KEY
NS = Nonsignificant effect on outcome.
⊕= Positive effect on outcome.
There were no negative effects on outcome.

FIGURE 3-1 Chart from the Academy of Nutrition and Dietetics' 2013 Evidence Analysis Library summarizing studies that document relationships between nutrition status and morbidity and mortality in adult oncology patients.
NOTE: H&N = head and neck; JCO = *Journal of Clinical Oncology*.
SOURCES: Mary Platek, March 14, 2016. © American Academy of Dietetics, *Relationship Between Nutrition Status and Morbidity Outcomes and Mortality in Adult Oncology Patients*. http://www.andeal.org/files/Docs/ON%20Nutrition%Status%20and%20Outcomes_%2007022013.pdf, copyright 2013, Academy of Nutrition and Dietetics, Evidence Analysis Library. Accessed August 8, 2016.

to a certain day of the week, which means the nutritionist sees only those patients who come in on that day. Also, these services are limited in terms of the amount of time available to care for cancer patients. Levin mentioned a new dietitian recently assigned to an outpatient oncology clinic who reached out to the AND's Oncology Nutrition Dietetic Practice Group (ONDPG) listserv, which has about 1,500 members, asking for advice on how to proceed and indicating in her email that she was "desperate." That desperate feeling, Levin said, is a very common feeling among oncology dietitians—not just because you cannot see everyone, but because you cannot see everyone who needs to be seen. People who are turned away, she said, end up turning to the internet, their neighbor, or the health food store for relief.

The last and "best" hospital-based option, in Levin's opinion, is to have nutrition staff embedded within the outpatient oncology clinic. But even in that situation, she said, there are no validated reliable benchmarking data regarding what constitutes an adequate full-time equivalent (FTE) for outpatient oncology nutrition. The recent National Hospital Oncology Benchmark Study found that 24 percent of the 58 infusion and 37 radiation facilities that responded to the questionnaire indicated they had nutritionists on staff. Still, it is unclear how many nutritionists are on staff at those facilities and whether the FTE numbers are adequate. At a facility where Levin used to work, the multidisciplinary care staff included an oncology dietitian. Funded by a National Comprehensive Cancer Control Program grant, the center saw what Levin described as "the most complex" patients. Based on a survey published in the *Journal of Supportive Oncology*, referrals to the clinic included nutrition-related diagnoses such as weight loss and nausea (Mancini, 2012). The most frequent interventions, exceeding all other interventions required, were nutrition interventions. For Levin, these data indicate that when a dietitian is present at the right time and in the right setting, nutrition interventions are the most frequent intervention required for patient care.

In addition to these various hospital-based models of care, there are a range of non-hospital-based models of care in the United States. These include specialty infusion companies that may have dietitians on staff who provide consultation for patients receiving tube feeding or total parenteral nutrition; and for-profit free-standing oncology centers that provide either radiation and/or chemotherapy but for which there are no standards regarding what is required or available for oncology care. A third non-hospital based model of care is the private practice registered dietitian or nutritionist. The question with this model of care, Levin pointed out, is whether these individuals have resources available to them, including patient information from the patient charts or from the centers where patients are receiving treatment. Lastly, many patients turn to alternative medicine providers.

Another U.S. model of care is nursing-based nutrition care. Given that nutrition is part of the scope of practice for nurses, it is appropriate for nurses to be able to handle and intervene in some of the early nutrition issues that come up for patients, Levin said. However, given that nurses are on a minute-by-minute, procedure-by-procedure schedule, they face many time constraints and tend to get drawn into focusing on medication management.

Other nutrition care venues available to patients include online resources provided by government, academic, and voluntary health organizations (e.g., ACS, NCI), which allow patients to treat themselves via links to symptom management materials. Often, Levin said, these are the only resources available to patients.

Finally, one of the newer models of care is what Levin called "fee-for-service." The idea, she explained, is that through your smart phone you can "hire a dietitian in your pocket." But this model of care raises questions about whether patients have the ability to pay out of pocket and whether smart phone technology can replace informed medical care. What is the credibility of these resources? Are they safe? Are they appropriate for complicated oncology patients?

Data on Nutrition Care for Cancer Patients

Colleen Gill at the University of Colorado conducted surveys of 56 NCI centers in 2011 and 2013 on dietitian FTE compared to patient numbers. Responding centers (28 in 2011, 23 in 2013) reported, on average, a little more than 3 fulltime dietitians per 5,000-6,000 patients. Clearly what happens in these situations, Levin said, is that only the very highest risk patients receive care.

In an online survey that Levin conducted with the ONDPG listserv, about half of the 177 clinics that responded reported using a validated malnutrition screening tool. Levin stated that use of such a tool is tremendously important, as it is what identifies the presence of malnutrition. It is unclear and a good follow-up question, in Levin's opinion, to ask whether those clinics that use the tool are using it repeatedly throughout treatment. If the tool is applied the moment a patient walks into the clinic, before he or she has started treatment, there might not be any indication of malnutrition. But that doesn't mean the patient will not be malnourished 1 week, 3 weeks, 6 weeks, or 32 weeks later. "We have to be repeating those processes," Levin said.

In the same survey, when asked whether dietitians bill for their services, more than 80 percent of respondents reported they do not. Levin interpreted those results to mean "We are dependent on the good graces of the administration to hire and to staff the dietitians adequately." When asked to provide their opinions on whether their clinics have adequate oncology nutrition FTE to provide for their patient needs, the overwhelming response was "no." When asked about perceived barriers to achieving ideal oncology nutrition care, most responses related to staffing, funding, and that dietitians are usually consulted only after malnutrition has already occurred. Levin remarked that these were the responses she was expecting. Still, it was interesting for her to hear from the ONDPG group.

One thing often reported in the literature, Levin observed, is that there are certified specialists in oncology nutrition "out there." But typically when you use the "click here" link on a website "to find a board Certified Specialist in Oncology Nutrition," most dietitians listed actually work at particular cancer treatment centers, and are not available to see patients outside those facilities. Thus, these links do not work for the thousands and thousands of patients receiving their care at one of the 75 percent of facilities without dietitians on staff, raising the question, how can access to board certified oncology dietitians be created? The answer, Levin suspected, will probably lead in the direction of requiring facilities to have some sort of specialist available. It is a question that needs to be addressed, she urged, because, without access, who is providing nutrition advice (a store clerk? the Internet?) and at what cost? Imagine you are a patient or the parent of an 8-year-old patient, she suggested, and you are desperate for information and you do not have access to a dietitian. So you go to the Internet. These are the kind of titles you will come across: "Reversing Cancer: A Journey from Cancer to Cure," "The Cure of Advanced Cancer: A Summary of 30 Years of Clinical Experimentation," "Nutritional Healing from Cancer: The Fundamentals of an Alkaline Diet," "Take a Crash Course on 'What Is Alternative Therapy?'," "Alternative Cancer Therapies Available: Click Here," "Read Stories of People Who Have Overcome Cancer," "Choose an Alternative Doctor or Clinic: Click Here," "Cure Cancer Now: Clear Out Negative Attitudes and Influences," and "Fire Your Doctor: Health Truths." This list, in Levin's opinion, "ought to horrify just about most of you." It is not just the out-of-pocket financial cost to the patients, Levin said, but potential reduced efficacy of cancer treatment (which is a huge expense), ultimately creating a burden to society because of a lack of patient access to evidence-based nutrition.

Beyond the basic nutrition care that is fundamental to healing among all cancer patients, Levin identified several areas of special interest where what she described as "mounting" evidence indicates that access to adequate oncology nutrition services would make a difference: nutrition in pediatric oncology treatment, nutrition for pediatric survivorship, nutrition for sarcopenic obesity and sarcopenic weight loss, nutrition for cachexia and pre-cachexia, nutrition for adult survivorship, nutrition for the prevention of primary and secondary cancers, and oral chemotherapy medication interactions with food and nutrients (Prado et al., 2013).

Developing a Culture of Nutrition

In closing, Levin asked, what is an ideal situation for oncology nutrition care in the United States? She repeated the need to train and develop dedicated nutrition staff and emphasized the need to develop what she called a "culture of nutrition" among all cancer care staff, from physicians to radiation therapists, so that everyone is providing surveillance for malnutrition. She also emphasized the importance of using validated malnutrition screening tools on a routine basis in all cancer centers. Additionally, she called for all cancer centers to implement evidence-based medical nutrition therapy and provide ongoing monitoring and evaluation of patient success.

NUTRITION CARE FOR ONCOLOGY OUTPATIENTS: INTERNATIONAL PERSPECTIVE[2]

There are good data not just from the United States, but also from Australia, demonstrating that patients with cancer face significant nutritional challenges, Liz Isenring began. Data from the Australasian Nutrition Care Day Survey, a study involving 56 hospitals across Australia and New Zealand, found that, within the hospital setting and compared to other patient diagnostic groups, patients with cancer were 1.8 times more likely to be assessed as malnourished and to be eating less than 50 percent of offered food and 1.7 times more likely to have unplanned hospital admissions (Agarwal et al., 2012).

Unlike in the United States, a range of different evidence-based practice guidelines have been developed in Australia for the nutritional management of cancer patients, some of which Isenring remarked she has been lucky to have been involved in developing (Isenring et al., 2008, 2013; Brown et al., 2013). The first guidelines she was involved with were for cancer patients receiving radiation therapy because, this is where most of the evidence was (Isenring et al., 2008). Those guidelines have since been updated to include patients receiving chemotherapy, with a focus on patients with head and neck cancer, again because that is where most of the evidence is (Isenring et al., 2013). Isenring acknowledged the several other international evidence-based guidelines that have been developed by various enteral and parenteral nutrition societies (e.g., Arends et al., 2006; Weimann et al., 2006; August et al., 2009).

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[2] This section summarizes information and opinions presented by Liz Isenring, Ph.D., Bond University, Australia.

Developing Outpatient Models of Care: The Importance of Evidence and Collaboration

The development of oncology outpatient care pathways begins with a thorough literature search. “Being aware of the evidence,” Isenring said, “is always the first step.” The next step is collaborative development, which Isenring described as using a multidisciplinary team approach and involving all stakeholders in critiquing the evidence and coming up with an effective care plan. In her experience, she has found that when the whole team feels responsible for developing the care pathway, then the whole team is more likely to ensure that the pathway is being implemented and that nutrition is on the agenda. In addition to being based on the evidence and on collaborative development, care pathways should also promote consistency and reduce variation in practice. Once developed, care pathways also provide a baseline for data collection. A variety of oncology outpatient models of care exist, depending on the type of cancer, type of treatment (i.e., surgery, chemotherapy, radiation therapy), available health care services, and financial and insurance considerations. Isenring described examples from Australia, Europe, and Canada.

Outpatient Models of Care: Examples from Australia

The Australian Screen-IT model was developed for use with patients with head and neck cancer by Laurelie Wall and colleagues at the Princess Alexander Hospital in Brisbane. It was developed because, despite good evidence indicating that patients with head and neck cancer benefit from seeing a dietitian weekly throughout their treatment, anecdotal evidence suggested that, while weekly visits might be enough for a couple of weeks, many patients reach a “crash and burn” point when they would likely benefit from several visits per week. Meanwhile, other patients could actually go 2 weeks without nutritional treatment. Screen-IT provides a way to triage existing resources to where they would be of greatest benefit, with a focus on nutrition, swallowing, and distress outcomes. Isenring emphasized the multidisciplinary nature of this model of care, which is led by speech pathologists and dietitians but also involves oncologists, psychologists, counselors, and nurses. Additionally, in Isenring’s opinion, Screen-IT is a good example of not only being evidence based, but also taking that evidence one step further and allowing patients and caregivers to provide input themselves and highlight areas where they would like more support (see Box 3-1).

With Screen-IT, patients are provided an iPad when they come in to receive radiotherapy. On the iPad they are asked a series of questions assembled from a few different validated screening tools related to nutrition,

BOX 3-1
One Perspective on Nutrition Screening Tools

In Liz Isenring's opinion, an essential message from this workshop was the importance of evidence-based, validated nutrition screening tools. Such tools can be used not only to identify oncology patients at high risk who would benefit from nutrition treatment, but also for monitoring.

speech, and psychological distress. For example, they are asked whether they have experienced any taste changes or nutrition impact symptoms that have affected their ability to eat. They are also asked about texture and swallowing and, if the patient is tube feeding, how they have been managing. They are asked about their weight too, although Isenring expressed hope that weight will eventually become automated (i.e., the patient will be weighed when they arrive for their visit, and the weight automatically entered into the report). Other questions focus on a range of other topics, from acute changes the patient has experienced in just the past day to distress (i.e., patients are asked not only about any distress experienced during mealtime, but also distress related to family, finances, or anything else). The caregiver also has the opportunity to answer questions about distress.

After patients and caregivers answer the questions, an algorithm is used to flag patients at greatest risk and who need to be seen immediately, patients who have indicated they would like to discuss something in particular with a dietitian, and patients experiencing significant distress. Among those experiencing distress, guidelines are in place to determine whether or not the distress can be addressed in the joint speech pathology/dietetic clinic at the hospital (i.e., if the distress is related to eating), as opposed to the patient being referred to a counselor for ongoing psychological support (i.e., if the distress is related to other factors).

According to Isenring, at the time of this workshop, Wall and her colleagues were in the final stages of evaluating the effectiveness of Screen-IT. Isenring remarked that the tool has probably not increased the overall number of referrals, but that it has changed the pattern of referrals. That is, instead of all patients being seen once a week, some are being seen more frequently and others less frequently.

Another model of care being used in Australia, this one at Peter MacCallum, a cancer-specific hospital in Melbourne, similarly uses particular measures to identify high risk patients and determine how frequently patients should be seen (e.g., most head and neck cancer patients at high risk are seen weekly, followed by regular follow-up every couple of weeks, but some are seen more frequently), whether they should be considered for tube feeding, and what other disciplines might need to be involved.

Yet another hospital-based model of care being implemented in Australia is a head and neck cancer pathway developed by Theresa Brown and colleagues at the Royal Brisbane and Women's Hospital. Again, a range of measures are used to identify risk and streamline decision making around the use of prophylactic percutaneous endoscopic gastrostomy (PEG) or tube feeding. It used to be, Isenring recalled, that this decision depended on clinician interest, with some clinicians being very pro-PEG while others viewed it as a last resort. This model of care represents a multidisciplinary effort to develop a more evidence-based and consistent decision-making process around the use of prophylactic PEG.

While hospitals in Australia generally provide good nutrition care in the hospital setting, Isenring observed, there is what she described as a "big gap" in post-hospital nutrition care. Outside of hospital settings, there are some specialist outpatient clinics in Australia, Isenring remarked, but waiting lists are long. There are also private practitioners, but their focus tends be on lifestyle modifications. Thus, their familiarity is with helping people to lose weight or manage their diabetes, and they may not have the resources to help patients manage complicated head and neck cancer cases. Additionally, something Isenring is starting to see at her facility, which is associated with a university, are specialists, often consultants from local hospitals, who come in to run clinics.

Outpatient Models of Care: An Example from Europe

From Europe, Isenring highlighted efforts by Hinke Kruizenga and the Dutch Malnutrition Steering Group to manage malnutrition in Dutch hospitals. The steering group developed 10 steps to managing nutrition treatment, two key ones being "quick and easy screening tools with treatment plan" and "screening as a mandatory quality indicator." Dutch hospitals use a simple nutrition screening tool called SNAQ (Short Nutritional Assessment Questionnaire). Like the other screening tools Isenring described, this one helps with decision making to determine whether someone is high risk by asking a flowchart of questions.

In addition to addressing challenges around outpatient nutrition care, the Dutch Malnutrition Steering Group has also addressed what happens when patients finish cancer treatment. Not surprisingly, Isenring said, they found that one of the challenges is to find dietitians to whom patients can be referred. While patients are in the hospital, they have access to oncology dietitians. But after they are discharged, there are often questions around who has the expertise, the oncology dietitian from the hospital or a private practitioner; gaps in communication between dietitians; and other problems related to discharge planning and handover from the medical team. Based on these findings, the steering group put together a toolkit with resources to help "up-skill" private practice dietitians in the community who see these complicated post-hospital cancer patient cases. Isenring mentioned that it is not necessary to know Dutch to use these tools. They can be accessed in English through www.fightmalnutrition.eu.

Outpatient Models of Care: An Example from Canada

As a final example of an outpatient model of care from outside the United States, Isenring described a multidisciplinary rehabilitation clinic for patients with cancer in Canada where the patient and family caregivers are at the center of the model and surrounding them is a multidisciplinary team with a dietitian, occupational therapist, oncologist, psychologist, social worker, nurse, and physiotherapist. The model was developed by Martin Chasen and colleagues as part of the Prostate Cancer Intervention Versus Observation Trial (PIVOT) study, an 8-week intensive program during which patients saw a physiotherapist for exercise treatment a couple times per week and nutrition impact symptoms were used to guide nutrition counseling sessions by the dietitian. A "whole battery" of outcome assessments were measured, according to Isenring. Not only did patients love the program and want to continue it, they also experienced what Isenring described as "impressive" improvements in nutrition, physical function, and quality of life (Gagnon et al., 2013).

Where to from Here?

Echoing earlier remarks by keynote speaker Steven Clinton, Isenring repeated that good evidence now exists and some guidelines too for certain groups of cancers, namely head and neck and GI (see Figure 3-2). "Let's be aware of it," she said. The challenge is implementing and translating that evidence into practice.

In summary, Isenring highlighted, first, that patients with cancer have significant nutritional issues, which affect not only the patient, but the caregiver too. Second, for the many cancers that are chronic conditions, nutrition requirements change over the continuum of care. Third, there are several sets of international evidence-based nutritional guidelines available that Isenring thought make for a good starting point for deciding what to do next. Fourth, there are several examples of models of care from around the world. Isenring praised the work being done by these various groups. Finally, just as all the anti-cancer treatments continue to evolve, so too should nutritional management of these same conditions. Isenring ended, "Nutrition is a fundamental right. It has to be there."

FIGURE 3-2 The challenge to oncology nutrition is not so much collecting more evidence, but translating the body of evidence that already exists into practice.
SOURCE: Liz Isenring, March 14, 2016.

A PERSONAL PERSPECTIVE[3]

Diana Dyer was attending the workshop "wearing many hats," she said, including as a childhood cancer survivor, survivor of two subsequent breast cancer diagnoses, and dietitian. She told the workshop audience how, at the end of her therapy for the second primary breast cancer diagnosis, she asked the oncologist, "What do I do now to help myself?" He looked at the floor for quite some time before looking up, meeting Dyer's eyes, and saying, "Eat right and exercise." She thought, "Wow, I'm on my own." Even though she was a dietitian with 20 years of experience at the time, working in intensive care units and providing critical nutrition care support, she felt like a "patient floundering by herself in the trenches." She made a call to

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[3] This section summarizes information and presented by Diana Dyer, M.S., RD, Consultant, Ann Arbor, Michigan.

Cheryl Rock, who Dyer said "got me started," but basically she was on her own. She had to "piece this together," she said.

As she was piecing her care together, a medical journalist from the *Detroit Free Press* called Dyer for an interview for an upcoming story about "the race for the cure." When the article ended up as a front page article, "overnight my life changed," Dyer said. This was back in the pre-Internet 1990s. The newspaper article was printed in more than 60 newspapers. Dyer received more than 1,500 phone calls from people who had read the article and then found her number. People she spoke with said the information provided in the article had given them hope. But at the same time, they were angry that the information in the article was not being provided to them as part of their comprehensive cancer care. Immediately, Dyer started seeing patients in private practice. She was also asked to write a book, which is still in print and with proceeds being donated to the American Institute for Cancer Research (AICR) to fund research on nutrition and cancer survivorship. Dyer also started receiving invitations to speak at events around the country to raise awareness of the need for and benefit of nutrition for cancer survivorship, starting from the day of diagnosis onward.

Although her private practice eventually grew to where she had a months-long waiting list, with people flying from all over the country to see her, Dyer decided to leave her private practice after overhearing a comment by an oncologist at a meeting about how the cancer center where the oncologist worked did not have to do anything about nutrition because, the oncologist said, "We have Diana locally in private practice." That was when Dyer realized that her private practice had been enabling cancer centers to not have dietitians on staff and that she had to do something on a much larger scale to break down the barriers to nutrition care for oncology outpatients. She said, "I don't know what I've personally accomplished, but as a group, the fact that we are here today is an amazing step forward."

"Cancer does not happen in a vacuum," Dyer said. Food, she stated, is "the nexus" between prevention and treatment of chronic disease. She finds it painful that the public is fed by a food industry that pays no attention to health and treated by a health industry that pays no attention to food. Not only is it painful, but in her opinion, neither is it sustainable. The cost of cancer is astronomical, given the number of patients affected, with many patients already having other chronic diseases when they are diagnosed with cancer and with their increased risk as cancer patients for even more comorbidities. According to Dyer, 86 percent of U.S. health care costs are for chronic diseases.

Dyer emphasized that the role of food in cancer prevention and treatment is something "we know." She said, "It is not a belief system." Many foods or bioactive components of foods are known to decrease the activity of cancer stem cells. These include, for example, genistein, a component of soy, and polyphenols in blueberries (Vanamala, 2015). "Food is not just food," she stated. Dietitians are in the perfect role, in her opinion, to help patients understand which foods are going to be more effective, such as that half a purple potato has the same amount of cancer-fighting molecules as three and a half Yukon golds.

Dyer referred to the Hippocratic Oath (i.e., "first, do no harm") and stated that it is the responsibility of the physician to order the right diet. The responsibility of dietitians, according to the motto of the Academy of Nutrition and Dietetics, is "to benefit as many as possible." Additionally, she referred to an African proverb: "If you want to travel fast, travel alone. If you want to travel far, travel together." She said, "It's time to travel together." We have to move forward on this, she said, not just because it is the right thing to do, but because nutritional oncology solves problems. "We have the tools," she said. They include everything from medical nutrition therapy to understanding how to sort through dietary supplements. Plus, registered dietitians can now attain board certification as a specialist in oncology nutrition (CSO).

Dyer noted the helpful role that gardening programs are beginning to serve in both survivorship and prevention programs. Based on her work at the farm at St. Joe's Hospital (St. Joseph Mercy Hospital, Ann Arbor, Michigan) and the Harvest for Health gardening intervention study at the University of Alabama, Dyer said the message that "life begins the day one plants a garden" really resonates with cancer patients. Moreover, in her opinion, and referring to work by Wendell Berry, a farmer, poet, activist, and winner of the National Humanities Medal, for Dyer to be interested in food but not food production is "absurd." In fact, the reason she and others started the farm at St. Joe's, which is a certified organic farm, was not only to reduce potential carcinogens in foods consumed by cancer patients and survivors, but also to enhance intake of polyphenols (President's Cancer Panel, 2010).

In closing, Dyer emphasized, "This is more than a call to action." This is a call to reach what Dyer called a "big hairy audacious goal." Implementation is critical to meeting such a goal.

PANEL DISCUSSION WITH SPEAKERS: DATA GAPS IN MODELS OF CARE

Following Dyer's presentation, she, Robien, and Isenring participated in a brief panel discussion with the audience. This section summarizes that discussion.

Gaps in RD Care

Steven Clinton asked how different health care systems around the world incorporate or support RD care. Isenring replied that the Australian models of care she described during her presentation were being implemented in publicly funded hospitals and that publicly funded hospitals have higher FTEs of dietitians compared to private settings. That most costs of that care are provided by public funding may explain why Australia has what she considered "better" models of care. Australia's Medicare scheme allows up to five visits per year for chronic conditions, including cancer, and according to Isenring, she and others were working with general practitioners to try to maximize nutrition care during some of these visits. In Australia, the gaps in care exist where the patient has to pay, which is where the challenge lies. Isenring agreed with Dyer that one goal should be to reach for the "big hairy audacious goal," which she interpreted as examining the evidence and determining the best model of care. At the same time, however, Isenring urged also considering what is feasible and realistic and called for inclusion of more health economic outcomes in nutrition studies.

Physician Knowledge About Nutrition

An audience member remarked that physicians are often unable to answer patient questions about food and nutrition, such as whether tumors feed off sugar or gluten. Physicians often tell their patients to "just eat whatever you want" and that it is more important to stay well-nourished than to eat specific foods. She asked the panelists their opinions on gluten, sugars, and tumors. Rock replied that this workshop was not the appropriate arena for delving into those details. In Rock's opinion, the questioner's observation about physician knowledge of nutrition is a good example of why dietitians with specialty training in oncology are needed. "There's so much confusion among health care providers," she said.

Emergence of Medical Homes for Oncology Care

A webcast participant asked about the involvement of RDNs in the emergence of medical homes for oncology care (e.g., patient-centered medical homes). Clinton remarked that the medical home model has yet to reach Ohio, but the model warrants being studied and evidence-based recommendations being made (i.e., based on measured outcomes) for integrating food and nutrition.

Role of Telemedicine and Technology in Oncology Nutrition Care

The panelists were asked their opinions on how telemedicine and technology will likely affect oncology nutrition care in the future, not as a replacement for in-person care, but as a way to augment in-person care. In Clinton's opinion, what the patient is doing is one of the most important pieces of information health care professionals need when counseling a patient in the outpatient setting. So any technology that provides that information, such as pictures of what the patient has been eating, has enormous potential to provide instant data on consumption. That way, when sitting down with a patient to council them on their dietary pattern, the counseling can be based on actual data, not a "guesstimate" based on a partially filled out food diary. That technology is advancing rapidly, he said, and "offers great potential." Robien added that, as a researcher, she would advocate finding a way to somehow feed these collected data back into the evidence base.

Validated Nutrition Screening Tool for Pediatric Oncology

An audience member asked if there were any validated nutrition screening tools for use in pediatrics or guidelines to help identify patients with the greatest nutritional care needs. Isenring mentioned that an Australian group is in the final stage of validating a pediatric tool. Levin remarked that she recently took a position as a pediatric oncology dietitian and was surprised there was not more information. She added that this will be one of ONDPG's next projects.

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Benefits and Costs of Care

OVERVIEW

In her opening remarks, Session 3 moderator Wendy Johnson Askew[1] agreed with the earlier call for more health economic studies and also called for more culturally competent approaches to care. Without the latter, she predicted huge disparity issues around some outcomes. Without taking into account what is going on in a patient's life, she said, "We are not going to achieve our 'big hairy audacious goal' of making this available to others." The goal of Session 3 was to address financial challenges to reaching this goal, Johnson Askew continued. This chapter summarizes the Session 3 presentations and discussion.

First, Jim Lee discussed several key points to keep in mind when considering the cost of nutrition intervention benefits, including the complex and costly nature of measuring that cost. During the panel discussion at the end of the session, Lee called for more combined clinical outcome and budget impact studies, rather than full cost–benefit analyses.

Next, Brenna Shebel discussed ways that employers can help employees who have cancer or are serving as caregivers and how the National Business Group on Health (NBGH) is aiding in this effort. In collaboration with the National Comprehensive Cancer Network (NCCN), in 2013 the NBGH issued a series of recommendations, including one nutrition recommendation, to help employers align employee benefits with evidence from across the continuum of cancer care.

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[1] Session 3 was co-moderated by Wendy Johnson Askew and Nico Pronk.

COST–BENEFIT CONSIDERATIONS[2]

Twenty-two years ago, Jim Lee began, a nutrition researcher was telling him about the struggle to determine the cost and benefits of nutrition intervention, to which Lee replied, "That is easy." But 22 years later, he is still struggling to figure out not so much how to do it, but how to get people to act on the information. This is a particularly difficult challenge in the United States, he said.

He listed four key points to keep in mind when considering the cost of nutrition intervention benefits and then, for the remainder of his talk, discussed each in further detail:

1. Understand how malnutrition affects high priority outcomes.
2. Carefully consider co-morbidities and primary therapy effects. These are not simple cause and effect relationships, Lee explained.
3. Measure costs and benefits commensurate with the intervention and from multiple perspectives. Fortunately, nutrition interventions are not very costly, which Lee said needs to be understood when studies are designed.
4. Understand that measuring costs is complex, often costly, and best done within a clinical study. Because the United States does not have the benefit of a single payer system, the data get very messy very quickly, Lee remarked.

Understanding How Malnutrition Affects High Priority Outcomes

Lee emphasized the importance of considering outcomes, like mortality, that are important not just from a financial perspective, but also from a patient perspective, when examining the effects of malnutrition in oncology patients. An observational study of approximately 800 hospitalized patients in Singapore, including 55 oncology patients, showed that both costs and 1-, 2-, and 3-year mortality were significantly different between malnourished and well-nourished patients (after both statistical and risk adjustments) (Lim et al., 2012). Three-year mortality among malnourished patients was 48.5 percent, compared to 9.9 percent among well-nourished patients. Of the 55 oncology patients, 71 percent were malnourished within 48 hours of admission, based on a subjective global assessment of nutritional status. While these results do not imply causality, only correlation, Lee speculated that if you were to ask any patient if a five-fold difference in risk of mortality is an important factor, all would say yes.

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[2] This section summarizes information and opinions presented by Jim Lee, M.S., Altarum Institute, Ann Arbor, Michigan.

Another high-priority outcome from both financial and patient perspectives is hospital readmission. Patients have busy lives, and few like to be readmitted. Moreover, hospitalizations are a major event not just for the patients, but also their caregivers and families. In the same Lim et al. (2012) study, while the difference in readmissions between malnourished and well-nourished patients was not statistically significant, nonetheless, in Lee's opinion, the trend was clinically significant, with the higher readmission rates among malnourished patients.

Carefully Consider Comorbidities and Therapy-Related Effects

In addition to high priority outcomes, Lee emphasized the importance of also considering comorbidities and therapy-related effects when evaluating cost of care. In a study of what Lee considered a relatively inexpensive and generalized intervention, specifically a palliative care consultation within 2 days of admission among oncology patients, May et al. (2016) found that, compared to usual care, receipt of the palliative care was associated with 22 percent lower costs for patients who had comorbidity scores of 2-3 and 32 percent lower costs for patients with comorbidity scores of 4 or higher.

Lee emphasized the importance of understanding not just comorbidities but also treatment-related effects from a patient perspective. "We can get lost in the very important science and miss out on what is, in fact, most important to sometimes gravely ill patients," he said. For example, sharing a meal together does not have just a nutritional effect. "It can be a very meaningful event," Lee said.

Additionally, certain patients are at greater risk for higher costs due to completely independent factors, such as whether they have a spouse at home who will care for them. For example, Lee observed that elderly men often have a wife at home who will care for them, whereas elderly women do not. Where patients go after they leave inpatient care and who they have at home to support them are factors that often are not considered in economic analyses or outcome studies. Yet, Lee said, these can be very important determinants of risk of readmission, adherence with a care plan, and other outcomes.

While not designed for this type of risk adjustment, there are several methods available that can provide some risk adjustment in these types of situations. These include the Elixhauser Comorbidity Index, a method for measuring patient comorbidity based on *International Classification of Diseases* (ICD)-9 and ICD-10 diagnosis codes in administrative data (Elixhauser et al., 1998). Lee referred workshop participants to an Agency for Healthcare Research and Quality (AHRQ) website that provides software for generating Elixhauser Comorbidity Indices.[3] Others are the Edmonton Symptom Assessment Scale (Bruera et al., 1991) and the Condensed Memorial Symptom Assessment Scale (Chang et al., 2004). These methods can be especially helpful for understanding why expected outcomes are not observed in some subsets of patients, according to Lee.

Measure Costs and Benefits Commensurate with the Intervention and from Multiple Perspectives

Lee challenged nutrition researchers to help payers understand the cost of nutritional interventions. He told the workshop audience how he used to joke with a colleague about diagnostic tests for $125,000 therapies that cost only a few hundred dollars and how they would refer to those few hundred dollars as "budget dust." However, as Kathryn Phillips and colleagues at the University of California, San Francisco, have shown, often there is no evidence that these "budget dust" diagnostic tests were actually conducted (i.e., before therapy). Yet, Lee said, he gets "beaten up" over a $200 nutrition counseling session. He urged researchers to measure the costs of nutrition interventions. In many of the studies he has seen, there has been no attempt to at least try to measure some of the cost even when doing so would typically not be that difficult.

When costs also have financial benefits, however, measuring the overall costs becomes more complex, Lee continued. For example, using a medication can also lead to a better outcome (i.e., with financial benefits). Adding to the complexity, even in a single institution, there are typically multiple payers, each with different reimbursement methods for the same treatment and case management. Taking into account not just payer costs and financial benefits, but also employer costs and financial benefits (e.g., disability payments), as well as employee costs and financial benefits (e.g., out-of-pocket costs, lost wages), adds further to the complexity. Lee remarked that out-of-pocket costs for oncology patients were lower in 2012 compared to all other years Lee and colleagues had been measuring them. That was prior to the rapid expansion of high-deductible health plans, he noted. He did not expect to see such low costs again.

Finally, provider costs and financial benefits also need to be considered. Lee mentioned that he is looking forward to finding out if there is a nutrition component to the new Oncology Care Model being developed by the Center for Medicare & Medicaid Innovation (CMMI) and, if so, how the different incentive structure of the model (i.e., reimbursement being based not necessarily on treatment, but on how a treatment contributes to

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[3] See https://www.hcup-us.ahrq.gov/toolssoftware/comorbidity/comorbidity.jsp (accessed August 3, 2016).

outcome) will affect the costs and financial benefits of nutritional intervention. In his opinion, the model provides a tremendous opportunity to start measuring these costs and benefits in relatively carefully controlled studies.

When direct measures of costs and financial benefits are too costly or difficult to obtain, Lee suggested that proxy measures be used. For example, instead of trying to obtain highly confidential data from 12 different payers, a good proxy would be what Medicare would pay for a service. Additionally, he suggested conducting studies in places where there is a single payer. Most of his own research has been done in Canada, the United Kingdom, and other places where the data are much more readily available than they are in the United States.

Understand That Measuring Costs Is Complex and Often Costly

Finally, Lee emphasized the complexity and cost of measuring costs. Costs have very high variance, not only because treatments are different among practices but because prices are different. The statistical significance of cost is "incredibly difficult" to obtain because of sample size and the cost of a large study, according to Lee. That said, very rarely has he come across decision makers who insist on studies being designed for statistical significance of costs. Most understand that it is unlikely.

In addition to high variance requiring large sample sizes for statistical significance, exogenous factors often dominate the intervention effect. This is true even for very large sample sizes, Lee said. Exogenous factors include things like reimbursement, facility cost structure, and practice patterns. He noted that some of the work he had been involved with recently had engaged the two or three key payers (i.e., in either the institution or the state) from the beginning, including during the study design, to help control for these factors.

A final factor to consider is that even single-site studies may involve several payers, requiring intensive data collection and a tremendous amount of work even just to find out what happened (e.g., whether a patient was readmitted, the cost of readmission).

To close, Lee said, "Twenty-two years ago, I thought this was going to be easy. Now I stand here today and tell you, it is not. But it is well worth doing."

PERSPECTIVES ON ONCOLOGY NUTRITION CARE: EMPLOYERS AND OTHER PURCHASERS[4]

Brenna Shebel and colleagues at the NBGH collaborated with the NCCN on a 3-year initiative to establish a set of criteria and recommenda-

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[4] This section summarizes information and opinions presented by Brenna Haviland Shebel, M.S., National Business Group on Health, Washington, DC.

tions for employers to adopt as a way to make cancer a priority within their workplaces. Shebel went on to describe some of these 56 recommendations, one of which was on nutrition care, and how the recommendations help employers to align their employee benefits with evidence. The Business Group, Shebel explained, is a membership organization of mostly large employers, including 70 of the Fortune 100.[5] The employers Shebel serves work very closely with their health plans to ensure the benefits being offered to their employees meet certain evidence metrics. Because they are self-funded, NBGH members have a lot of flexibility within their benefit programs. So while serving a broad and diverse workforce is a challenge, this challenge is something Business Group members are "up for," Shebel said.

How Employers Are Serving Employees Who Have Cancer or Are Serving as Caregivers

Shebel listed several reasons why employers are making cancer a priority. First is the very high incidence of cancer among the working population. About half of men and one-third of women are diagnosed with cancer at some point in their lives, and virtually everyone is touched by cancer in some way (e.g., being a caregiver, having a colleague who has cancer). Second, Business Group members are very concerned about variation in quality of cancer care and are becoming increasingly interested in matching their employees, particularly those with rare and aggressive cancers, with the best providers and with access to evidence-based information about cancer. Third, cost is a huge factor. While employers want the highest-quality care for their employees, they are also concerned with cost. The cost of cancer treatment is typically among the top three most costly medical conditions, representing, on average, 12 percent of total medical expenses for employers. Moreover, Shebel added, the cost of cancer treatments are rising faster than general medical costs. Lastly, employees want to return to work during treatment if they can, and employers want their employees to return to work. Returning to work is important for a patient's sense of normalcy.

With respect to what employers are doing to address cancer among their employees, first is the provision of medical benefits. In fact, Shebel said, the bulk of recommendations put forth by the Business Group are in the area of medical benefits. These include ways to adapt evidence to an employer's benefit design; ways to provide employees with access to evidence-based information and services, including behavioral services for the treatment of depression and anxiety; and recommendations relating to centers of excellence (COEs). COEs are subsets of in-network providers

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[5] The Fortune 100 is an annual list of the 100 largest public and privately held companies in the United States.

that provide condition-focused care and that employers either directly or indirectly contract with through their health plans, with participating providers having proven track records of positive outcomes. In a recent survey, the Business Group asked their members if they were or would be offering COEs for a variety of conditions. While cancer was not at the top of the list (transplants were), Shebel said, "It is definitely growing." Twenty-nine percent of NBGH members offered a cancer COE in 2016, although only 3 percent used incentives (e.g., by waiving deductibles or making it less expensive for employees to seek care at a COE provider). Another one-third reported that they were considering offering cancer care COEs in the future.

The cost of medications, including parity of costs between oral oncolytics and infusion medications, is another key cancer care issue for many Business Group members and their employees. Cost should not be the main deciding factor for patients when choosing medications, Shebel said. Patients should be choosing the medications that are right for them. NBGH recommendations include ways to make medications more affordable for employees.

While many employers offer care management programs for their employees, including the provision of some kind of support for employees with cancer, the Business Group recommendations also include ways to bolster that support and the training of staff within those programs. A recent Business Group survey of employees indicated that, more often than not, employees want health information and support not so much from their employer, rather from their health insurer or another third party. This was not a surprising finding, Shebel said. From a privacy perspective, it is not as comfortable for employees to see that kind of support from their employers. When asked what type of support they want from their employer, flexibility was at the top of the list. That is, employees want to have flexibility around their work schedules so they can get to appointments, treatments, tests, and so on. Another important finding from this same employee survey was that getting a second opinion from a specialist is important for cancer patients.

In addition to medical benefits, pharmacy benefits, and care management programs, a fourth way that employers are addressing cancer among their employees is by offering short term disability (i.e., typically up to 6 months). Thus, that is another area where the Business Group provides a number of recommendations, including ways to work with treating physicians to determine duration of leave and ways to structure short-term disability to help people return to work when they are ready.

The Business Group also makes recommendations around family medical leave, which is protected leave that both patients and caregivers can take and which is often unpaid. Employees who need to take family medical leave are usually people who have cancer, have already faced very high medical costs, and need to be routed to the right providers, including providers of financial assistance.

Employee assistance programs are another way employers address cancer among their employees. While many NBGH employers offer such programs, the programs are highly underutilized, Shebel said. Employee assistance programs are designed to support employees around any type of life challenge or transition, whether it be financial, legal, related to child care, or something else.

Health improvement programs are another relevant benefit that employers provide, but one that is often misunderstood, according to Shebel. Because of their focus on cancer risk reduction, Business Group recommendations for health improvement programs cover strategies that support not just employees with cancer, but the entire working population as a way to reduce their risk of cancer.

All of these various benefits and programs are great for employees, Shebel said. But what if employees, when diagnosed with cancer, do not know these benefits exist? The Business Group has not only issued recommendations around employee communications, but the group has also actually written materials, with the help of NCCN, that employers can use to communicate with employees who are either newly diagnosed cancer patients or caregivers.

The Business Group's Recommendation on Nutrition Care

> "*All health plans should provide coverage for nutrition counseling and medical nutrition therapy with a diagnosis of cancer.*"
> —Business Group recommendation on nutrition care

More specifically (than stated in the quote above), the Business Group nutrition recommendation suggests that in-network providers be registered dietitians (RDs) who are board-certified specialists in oncology and that patients pay out-of-pocket as they would for other in-network services. The Business Group also recommends that employers adopt the *NCCN Clinical Practice Guidelines in Oncology*, which state that providers should conduct assessments to evaluate weight gain and loss and other nutrition-related conditions, consult or refer to nutritional experts in the case of any abnormalities, and manage deficiencies resulting from anorexia, diarrhea, nausea, and vomiting.

The genesis behind the nutrition recommendation, Shebel explained, was to help employees in treatment to maintain quality of life and ability to function both during and after cancer treatment. This is especially important for employees who want to continue working. Recognizing the data presented by previous workshop speakers, Shebel noted that the statistic she uses with employers is that approximately 50 to 60 percent of patients diagnosed with cancer experience significant weight loss and poor nutrition during the course of their illnesses.

Future of the Employer Role

Based on her weekly work with corporations to improve their cancer benefits, as well as media interviews, Shebel speculated on several future employer roles in cancer care. First, as Lee had mentioned, consumer-driven health plans (CDHPs) and high-deductible plans are certainly the wave of the future, based on Business Group data. In fact, that future is already here, with 83 percent of Business Group members offering some sort of CDHP and one-third offering only CDHPs (i.e., only choice for their employees). For Business Group members, Shebel said, "what really keeps them up at night" are individuals with these plans who are facing major medical decisions and costs. With a lot of upfront or out-of-pocket costs, these individuals may not be able to meet other financial demands, like mortgages and bills. So some employers are looking into critical illness coverage to help with some of these financial issues.

In addition to offering critical illness coverage, employers are increasingly focusing on supervisors of employees as a source of support. Although employees do not need to disclose that they have cancer, because supervisors play key roles in helping employees to manage their schedules, employees often choose to disclose. As such, the Business Group is continuing to push their members to recognize the importance of training supervisors so that when a patient does discloses that he or she has a cancer diagnosis, the supervisor knows how to react, including avoiding the "wrong" thing to say, the "right" thing to say, and where the supervisor should direct the employee for benefits. Also increasingly, Shebel continued, employers are also looking at the evidence and wanting their providers to use evidence and to share outcomes.

Finally, many employers are providing concierge services to their employees. Concierge services provide employees with a single "advocate" who helps with all health care needs, whether that is enrolling in benefits, improving health (e.g., losing weight), or facing a major diagnosis. "You have one single person to work with," Shebel said. In her opinion, it is a "fantastic" option because employees don't have to figure out which number to call or who to talk to. Concierge advocates know exactly where to direct employees with respect to both providers and support.

In closing, Shebel noted that NBGH's tools are open to the public, even though the group is a membership organization.[6] Printed copies of the recommendations are also available upon request.

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[6] See http://www.businessgrouphealth.org/cancer (accessed August 3, 2016).

PANEL DISCUSSION WITH SPEAKERS: DATA GAPS IN OUTCOMES AND COSTS OF CARE

Following Shebel's presentation, she and Lee participated in a panel discussion with the audience. This section summarizes the discussion that took place.

The Role of the Centers for Medicare & Medicaid Services (CMS), Reimbursement, and the Value of Nutrition Services

Pronk opened the discussion by asking the panelists if any policy work was being done to align interests of Medicare with investments that employers make in keeping people healthy before they retire.

Shebel observed that, with all the Medicare payment models being tested, employers now are looking to Medicare as the innovators and taking a "wait-and-see" approach to what emerges from all of the "exciting movement" around these models. She expressed hope that there is some place within CMMI's work on oncology to address nutrition care. Lee added that the fact that the United States is fifth best in the world with respect to smoking rates among adults (i.e., fifth lowest) is a good example of how public policy can have a substantial effect on health, with both CMS and large employers being beneficiaries of that.

Observing that "the theme" among suggestions to "change the scope of things" with respect to reimbursement for nutrition services is to have a conversation with CMS, an audience member asked the panelists how they would suggest doing that. What kind of outcomes data are needed? Should data be collected nationally? What would be a good case to take to the CMS to make the necessary changes? Lee replied that CMS is primarily interested in examining different models of reimbursement, rather than adding more professional groups to a fee-for-service model, creating a challenge for those groups not currently part of the current fee-for-service reimbursement model. He would suggest approaching Medicare Advantage plans and others, rather than CMS directly, at least in the near term, or participating in some of the CMMI initiatives and demonstrating the value of nutrition care using what he described as "their experimental design."

"I think if we are going to go up to ask for reimbursement and support, we have to go armed, which means we have to have the data," Clinton remarked. But we also have to pick our battles, he added. This raises the question, where will nutrition support services have the greatest affect on outcome? After deciding what to fight for first, then organizations should conduct the necessary systematic reviews "to carry that battle up and down the spectrum of outcomes." Gathering data on long-term outcomes among cancer survivors will be a challenge. However, the same evidence used to develop the *Dietary Guidelines for Americans* and the American Institute for Cancer Research recommendations could also be used for this purpose. The greater question, Clinton opined, is, "How do we pay for that kind of quality intervention, which is labor intensive?" Four consults a year will not change someone's diet. That amount of care would be "woefully inadequate" given the limited reimbursement dietitians currently receive for providing diabetes care.

While these new CMS models of reimbursement are going to be simpler, Clinton continued, in terms of eliminating paperwork and reimbursing a single set of money for the entire care process, which the hospital will have to figure out how to distribute among its providers (e.g., among the surgeon, the medical oncologist, the pharmacist, the RD, etc.), they will also have interesting effects. He predicted that this type of reimbursement will create internal battles, which "is not going to be helpful for our mission."

Rather than trying to monetize return on investment, Pronk suggested that the focus should be on value. Oncology nutritional services are incredibly valuable, he said, but their return on investment is difficult to monetize.

Shebel commented on the team-based nature of the new payment models. For her, what is exciting about the models is that the patient is "absolutely at the center," with shared savings among providers. Providers will not receive payment if the care provided is not evidence-based and the outcomes are not positive. Robien opined that the accountable care organization (ACO) model in particular is a "great place" for dietitians to become involved in these teams, especially in early cancer care. One of the reasons diabetes care is so successful, she said, is because dietitians can look at short-term biomarkers to evaluate how nutrition interventions modulate hemoglobin A1c levels over time. Oncology dietitians could do the same sort of short-term monitoring during early cancer care. She noted that most dietitians are not trained in this area, but that it is an area with which they need to become more familiar and soon. She encouraged dietitians to be more assertive about being part of this new model of care.

Evidence from Electronic Medical Records

Wendy Johnson Askew asked whether electronic medical records can help to facilitate calculating costs in some of these new benefit models and looking at long-term outcomes as a way to provide evidence for viable options. She recalled a frustrating time when dietitians did not have a systematic way to talk about the value of their services. "We knew anecdotally that dietitians saved money," she said, "but we didn't have any way to talk about it." Now, with electronic medical records, she said, "It is unfortunate that we haven't been able to capture more of this." She asked, "How can we organize ourselves in a way that we can capture this data?"

In Lee's opinion, there is still potential for the electronic health record in the long-term. But currently, the U.S. health care system is so disparate that very seldom is one group taking care of all of a patient's care. He said he often brings his own electronic health record up to date before he goes to the doctor. Interim solutions include, first, participating in professional registries and studies and, secondly, working with information technology groups to standardize data and move away from manual processes. It is going to take many steps, he said. That said, in his opinion, there are some good role models. He suggested looking at the Australian and Dutch models.

Clinton added that The Ohio State University and many other research institutions and comprehensive cancer centers have what are known as honest broker data warehouses. In his opinion, dietitians need to be trained on how to use those warehouses. At Ohio State, they will actually pull for free whatever you ask them to pull from the medical records. For example, you can obtain nutrition-related symptoms. This is very helpful, and he has trained a couple of their oncology dietitians to know how to do this. The information is de-identified and can be published.

Shebel suggested that ACOs, which she identified as one of the fastest growing trends for NBGH members, may someday be helpful in this effort.

Employer–Employee Relations

There was some brief discussion around employer–employee relations with respect to the provision of nutrition care for oncology patients. An audience member observed that, while many employers are supportive of their employees going through treatment, the opposite is also true, with patients struggling to make it through treatment because they feel they need to be at work so they do not lose their job or benefits. This raises the question, what conversations should employees be having with their supervisor to gain that support? Shebel agreed that this situation exists and that not every supervisor "is perfect" in this area, which is why it is so important that supervisors receive training in this area at least at a "baseline" level so they know what benefits exist when they have that first conversation with an employee facing a diagnosis. She emphasized that the culture of the organization also matters. It is not just the supervisor who should be involved with providing support for employees facing diagnoses, but also human resources, the employee assistance program, and maybe even the legal department.

A webcast participant asked Shebel what else employers could be doing to expand employee access to evidence-based nutrition care and what it will take to get payers to incentivize the delivery of nutrition care. Currently, Shebel replied, payment and delivery methods are focused more broadly on cancer care. "We have a way to go," she said, "to drill down all the way to nutrition care." NBGH makes recommendations to its members to provide evidence-based information to its employees who are newly diagnosed. Specifically, they promote patient information from the American Cancer Society, NCCN, and the American Board of Internal Medicine Foundation's Choosing Wisely campaign. Lee added that clinical guidelines can be very influential with payers. When he talks with payers, one of the first things they want to know is standard of care. They often turn to third-party sources to help make decisions about what to cover.

Gaps in Research and Communication

Pronk observed that both speakers emphasized the strength of the evidence, but neither touched much on research gaps. He asked which major research gaps would need to be closed for this area of the field to move forward in a productive manner. Lee identified the need to combine clinical outcomes and budget effects, rather than conduct full cost–benefit analyses. Employers want to know roughly how much something is going to cost to cover their employees and that a professional society has reviewed the care and determined it to be evidence based. He has seldom seen full cost–benefit analyses and did not think they should be the final arbiters.

Shebel agreed that clinical outcomes associated with providing services are very important. Recognizing the "great information" presented thus far in this workshop, she wondered whether the greater challenge is not gaps in research, rather that already existing data might not be getting to the hands of payers and employers. In addition to getting outcome data and information "out there," she also pointed to the need for providers to provide data. For example, in reference to a question in an earlier session about oncology medical homes, she said, "We want to know more about that."

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Dissemination and Implementation: Reaching the Ideal

OVERVIEW

An overarching theme of the workshop presentations and discussions, opined Session 4 moderator Marian Neuhouser, was, “What do we next? Where do we go?” The goal of Session 4 was to discuss the dissemination and implementation of nutritional care among outpatient oncology patients and survivors. This chapter summarizes the Session 4 presentations and discussion.

First, Barbara Grant described the registered dietitian nutritionist (RDN), registered dietitian (RD), and specialist in oncology nutrition (CSO) credentials and emphasized the importance of fostering relationships between the nutrition community and organizations like the Commission on Cancer (CoC) that provide accreditation and program guidance for cancer centers.

Next, Colleen Doyle discussed the opportunities and challenges of community-based nutrition support for cancer survivors. She emphasized the need to increase awareness of and access to nutrition services and issued a call to action to everyone in attendance to “use your voice” and described the effort reflected in this workshop as the beginning of a national movement to bring dietitians not just into cancer centers and hospitals to help cancer patients, but also into community-based settings to help support survivors.

Lastly, Joan McClure discussed the National Comprehensive Cancer Network (NCCN) clinical practice guidelines and their relevance to nutritional care among cancer patients and survivors. She encouraged dietitians who work at NCCN member institutions to seek out people who are on the guideline review panels and participate in the institutional reviews. "That is the way to get [nutrition] data into the deliberations of the panels," she said. She also suggested integrating nutrition studies into large treatment clinical trials. With those data, she said, "you would have a much better sell to the medical community." The opportunities for and challenges to including nutrition data in treatment clinical trials was a major topic of discussion in the panel discussion following McClure's talk, as well as in the final session of the workshop (see Chapter 6).

DISSEMINATION AND IMPLEMENTATION OF NUTRITIONAL CARE IN ACUTE CARE AND SPECIALIZED CENTERS[1]

Who Are the Oncology Nutrition Practitioners in Today's Outpatient Cancer Centers?

Barbara Grant began by describing "who we are." The Academy of Nutrition and Dietetics' (AND's) Commission on Dietetic Registration (CDR) awards and administers both RD and RDN credentials, which can be used interchangeably. The credentials are maintained through continuing education. As of February 2016, there were 94,838 RDs/RDNs.

The CDR now also awards and administers a practice-based specialist RDN/RD credential in oncology nutrition (CSO). CDR's definition of oncology nutrition is:

> RDNs working directly with individuals at risk for, or diagnosed with, any type of malignancy or pre-malignant condition, in a variety of settings (e.g., hospitals, clinics, cancer centers, hospices, public health) OR indirectly through roles in management, education, industry, and research practice linked specifically to oncology nutrition.

The Oncology Nutrition Dietetic Practice Group (ONDPG), a practice group of the Academy, was established in 1992 with 300 members. As of February 2016, it had 2,301 members, according to Grant. But it was not until 2006 that ONDPG brought forth what Grant described as a "crazy idea," which was that the CDR ought to credential RDs/RDNs working in oncology nutrition, given the "certified world" of cancer centers, with oncology nurses, therapists, and doctors all being board-certified. In addition to feeling it was important to have that credential, Grant and her colleagues also wanted to establish minimum competency for taking care of

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[1] This section summarizes information and opinions presented by Barbara Grant, M.S., RDN, CSO, FAND, Saint Alphonsus Cancer Care Center, Boise and Caldwell, Idaho.

individuals diagnosed with cancer. In response to their "crazy idea," in fact, Grant said, of all the specialist RD/RDN credentials, theirs took off on the most rapid trajectory. CDR implemented the CSO credential in 2008, with the first exam conducted in 2010. Eligibility criteria include current RDN status with the CDR and 2,000 hours of oncology nutrition practice experience. The credential is maintained through examination every 5 years. As of March 2016, there were 693 practitioners holding the CSO credential, with CSOs in every U.S. state, in Canada, and overseas.

Noting that dietetics was the first health care profession in the United States to have validated practice competencies, Grant listed several foundational documents and resources:

- CDR's *Essential Practice Competencies for Credentialed Nutrition and Dietetics Practitioners* (Worsfold et al., 2015);
- AND's Standards of Practice and Standards of Professional Performance for Registered Dietitians (Generalist, Specialty, and Advance) in Oncology Nutrition, which were established in 2006, updated in 2010, and slated for further update in 2016, according to Grant (Robien et al., 2010);
- AND's Evidence Analysis Library: Oncology Nutrition Evidence-Based Nutrition Practice Guidelines, 2007 and 2013 (www.andeal.org); and the Academy's Evidence-Based Oncology Toolkit, 2010 (www.eatright.org/Shop).

Dissemination of Oncology Nutrition RDNs and CSOs in Cancer Centers Across America

Grant attributed the dissemination of oncology nutrition RDNs and CSOs in cancer centers across the United States to four key factors:

1. Relationships that she and her colleagues have forged and fostered with organizations that provide accreditation and program guidance for cancer centers;
2. Collaboration with national cancer information, survivorship, and advocacy organizations and efforts;
3. The vision of ONDPG members and support from the Academy; and
4. The networking of ONDPG members and allied oncology health care professionals. Grant said, "As you have heard today, we are a passionate and very committed group of individuals."

The first group that ONDPG "set their sights on," according to Grant, back in 1992, was the American College of Surgeons' CoC. The

CoC, Grant quoted, is "a consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through setting standards, which promotes cancer prevention, research, education, and monitoring of comprehensive quality care." More than 70 percent of all newly diagnosed patients are treated in the more than 1,500 CoC-accredited cancer programs nationwide. Grant's own cancer center, Saint Alphonsus Cancer Care Center, in Boise, Idaho, is one of these. She and her practice group decided they wanted to be a member organization of CoC within 3 years, and by 1995, they were, with Grant serving as the first liaison representative. At the time, there were only about 20 CoC member organizations. Now there are around 50. Today, Kathryn Hamilton, a CSO RDN, represents AND on the nine-member steering committee for the CoC's 50 member organizations and the CoC advocacy committee that examines state and federal legislation. "We now have a seat at the table," Grant stated.

Hamilton also sits on the CoC accreditation committee, Grant continued. CoC visits its accredited programs every 3 years for site evaluations. Programs must meet eligibility criteria relating to seven services: (1) diagnostic imagining services, (2) radiation oncology services, (3) systemic therapy services, (4) clinical research information, (5) psychosocial support services, (6) rehabilitation services, and (7) nutrition services. The last, nutrition services, were the more recent criterion added, in 2012. When Kathryn called to tell her, Grant said, "this actually brought tears to my Hamilton." Effective in January 2016, all CoC-accredited cancer programs must have policies and procedures in place to ensure that patients have access to an RDN and that nutrition services are available either on-site or by referral. Additionally, rather than stating simply that "nutrition services" must be available, the eligibility requirements spells out the spectrum of services that must be available (screening and referral for nutrition-related problems, comprehensive nutrition assessment, nutrition counseling, and education). "This is huge," Grant said. Based on her experience, she said what start as eligibility requirements often eventually become standards. She expressed hope that, in her lifetime as a clinician, these new eligibility requirements will become a standard for nutrition services. She described the process as being like "dribbling water on a stone."

In addition to these nutrition-specific achievements, one of the CoC standards (standard 1.2) is that all cancer programs must have cancer committees. In the past, Grant said, dietitians would come and "kind of sit in the back row." But as of 2012, while not required to be members of the cancer committees, it is strongly recommended that dietitians be members. Again, she said, "We are making our presence known."

In addition to the CoC, another organization with whom Grant and her ONDPG colleagues thought it would be important to be involved was the

Association of Community Cancer Centers (ACCC). The ACCC has more than 700 members and more than 40 years of service. Their core purpose is to be a leading education and advocacy organization for multidisciplinary cancer teams. While they do not have accreditation standards or eligibility criteria, they do put together program guidelines that reflect optimal components for a cancer program. In 2012, after the ACCC reached out, a group of four nurses and 12 dietitians, including CSOs, put together some nutrition service guidelines. As a result of these efforts, rather than the ACCC guidelines simply stating that patients should have access to nutrition, there are four detailed nutrition services guidelines relating to the nutrition care process, medical nutrition therapy, cancer risk and cancer recurrence risk reduction, and survivorship. These are available on the ACCC website.[2]

In Grant's opinion, probably the greatest opportunity for fostering a relationship to help disseminate and implement oncology nutrition services is via the NCCN, given that most of the *NCCN Guidelines for Treatment of Cancer by Site* do not even mention nutrition. The only ones that do are for esophageal and gastric cancers and head and neck cancers. While it may not be possible to achieve a whole nutrition guideline on its own, she suggested starting "by dribbling that water on a stone" and getting nutrition into the guidelines that already exists. The *NCCN Guideline for Survivorship*, however, does include a nutrition and weight management section and encourages referrals to RDNs and especially CSOs.

Recognizing the importance of nutrition across the continuum of cancer care, including prevention, Grant called for continued advocating and collaborating with the National Cancer Institute, American Cancer Society (ACS), American Institute for Cancer Research, CancerCare.org, and others.

Implementation of Oncology Nutrition Care

Based on a Commission on Dietetic Registration 2014 survey of about 1,000 ONDPG members and another 600 CSOs and with a 21 percent response rate (www.cdrnet.org/CSO), 51 percent of oncology dietitians are working in ambulatory/outpatient settings (specifically, 28 percent work in a hospital/inpatient setting, 17 percent in a medical center setting, 13 percent in a community hospital setting, and 7 percent in a university/college/educational setting), with 37 percent (across all settings) seeing 76-100 patients per month, 24 percent seeing 51-75 patients per month, 21 percent seeing 26-50 patients per month, and 15 percent seeing 1-25 patients per month. With respect to geographic reach, these practices are spread across the United States, with one-third of survey respondents being

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[2] See http://www.accc-cancer.org/publications/cancerprogramguidelines-overview.asp (accessed August 3, 2016).

from the south and equal distributions (21-22 percent) in the northwest, Midwest/Northeast, and West. Again, Grant, said, "We are a very committed group," with 27 percent of respondents working more than 40 hours per week providing oncology nutrition services.

Based on a 2015 national benchmarking study conducted by the Advisory Board Company's Oncology Roundtable, 76 percent of the 140 institutions surveyed reported having a dedicated dietitian working with cancer patients. Of these, 53 percent were generalist RDNs, and 44 percent were CSOs. The annual patient load per full-time equivalent (FTE) (among outpatient staffing) was 2,485 patients per dietitian, compared to 1,898 patients per financial counselor FTE and 1,408 patients per social worker FTE. According to 2014-2015 data collected by ACCC, while 98 percent of surveyed programs offered nutrition services, these programs did not have as many oncology dietitian FTEs (1.0) as they did social worker FTEs (1.6).

Barriers and Gaps

Oncology dietitians are often in competition with staffing that generates income, such as people who work in navigation services (i.e., navigating patients through the system), financial counselors, and people who work directly in patient treatment and care. Additionally, dietitians often feel like they are so busy with daily patient demands that they do not have time to document their need or value. Other "brutal facts," Grant continued, include inadequate RDN staffing, referrals to RDNs that occur after patients have experienced significant side effects and/or malnutrition, and lack of funding resulting from RDN services not being billed.

Opportunities for Providing Optimal Nutrition Care

In closing, Grant briefly identified opportunities for providing optimal nutrition care. First is something she said she "stumbled upon." It is a code (CPT Code 77470) that cancer centers can use to bill for both professional and facility fees and that has as one of its justifications that a patient needs more frequent monitoring, including nutritional consultation. These are patients receiving radiation treatment who are experiencing added toxicity that occurs with concurrent chemotherapy. Since she stumbled upon it, she investigated its history and found that billing for this code had tripled over the past 2.5 years.

Finally, Grant encouraged additional benchmarking studies and taking the lead or partnering to develop outcomes research that "shows our value." She also called for continued advocacy and forging and fostering of relationships with accreditation organizations and organizations that are developing care pathways for the treatment of cancer.

DISSEMINATION AND IMPLEMENTATION OF NUTRITIONAL CARE IN COMMUNITY SETTINGS[3]

"We have been hearing it all day today: Cancer patients need our help," Colleen Doyle started. She told two stories illustrating this. First, at a books expo in 2015, the individual who runs the ACS books department was approached by a distraught gentleman who said, "You know, you medical professionals, you medical organizations—you don't know how to help my wife. She is undergoing treatment. She can barely eat. She is losing weight. And nobody can help. Nobody knows what to tell her." The individual in the booth gave the distraught gentleman two books and flipped through the books and showed the gentleman some pages (Besser et al., 2009; Grant et al., 2010). The gentleman cried. "He was so happy and so relieved to have some resources," Doyle said.

The second story was one told to her by Hamilton, co-editor of the ACS's *Complete Guide to Nutrition for Cancer Survivors* (Grant et al., 2010), who witnessed the joy expressed by a husband and wife when they came into a cancer center where Hamilton was working and saw a copy of the book. The copy had been used so much that its binding had been broken and its pages filled with notes and marks. The joy expressed by the husband and wife illustrated for Hamilton how valuable and helpful this type of resource is.

Community-Based Settings for Supporting Cancer Survivors in Healthy Behavior Change

Through her work with the ACS, Doyle has been fortunate to visit many different hospitals, cancer centers, and other entities that have survivorship wellness programs. It has been a "real delight," she said, seeing the social support provided by community groups. She emphasized the many other opportunities that exist in the community for nutrition intervention, for example, retail-based clinics and recreation facilities. She mentioned having recently heard that one retailer was about to begin pilot testing having dietitians in their clinics. She pointed to diabetes prevention programs being implemented in the YMCA as an example of what can be done in recreation facilities. This is a "hot topic" right now, Doyle said. When she searched the Internet for community-based nutrition programs for cancer survivors, more than 3.5 million entries came up. She added, "With our survivorship numbers increasing, this issue is only going to be growing and presents us with a lot of need and opportunity."

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[3] This section summarizes information and opinions presented by Colleen Doyle, M.S., RD, American Cancer Society, Atlanta, Georgia.

Doyle mentioned two research projects on community-based nutrition support for cancer survivors that she thought had innovative components that speak to "a lot of what happens if we are really going to . . . grow our initiatives for cancer survivors." The first project, Growing HOPE, is a garden-based nutrition and physical activity education program for cancer survivors. For Doyle, both the results of the project (increased physical activity, decreased weight, improved dietary patterns, and improved biomarkers of health) and "the legs" that the initiative has in the community are "really exciting." As opposed to "just being one gardening program," the project has opened doors with relationships to Federally Qualified Health Centers and other collaborators in the community.

The second project, Moving Forward, a weight loss intervention trial for African-American breast cancer survivors, showed positive results after an Illinois pilot test (i.e., significant decreases in weight, daily calories, and dietary fat; significant increases in daily vegetables, fiber, daily vigorous activity; and a trend toward increased moderate activity). At the time of this workshop, the project was being tested as part of a randomized controlled trial. The innovative component of this project, Doyle said, is its partnership with the Chicago Park District. The park district is training their own staff so there is some potential for sustainability when funding runs out, according to Doyle. She said, "There are many different types of partners that we need to be tapping into to help advance this issue for cancer survivors. This to me was just another really great example of a nontraditional partner really stepping up to help advance initiatives for cancer survivors."

Doyle referred workshop participants to a 2015 meta-analysis published in the *Journal of Cancer Survivorship* that covered a variety of effective telephone, print, and Web-based interventions (Goode et al., 2015). She encouraged all dietitians to be aware of these different types of interventions and to be thinking about how to promote and work them into their systems.

Challenges for Communities

Many articles on community-based nutrition intervention in cancer survivors conclude, "We need more research." While she agreed, Doyle said, "But there is a lot of really good work going on out there that is ready for implementation." The question for Doyle is, what works for whom? What works with African-American breast cancer survivors in Chicago, for example, might not work with Caucasian breast cancer survivors in San Francisco. That different interventions work for different groups of survivors has implications for what to do within any given survivorship community.

Upon figuring out what works for whom, the next question for Doyle is, "How do we take [that] to scale?" How can something that yields such positive results be expanded across the country? Or, how can obesity interventions that work in Mississippi, for example, be taken to scale in other Southern states where obesity problems exist?

Another critical challenge, one that Doyle said the ACS thinks about all the time, is how to help navigate survivors to effective programs in their communities. The ACS has what they call their "community resource connection," and people can find their local ACS community resource connections online. Doyle noted that a 2017 Food and Nutrition Board workshop, Incorporating Weight Management and Physical Activity into Cancer Treatment: Overcoming Barriers in the Delivery of Care, was being planned and that some of the questions likely to be addressed include: What are the criteria for effective programs? What programs are out there? How can survivors be navigated to these programs?

A final challenge, in Doyle's opinion, is that there are not enough RDs to go around. She mentioned two nutrition-related interventions tested by the ACS that were partially created and tested by dietitians, but delivered by lay health workers. Both programs, despite not being delivered by dietitians, nonetheless yielded positive results. The first was Body & Soul, a telephone-based intervention that led to a significant increase in fruit and vegetable consumption (NCI, 2014). The second was Choose to Change, a dedicated counselor program that led to significant weight loss among overweight and obese participants and a significant increase in fruit and vegetable consumption among all participants.

Post-Treatment and Survivorship: Awareness of National Guidelines

The ACS's national survivorship guidelines have been available only since 2012 (ACS, 2012) because, according to Doyle, the evidence up until then was not strong enough to make certain recommendations for some groups of cancer survivors. Unfortunately, she opined, as already mentioned earlier during the workshop, obesity rates are high among cancer survivors (28 percent), with 32 percent reporting no leisure time activity and with many survivors (15 percent) reporting they still smoke (Underwood et al., 2012). Even though evidence of the importance of eating well and being active continues to grow, results of a survey conducted in 2008 indicate that survivors are no more likely than the general population to meet ACS health behavior recommendations (Blanchard et al., 2008). Yet, cancer survivors who follow the guidelines not only are at lower risk of recurrence and second cancers, but they are also at lower risk for other health problems (e.g., cardiovascular disease) and generally have a better quality of life (McCullough et al., 2011; Kabat et al., 2015).

To determine whether people understand connections between health and various factors, such as where they live, Doyle and colleagues conducted a series of video focus groups with survivors and non-survivors both, people with a healthy body mass index (BMI) versus an unhealthy BMI, and among different racial and ethnic groups. Across the board, Doyle said, while respondents were aware of other diseases and chronic conditions related to overweight and obesity, lack of activity, and poor nutrition, most respondents did not mention cancer. Likewise, when participants talked about healthy living, many talked about longevity and, when pushed, talked about heart disease or diabetes, but again, most respondents did not talk about cancer. Some respondents, Doyle said, almost seemed to be experiencing some kind of fatigue around messages, that is, that the messages were just "more and more stuff about how bad it is to not be at a healthy weight." Interestingly, Doyle noted, survivors were only slightly more aware of the link between cancer and obesity than non-survivors were.

"We have got a big awareness problem," Doyle said. She did not know of any national study on the awareness among cancer survivors of the effect of nutrition and physical activity on cancer. Learning how to communicate with cancer survivors about this issue "is really important," Doyle said. "We don't want them to feel like we are putting the blame on them." She emphasized the importance of learning how to send messages not only to individuals, but also health care providers.

She also highlighted the important role that the community plays in making it easier for people to eat better and be more active and shared with the workshop audience a story about being on vacation many years ago and calling her office when she and her husband arrived at their vacation beach house. She left the beach house phone number with her office and instructed them not to call her unless there was an emergency. She hung up the phone, turned around, and her husband was looking at her like she had lost her mind. He said, "Do you mind telling me what nutrition-physical activity emergency there could possibly be?" Doyle said she thinks about that a lot because, in her opinion, "We are in an emergency right now in this country." Interventions have been tested and shown to be effective in survivors. She said, "We then turn them back loose into these communities" where people do not have access to healthy, affordable fruits and vegetables or where they may not be able to safely play. "We have got a lot of work to do," she said. She referred workshop participants to the ACS's 2012 recommendation for community action. Without community involvement, Doyle said, "we can't sustain lifelong healthy eating [and] active living." She noted from an Institute of Medicine report (IOM, 2003), that it is unreasonable to expect that people will change their behavior easily when so many forces in the social, cultural, and physical environment conspire against such change. The true determinants of health, she said, are "where we live, work, eat, play, and pray."

Engaging Cancer Survivors as Advocates

There are more than 14 million cancer survivors in the United States. Doyle said, "We have a lot of opportunity to engage them in new and different ways . . . to support healthy eating." Imagine passionate breast cancer survivors up on Capital Hall advocating for nutrition intervention work or a cancer survivor approaching a school district and asking, "Why are you cutting recess?" In her experience, one of the first things people who are diagnosed say to her is, "Tell me what to do to not get this again." Then they ask what they should be telling their family to do to avoid getting cancer. In Doyle's opinion, cancer survivors are very powerful advocates for change in their communities.

Engaging Others as Well

But it is not just cancer survivors, but everyone "in this room," Doyle said, who is a champion for this issue of nutrition and nutrition support for cancer survivors. She said, "We need to use our voice and grow that field of champions out there." In addition to using their voice, she urged workshop participants to leverage relationships, stay committed, collaborate, think outside the box, implement and evaluate, and then figure out how to get tested interventions to where they need to be and how to sustain them so they really make a difference for people. Doyle viewed the effort reflected in this workshop as the beginning of a national movement to bring dietitians into cancer centers and hospitals and into community-based settings where they can help support survivors. She said, "I hope that when you leave here today, you will be able to think of at least two or three things you could do in addition to what you are doing now to really help support cancer patients."

DEVELOPING GUIDELINES FOR NUTRITION IN CANCER PATIENTS[4]

NCCN is an alliance of leading U.S. cancer centers devoted to patient care, research, and education, Joan McClure began. Its mission is to improve the quality, effectiveness, and efficiency of cancer care so patients can live better lives. One of its major initiatives over the past 20 years has been the development of clinical practice guidelines.[5] The purpose of the guidelines is to minimize variation in care, to set a standard of care for quality

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[4] This section summarizes information and opinions presented by Joan McClure, M.S., National Comprehensive Cancer Network, Fort Washington, Pennsylvania.

[5] See https://www.nccn.org/patients/guidelines/cancers.aspx (accessed August 3, 2016).

evaluation, to use as an assessment tool for payers to determine appropriate care, and to use as an educational instrument.

A high-quality guideline development process has several characteristics, McClure continued. First, it should be an explicit process. McClure noted that NCCN's process is published on their website, NCCN.org. Second, it should be evidence based when possible. With cancer, only about eight percent of recommendations across all treatment algorithms are based on what NCCN considers high-level evidence, according to McClure. "That is a problem," she said, and it highlights the need for more clinical trials. "It is not that the evidence is out there, and we choose to ignore it," she said. "It is that it doesn't exist." Much of oncology care is based on phase II studies or on historic practices. In many cases, clinical trials of current standards of care would probably be unethical (e.g., colectomies for colon cancer). A third characteristic of a high-quality guideline development process it that a level of evidence is identified for each recommendation. Fourth, the process should involve a multidisciplinary panel, especially in oncology, McClure said, because the care is shared across a number of different types of professionals. The core oncology group typically comprises a surgeon, pathologist, medical oncologist, and radiation oncologist. The NCCN guideline panels draw from about 40 different specialties, from nutrition to psychiatry. Fifth, panelists should be experts who understand the data. Sixth, conflicts of interest need to be managed and identified for users so they are aware of biases. Seventh, the guidelines should be updated frequently. NCCN guidelines are updated at least once per year, according to McClure, and some as often as five or six times per year as the standard of care changes. Eighth, the guidelines should be logical and follow the thought processes of users. It is much easier for providers to integrate new standards into their practices when the standards align with the way providers are accustomed to thinking about a problem. Lastly, guidelines should provide supporting documentation and extensive bibliographies.

The NCCN Guidelines

The NCCN guidelines have become the standard of clinical care and policy in the United States and increasingly around the world, according to McClure. In the 15 years she has been at NCCN, McClure has noticed a tremendous difference in the amount of acceptance the guidelines have received. They are downloaded about 6.5 million times yearly, with almost half of the downloads coming from outside the United States. She explained that they are continuum of care guidelines, which means that they follow the progression of disease from screening and diagnosis all the way through palliation and survivorship. There are a total of 62 different clinical practice guidelines in oncology, with 176 continuously updated algorithms, or decision pathways. The guidelines are widely available free of charge on the internet. They form the basis for insurance coverage policy and quality evaluation, with the Centers for Medicare & Medicaid Services (CMS) and all major payers in the United States using them for at least some portion of their coverage and reimbursement policies.

The guidelines are supported by 49 multidisciplinary panels, with 25-30 experts per panel. The panelists are nominated by NCCN member institutions. Together, these panelists volunteer more than 26,000 hours yearly. Most panels have patient advocates on them, and some panels actually solicit input from patient advocacy organizations. They also receive submissions from both the pharmaceutical industry and payer community, and also from community oncologists and oncology societies. In 2016, the American Society for Radiation Oncology (ASTRO) started conducting their own reviews of the NCCN guidelines and providing input to the NCCN panels. The panels also receive individual recommendations from patients or family members who ask for consideration of particular items.

McClure encouraged dietitians who work at NCCN member institutions to seek out people who are on the review panels. "Tell them that you want to participate in the institutional review," she said. "That is the way to get [nutrition] data into the deliberations of the panels. This is really important."

In addition to input from all these various sources, each year NCCN staff conducts a literature search for all phase II and III clinical trial reports and examines those that are relevant to decisions the guideline panels will be making. The panelists discuss the evidence and vote for changes in the guidelines, as needed. NCCN then updates the algorithms and references, working with the panel chair, vice-chair, and members to ensure accuracy. Even after posting newly updated guidelines on the NCCN website, NCCN continues to review new information. If there is anything that comes out that changes the standard of card, for example, if the U.S. Food and Drug Administration approves a new drug or if a clinical trial is stopped for efficacy or toxicity reasons, an interim meeting with the relevant panel is called to discuss the data and a decision is made as to whether the guideline needs to be immediately changed.

Each guideline is based on what the NCCN calls a "category of evidence" and consensus. Category 1 evidence, McClure explained, is what NCCN defines as "high-level" evidence, which means there are randomized controlled clinical trials or meta-analyses addressing that particular issue and the panel considers the evidence to be persuasive, with at least 85 percent of member institutions agreeing this is the case. Category 2A evidence is based on lower-level evidence, including phase II trials, case series, and even the clinical experience of panel members when other data are lacking. Again, at least 85 percent of NCCN member institutions must agree that the intervention is appropriate. Category 2B is also based on the same type of lower-level evidence, but with NCCN consensus being only between 50 and 80 percent that the intervention is appropriate. Lastly, Category 3 recommendations can be based on any level of evidence, but with major disagreement among member institutions (i.e., at least three institutions on each side) that the intervention is appropriate. Category 3 discussions are very spirited discussions, where participants feel strongly, she said. All NCCN recommendations are category 2A unless otherwise noted.

There are many gaps in the evidence along the continuum of care, McClure said. Panels fill those gaps with their expert experience, sometimes extrapolating from data in other situations and other times basing their decisions on their own clinical experience. For a number of low-incidence cancers, the gaps are especially large.

Over the last 2 years, in response to people who use the guidelines wanting to know how panel members make decisions about what to include and not include, McClure and her team at NCCN have been more explicitly categorizing the evidence so that clinicians and patients can make decisions based on their own values. Using a consistent "evidence block" methodology, which takes into account efficacy, safety, quality of evidence, consistency of evidence, and affordability, McClure explained that they started with systemic therapies (i.e., started explicitly categorizing the evidence) and are going to expand into radiation therapy, surgery, diagnosis and evaluation, and surveillance over the next few years. NCCN views these evidence blocks as potential tools not only for clinicians to evaluate therapies, but also for clinicians and patients to share decision making. The evidence blocks are being published alongside the guidelines. The more filled in the blocks, "the better," McClure said.[6]

NCCN Guidelines for Nutrition in Cancer Patients

NCCN has made three separate attempts to develop guidelines for nutrition in cancer patients. The first attempt was 15 years ago. The panel had a medical oncologist chair and was composed of equal numbers of physicians and professionals from the nutrition community (e.g., Ph.D. nutritionists, RD). McClure recalled, "The physicians and the nutritionists did not speak the same language. They didn't think the same things were important. They didn't think the same data were persuasive. We couldn't get to the point of even a draft guideline." Although that first attempt was what she described as a "disaster," they thought the need was important enough to try again.

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[6] For more information, see https://www.nccn.org/evidenceblocks/pdf/evidenceblocksuserguide.pdf (accessed August 3, 2016).

The second panel was composed almost exclusively of professionals from the nutrition community. The panel put together what McClure described as “a very complete draft from the perspective of the nutrition community.” But the draft was not approved by the NCCN guideline steering committee, which is composed of physicians. McClure said, “You need to get yourselves embedded with the physician community . . . learn to talk the same language and to look at data in similar ways.” While there have been a number of good studies on nutrition in breast cancer survivors, she continued, in comparison to most other cancers, that number is relatively small compared to the 3,000 or so studies on treatment for breast cancer that are published every year. She said, “The physician community regards your evidence base, in my opinion, as relatively poor.” Additionally, she said, physicians are very aware that, with nutrition, “One size does not fit all.” There are big differences in the nutritional needs and issue for patients with breast cancer versus head and neck cancer versus advanced ovarian cancer. She suggested “attacking” the issues one by one, disease site by disease site. Not only do different diseases have different nutritional issues, but each treatment intervention needs to be addressed separately. “It is going to be a long haul,” she said.

Thus far, the only “hard and fast” nutrition recommendations where consensus has been possible are with survivorship. The recommendations are for nutrition and weight management. They are publicly available on the NCCN website, McClure noted.

Some Strategies for Moving Forward

In closing, McClure suggested some strategies for moving forward. First and foremost, develop a more extensive evidence base. She suggested integrating correlative nutrition studies and nutrition status studies into large treatment clinical trials and seeing who responds versus who does not respond and what survivorship is for people with good nutrition status versus poor nutrition status. With those data, she said, “You would have a much better chance to convince the medical community.” Additionally, she encouraged, again, dietitians who work at NCCN member institutions to make themselves known to the guideline steering committee representatives from those institutions and to participate in the institutional reviews. She also encouraged dietitians who are not at member institutions to submit data to the panels.

PANEL DISCUSSION WITH SPEAKERS: DATA GAPS IN COMMUNICATION AND DISSEMINATION OF ONCOLOGY CARE

Following McClure’s presentation, she, Grant, and Doyle participated in a panel discussion with the audience.

Nutrition Screening

The first question was directed at Barbara Grant. An audience member asked whether nutrition screening in particular is required as part of the Commission on Cancer (CoC) eligibility criteria. Grant clarified that nutrition screening is something that is recommended, but it is not a required standard at this point.

The NCCN Guidelines: Get Involved

Suzanne Dixon was on that first NCCN nutrition panel and agreed with McClure, "It was a disaster." But that was 15 years ago. Dixon said, "We bemoan how little we have now, but we certainly had a lot less when I went through that experience." She learned a lot going through that experience, including that it was because she made herself visible to her institution that "somebody put me out there." She encouraged "everyone in this room to go back to your institution and make yourself visible. People will recognize that and invite you to participate."

In response to McClure mentioning during her presentation that ASTRO provides input to the NCCN panels, Grant remarked that there is some good nutritional intervention evidence in the Evidence Analysis Library (EAL) for certain cancers and at certain points along the continuum of care. McClure encouraged submissions from the nutrition community, particularly if a professional organization "mentored" the submission so that, to help manage time constraints, panels are receiving only single collated submissions rather than multiple separate submissions.

The Challenge of Testing Nutrition Interventions in Clinical Trials

Dixon wondered how to reconcile the need to collect and analyze nutrition intervention data with the knowledge that nutrition interventions do not fit the Western medical model of placebo-controlled, double-blinded clinical trials. In "free-living humans," she said, the level of evidence for nutrition intervention is never going to be the same as it is with pills. In clinical trials, some people take pills with active constituents. Other people take pills with no active constituents. Testing nutritional interventions is more complicated because of contributing factors, such as "bleed-over" from the intervention group to the control group. Bleed-over occurs when people in the control group suddenly start doing something different based on, for example, some popular diet that is in the media. McClure responded that these are the same issues that come up with "big data." She did not elaborate, but suspected that sorting through these issues will be part of the larger discussion around how to use big data.

McClure also reiterated the importance of including nutrition assessments in some of the large clinical trials of treatment interventions and conducting planned subsets of analyses based on nutritional status. If you can demonstrate in a large, well-controlled clinical trial that people with better nutritional status do better in either or both the experimental and control arms, she said, "you would be far ahead of where you are today."

The CSO Credential

An audience member asked about ways to expand the CSO credential and whether the numbers are small because there is no demand or because demand for the credential needs to be exhibited. Grant replied that it is a new credential and that its numbers are growing. Because it is not required the way the RD/RDN credential is required, many dietitians pay for it without institutional support. That makes it tough, she said. Robien added, based on what she has observed, that the credential seems to be limited to dietitians who need it for their jobs. She sees a lot of job advertisements for RDs indicating that they want the successful applicant to become CSO-certified within a certain period of time. Levin described it as a "catch-22" situation. If there were more positions for nutritionists in oncology, then more people would be interested in training in oncology. "But there just aren't that many positions," she said. Those that do exist, she added, "tend to be very grueling." An audience member suggested that recommendations be made on the employer end because those would drive payer demand which, in turn, would drive provider demand and create more job opportunities for CSOs (i.e., because they would be part of the employer–payer contract). Grant repeated that just having the RD/RDN credential in the CoC eligibility requirements is huge. She suggested that in another year or two, perhaps the CSO credential can be recommended as well.

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Evidence on Nutrition Care in Outpatient Oncology: Closing Discussion

OVERVIEW

In the final session of the workshop, led by Steven Clinton, Kim Robien, and Suzanne Dixon, speakers from all sessions participated in a facilitated discussion and were presented with five questions:

1. What is new and creative in oncology nutrition care that will move the field forward?
2. How can we make the registered dietitian (RD)/registered dietitian nutritionist (RDN) part of the health care system?
3. How can nutrition care become part of routine oncology care in the outpatient setting?
4. How will nutrition care in outpatient centers be paid for?
5. What is the evidence to justify the need for nutrition care in outpatient oncology?

Rather than directly answering these questions in turn, the speakers and other workshop participants used them more as backdrop for the discussion.

Three major overarching themes emerged during the course of this discussion. Each is discussed in detail below. First, prompted by a question from Dixon and given the range of topics addressed during the workshop, from minute clinical details to community-based interventions for survivors, there was some discussion around the need to engage dietitians across the continuum of cancer care. Second, Clinton highlighted a statement that Joan McClure had made during her presentation about the fact that for every one nutrition study in oncology, there are probably about 3,000 drug studies. This raised a question for Clinton about how to build the evidence base for nutrition interventions among oncology patients and survivors, which led to some discussion, first, around the value of observational nutrition evidence and, second, around ways to include nutrition studies in clinical drug trials. Third, there was some discussion around the value of nutrition services and ways to measure this value. This discussion was prompted by Dixon's reminder to the workshop audience that the idea for this workshop originated before the 2010 Affordable Care Act, back when a pressing question for dietitians working in oncology was, "How do we get reimbursement?" She suggested that this question is no longer relevant, given that reimbursement for cancer care is no longer being provided in the traditional "fee-for-service" sense, and urged the nutrition community to determine other ways to demonstrate value.

Finally, this chapter concludes with a summary of the workshop chair's closing comments.

TACKLING THE CONTINUUM OF CARE

For Dixon, one of the big tasks and challenges of moving the field of nutrition oncology forward is tackling the continuum of care. She asked, "How are we going to bring dietitians into this continuum of care?" Back when she served on that first National Comprehensive Cancer Network (NCCN) guideline panel 15 years ago, with respect to nutritional intervention during treatment, she said, "I would often hear, 'You don't really have any evidence that what you are doing matters.'" She would reply, "But we have plenty of evidence that what we do matters over the continuum of care for this patient's life. Wouldn't you feel horrible if you cured them of cancer and, five years later, they died of a preventable heart attack?"[1]

In Dixon's opinion, to capture all opportunities for dietitians to become involved in the treatment continuum, oncology nutrition needs to be considered from a "very big picture, chronic disease" perspective. She agreed with McClure's suggestion to measure nutrition status as part of cancer drug clinical trials to help determine whether people with better nutrition status are more likely to stay on their treatments. But even doing that is looking through a very short window of time—10 or 12 or 16 weeks for most cancer survivors. What about the next 5, 10, or 30 years of cancer survivors' lives? How should that care be addressed?

Rock wondered how the American Institute for Cancer Research (AICR) communicates new information across the continuum of care.

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[1] See Chapter 5 for summaries of Joan McClure's overview of the history of attempts to develop NCCN nutrition guidelines and Dixon's comments afterward.

Deidre McGinley-Gieser explained that, as with the American Cancer Society (ACS) and other organizations, what the AICR used to be called "education" has morphed into "communication." AICR is constantly evaluating how they are communicating scientific messages to ensure that the messages they send have broad appeal. They communicate both through print (e.g., brochures and leaflets) and electronically. In their print messaging, they choose language that makes sense and is "real" and "something that people can hold onto." In their electronic messaging, because it is a more cost-effective way to communicate, they are able to target their messages a little more narrowly and change the tone of voice depending on who they are targeting. Because AICR is a small organization, while they are able to promote their services and encourage people to join, they are not able to do the type of larger-scale community interventions that the ACS, for example, does. But they provide usable tools and information for the health professional community to use in its intervention work. Additionally, AICR holds an annual scientific conference that McGinley-Gieser described as a very important component of their whole program because it fosters discussion among multiple groups about what can be done differently, better, and more effectively. It is one of the few meetings where professionals from these different communities (i.e., oncology, dietetics) come together and discuss common issues.

McGinley-Gieser's description of AICR's work prompted Dixon to ask about inroads that other groups have made and whether there are lessons to be learned. For example, she mentioned the Lance Armstrong Foundation (now known as the Livestrong Foundation) and the YMCA and the work they do with physical activity. She suggested looking at work that these and other organizations have done to raise awareness and improve access to people who have relevant knowledge. These organizations could serve as models for moving forward and addressing the continuum of care.

INCORPORATING NUTRITION STUDIES INTO DRUG CLINICAL TRIALS

During her presentation on the NCCN guidelines, McClure had stated that, while the best nutrition evidence may be among breast cancer patients and survivors, for every one of those nutrition studies, there are probably some 3,000 drug studies. Clinton agreed with McClure that "the database is so profoundly different." Moreover, he observed, in nutrition research, much of the work is lab based. Much of the data are coming from cells in culture and from lab animals and, as such, are insufficient to define clinical standards. There is what he described as a "big barrier" in the translation of that work into the clinic. He called for "a stronger collection of good solid clinical studies." He suspected, however, that very few RDs have research grants. In his opinion, to compete with the drug treatment evidence base, "We need more RD/Ph.D. folks that have a foot in the clinic and have another foot in the laboratory." This will require getting the National Institutes of Health (NIH) to recognize that nutritional oncology warrants a "bigger slice of the pie." Meanwhile, the most important step to take now, as a group, in his opinion, is to identify which area of the evidence base is most substantial, significant, and compelling. He suggested targeting disease-specific NCCN guidelines where the evidence is the most compelling. He said, by "picking our battles, we win." Those wins will foster additional research, he predicted. "I see light at the end of the tunnel," he said, "as dim and flickering as it may be."

Rock found it interesting that nutrition guidelines for survivorship have been accepted,[2] given that there have been only two dietary intervention studies in survivors and that neither yielded very compelling evidence regarding the effectiveness of the dietary interventions. The NCCN survivorship guidelines are based mostly on observational data. McClure replied that the nutrition portion of the survivorship guideline falls within the healthy lifestyle section, alongside physical activity, immunizations, supplements (i.e., not taking them), smoking (i.e., not smoking), sleep, and hygiene, that is, things associated not only with lower likelihood of recurrence, but also lower risk of heart attack and stroke. Rock interpreted this to mean that the guideline is based more on the effects of comorbidities than on cancer-specific survival. McClure replied, "It is the big picture of healthy living." McClure mentioned the chair of the panel, Crystal Denlinger, a medical oncologist, and the "fabulous" job she did with the guideline.

Robien commented that several other (non-NCCN) recommendations are similarly based on observational studies. She named AICR, World Cancer Research Fund, and the ACS. When those guidelines are operationalized and applied to data from prospective cohort studies, Robien said, "They are being confirmed." So while a randomized controlled trial provides a stronger level of evidence, there is so much observational data and so much consistency that when the guidelines are evaluated this data should count as well, in her opinion.

With respect to which cancer and which area of the continuum of care has the strongest set of observational data, Clinton identified breast cancer survivors as having a very strong set of observational data in addition to a small amount of intervention data and lots of laboratory/mechanistic data. Colorectal cancer survivors who have had partial colectomies may be another "low-hanging fruit," in Clinton's opinion, not so much with

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[2] See Chapter 5 for a summary of McClure's overview of the history of attempts to develop NCCN nutrition guideline.

recurrence, where observational data are limited, rather with respect to preventing second primaries.

A great example of incorporating a nutrition study into a phase III clinical trial, Clinton continued is the colorectal cancer studies conducted by Charles Fuchs, a physician at the Dana-Farber Cancer Institute (Harvard Medical School). In a phase III trial, the Harvard food frequency questionnaire was used to survey participants. Clinton said, "It amazes me that we would even do a phase III chemotherapy trial and not spend the extra few hundred thousand dollars to collect that kind of data," for example, by conducting nutritional assessments or sampling blood for biomarkers of nutritional status. He wondered whether there was a way to push in this direction with the NIH with respect to phase III therapeutic trials.

Liz Isenring suggested that, rather than "reinventing the wheel," perhaps a first step toward developing site-specific guidelines would be to see whether those or other available guidelines are appropriate. She viewed updating or endorsing already existing guidelines as another type of "low-hanging fruit" and suggested looking at head and neck cancer in particular, given existing Wiki guidelines[3] that have been endorsed by multiple countries.

With respect to levels of evidence in nutrition compared to what is expected with the medical model, Isenring commented that she and colleagues are in the final stages of a large national psycho-oncology and nutrition collaborative research study in Australia and that some of the interventions in psycho-oncology are based on no evidence. "We have got to really put this [level of evidence] into context," she urged. For certain interventions, for example in the area of artificial nutrition support and tube feeding, while there might not be a meta-analysis of level I randomized controlled trials, there might be some "pretty good" evidence from level II or III studies.

Rhone Levin noted that the Clinical Oncology Society of Australia (COSA) guidelines for head and neck cancer were approved during the 2013 EAL update process as being appropriate for use in the United States and therefore were added to the library. The Oncology Nursing Society Putting Evidence into Practice guidelines were added as well.

In addition to building the evidence base for nutrition interventions among oncology outpatients, for Robien, another reason the nutrition community should become involved with clinical trials is to support standardization with respect to how body surface area is assessed and height and weight data are collected. There is a lot of what she described as

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[3] Guidelines developed by the Clinical Oncology Society of Australia (COSA) for the nutritional management of adult patients with head and neck cancer; available online at http://wiki.cancer.org.au/australia/COSA:Head_and_neck_cancer_nutrition_guidelines (accessed August 3, 2016).

"ambiguity" with respect to measuring even those "simple things." She agreed with Clinton that adding nutritional studies to phase III trials would be a "very small add-on." In fact, according to Robien, nutritional status data are already being collected for many outcomes of interest, such as ability to complete treatment regimens and the NCI's common toxicity criteria.

Part of the challenge for dietitians to become involved in clinical trials, Dixon remarked, is that many RDs do not feel confident putting themselves at the table that early in the continuum of care. She viewed it as an issue of education and training and the reality, based on her experience, that many RDs working in comprehensive cancer centers would not even know how to approach an investigator working on a phase II or phase III clinical trial and ask, "Have you ever thought of measuring the impact of nutritional status on whether or not your patients get their full course of treatment?" She encouraged more thought around how to change the culture of dietetics and empower dietitians to put themselves forward and say, "I really want to be part of this study and give you my expertise." Robien agreed with Dixon, but asked where "people who are in the trenches" are going to find the time.

Clinton cautioned against selecting NCCN guideline committee members based purely on experience as practitioners. A professional who has been trained to be what he called an "academic thinker" can still be a great practitioner who provides good care. That said, in Clinton's opinion, the field of dietetics needs a greater subset of professionals who are trained, perhaps with Ph.D.s, to also be the scientists who sit at the table to help design, execute, and analyze data. He was unsure how many of the approximately 94,000 RDs in the United States have additional training as scientists. Whatever the number, he said, "It is clearly not enough." He called for an expansion of research opportunities for RDs, perhaps through directed requests for training proposals from the NIH. Dixon replied that often, when RDs earn Ph.D.s, they are no longer clinically focused and no longer have that access. She agreed that efforts need to be directed toward fostering dietitians who have feet in both worlds. Robien added that, perhaps instead of specializing in nutrition, RDs who decide to work toward Ph.D.s should specialize in epidemiology, where there is more focus on study design and data analysis skills. "You can always go back to your clinical roots," she said. "I think that we need more methodologists."

While there were several calls for adding nutritional components to phase III trials and the comparatively minimal cost of doing so, a couple of workshop participants cautioned that the current structure of the NCI funding and the "hoops to jump through" pose a challenge. Rock remarked that the NCI now requires all phase III trials to operate as part of its community-based oncology group system, rather than be investigator initiated as in the past, and that many older study designs would not even begin to be evaluated by the NCI today. A workshop participant added, "It sounds easy to say, 'Oh, just collect dietary assessment on all the patients going through X, Y, Z trials.' . . . I think it is going to be more difficult." Collection of those data requires approval from multiple parties even before any funding decisions are made, the participant stated.

Revisiting earlier comments about the need to empower dietitians, there was some additional discussion about the importance of dietitians developing relationships with advocates and other oncology professionals as a way to "get the word out" and build momentum for conducting nutrition studies. Fonfa encouraged dietitians to attend as many conferences as possible and submit abstracts to "get the word out." Another workshop participant emphasized grassroots efforts within dietitians' workplaces and the importance of developing relationships with not only physicians, but also physical therapists, speech therapists, and nurses, so these other professionals begin seeking out dietitians' expert opinions, much like physicians send their patients to physical therapists because they recognize the value of physical therapy. Strengthening those relationships, the participant opined, would strengthen the case for incorporating nutrition into clinical trials.

In Clinton's opinion, dietitians "hold their own very nicely" when given the opportunity to work with professionals in other disciplines. The challenge, as he saw it, is that there are 6,000 new cancer diagnoses for every consult a dietitian is able to do. There is a "disconnect," he said, "between what we think we need right at the moment and what we actually have on the ground." Robien saw the same challenge. She asked where "people who are in the trenches" are going to find the time to participate in clinical trials.

DETERMINING THE VALUE OF NUTRITION SERVICES

Dixon reminded the workshop audience that discussion about this workshop originated before the 2010 Affordable Care Act. Back then, the question for dietitians who worked in oncology was, "How do we get reimbursement?" Now, without reimbursement being provided in the traditional fee-for-service sense, she said, "We really have to start thinking creatively about this." In her opinion, asking how dietitians will get reimbursement is no longer the relevant question. The nutrition community needs to define ways to determine value.

Mention of value spawned a brief discussion around coding, with an unidentified workshop participant suggesting that one way to justify employing full-time dietitians in oncology centers is to use codes that indicate cases where dietitians are needed. Clinton replied, "I have a strong opinion about this." Recognizing that coding is key to current billing, he did not think that health care providers should be the coders. "We have got better things to do," he said. Good physicians do their best to document what their patients' problems are in their notes, he said, but it is impossible to memorize the many constantly changing codes. Another workshop participant wondered if there were even some basic codes, for example a malnutrition code, which could be used. Dixon suggested that other ways to justify employing full-time dietitians include sharing information from this meeting (e.g., this workshop summary) and using the Academy of Nutrition and Dietetics' (AND's) Evidence Analysis Library (EAL) to make the case that, for example, a one-day-a-week dietitian is not enough to provide a given type of grade A level evidence-based care. Additionally, she suggested that perhaps the AND's Oncology Nutrition Dietetic Practice Group (ONDPG) could create an article for their newsletter that could serve as a resource for ways to code that may improve the recognition of malnutrition in the clinical setting.

Mention of the EAL prompted Clinton to wonder whether there might be a way to create a joint effort between the U.S. Department of Agriculture's Nutrition Evidence Library (NEL), which Clinton described as being "amazingly skilled" at conducting literature searches and evaluating data, and the AND. In his opinion, messages based on a joint effort and the level of objectivity associated with the NEL process might have greater value than messages coming from a professional organization by itself. Robien noted that the framework and process of the NEL are the same as those of the EAL. Clinton then wondered whether there might be a way to work with NIH, for example, to conduct these evaluations such that the AND does not have to bear the entire cost of what is a laborious process.

There was some brief discussion about insurers, with one participant wondering whether it might be possible to get them involved, for example, by engaging employers, and another agreeing that it would be a "great idea" and that Aetna and UnitedHealth Group (through Optum) both already have "fantastic" cancer advocacy programs. Dixon noted that a dietitian in ONDPG provides lectures and classes for Aetna. She viewed the challenge as, "How do you capitalize on that to reach beyond just the occasional once-a-quarter type of class?"

Another workshop participant suggested that Vice President Joe Biden's cancer "moonshot" campaign and his apparent openness to engage multiple stakeholders from different fields creates a unique opportunity to engage a broader national dialogue about nutrition in cancer. Robien agreed. Clinton, however, expressed uncertainty. He stated that, while Biden's "heart is in the right place," he questioned Biden's appreciation for the key role of prevention in the "war on cancer." At a recent Washington, DC, roundtable discussion on the topic, Clinton did not recognize any nutritional scientists at the table. The focus of the conversation, he said, was on molecular markers and sequencing, "big data," and ways for pharma to use those data to develop personalized targeted drugs. Acknowledging his own cynicism, Clinton said, "But right now, this is the line of thinking." In his opinion, it is "such a strong wave in the scientific community" that it obscures the fact that 15-20 percent of the population is still smoking despite 50 years of scientific evidence on the effects of smoking. One of the biggest challenges "in this current paradigm," he said, is just getting a seat at the table. He suggested that if some of the organizations represented at this workshop were to lobby at Biden's door on behalf of food, nutrition, and cancer prevention, "maybe we can at least get a foot in the door." Rock agreed with Clinton that, right now, there is no room at the table. Even "the physical exercise" people are not at the table. She said, "There is no mention of behavior at all." More generally, Rock emphasized the behavioral challenge that dietitians are up against. It is one thing to exercise every now and then. It's "quite another thing" to give up cheesecake and chocolate chip cookies. She said, "People eat food, not nutrients."

CHAIR'S SUMMARY

To conclude the workshop, Rock summarized some of the major overarching themes of the workshop presentations and discussions. First, the objective of the first session of the workshop was to describe the current status of nutritional care for oncology outpatients. "We concluded," Rock said, "that there was a fair amount of evidence." While there is still not "enough" evidence, as Joan McClure discussed during her presentation on the NCCN guidelines, Rock said, "We are on the road."

The second workshop objective was to describe the ideal care setting for nutritional care for oncology outpatients. Rock highlighted the international models of care, especially early care, described by Liz Isenring.

The third workshop objective relating to the potential benefits of outpatient nutritional care was met, Rock observed, over the course of several sessions.

With respect to the fourth workshop objective, that is, describe issues relating to cost–benefit assessments for both recent diagnosis and post-treatment care, Rock highlighted Jim Lee's discussion about ways to conduct cost–benefit assessments without collecting too much detail. Much of that detail, Rock said, can be daunting for people who are not health economists.

Lastly, with respect to the fifth workshop objective, there was plentiful discussion around barriers to achieving an ideal care setting and ways to overcome these barriers. Rock referred to some of the Session 4 discussion around using community-based organizations, like the ACS, to overcome barriers across the continuum of care (see Chapter 5 for a summary of this discussion). A target group that this workshop only briefly touched, Rock observed, was childhood cancer survivors. Another important point is that the bulk of medical care for all long-term cancer survivors is provided by primary care providers. We often criticize oncologists for neglecting nutritional issues Rock said, “but after the oncologists are done with initial care of cancer patients, there is a much larger group of health care providers that are really the first-line caretakers of these patients.”

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Appendix A

Workshop Agenda

Examining Access to Nutrition Care in Outpatient Cancer Centers

Planning Committee on Assessing Relationships Between Access to Standardized Nutritional Care and Health Outcomes and Cost-Effectiveness of Care in Outpatient Cancer Centers

March 14, 2016
The National Academies Keck Center
Room 100
500 Fifth Street, NW
Washington, DC 20001

WORKSHOP OBJECTIVES

- Describe the current status of nutritional care for oncology outpatients, including the availability of data during treatment and long-term survivorship.
- Describe the ideal care setting, including models of care within and outside the United States.
- Describe the potential benefits of outpatient nutritional care on morbidity, mortality, and long-term survival.
- Describe the issues relating to cost–benefit assessment for both recent diagnosis and post-treatment care.
- Describe the barriers to achieving an ideal care setting and the information resources available to patients.

7:30 am **Registration**

Introduction and Opening Remarks

8:00 Welcome
Cheryl Rock, University of California, San Diego, Planning Committee Chair

8:05 Keynote
Steven K. Clinton, The Ohio State University

8:25 **Sponsor Panel** (5 minutes each)

- American Institute for Cancer Research, *Deirdre McGinley-Gieser, Senior Vice President for Programs*
- National Institutes of Health, National Cancer Institute and Office of Dietary Supplements, *Elaine Trujillo, Nutrition Science Research Group*
- Alcresta, Inc., *Karen Sullivan, Director of Marketing*
- American Cancer Society, *Colleen Doyle, Managing Director, Nutrition and Physical Activity*
- Oncology Nutrition Dietetic Practice Group/Clinical Nutrition Management Dietetic Practice Group, *Katrina Claghorn, Advanced Practice Clinical Dietitian Specialist Patient & Family Services, University of Pennsylvania*
- Academy of Nutrition and Dietetics (AND) and the AND Foundation, *Alison Steiber, Chief Science Officer*

SESSION 1: Current Knowledge and Status of Nutrition Practice in Oncology Outpatient Care

Moderated by Cheryl Rock, University of California, San Diego, Planning Committee Chair

9:00 Nutritional Interventions and Issues in Early Oncology Treatment
Mary Platek, Roswell Park Cancer Center
Nutritional Interventions and Issues in Long-Term Oncology Care
Cheryl Rock, University of California, San Diego

10:00 Panel Discussion: Data Gaps in Current Nutrition Practice in Oncology Outpatient Care
Session Speakers

10:20 Break

SESSION 2: Models of Care: National and International Perspectives

Moderated by Kim Robien, The George Washington University, Planning Committee Vice Chair

10:40 Models of Nutrition Care in Outpatient Oncology in the United States and Barriers to Achieving Ideal Care
Rhone Levin, Dell Children's Medical Center
Models of Nutrition Care in Outpatient Oncology Internationally
Liz Isenring, Bond University, Queensland, Australia

11:30 Panel Discussion: Data Gaps in Models of Care
Diana Dyer, Consultant, Ann Arbor, Michigan
Session Speakers

12:00 pm Break for Lunch

SESSION 3: Benefits and Costs of Care

Moderated by Nico Pronk, HealthPartners, and Wendy Johnson Askew, Nestlé Nutrition North America

1:00 Cost–Benefit Considerations
Jim Lee, Altarum Institute

1:20 Perspectives on Oncology Nutrition Care: Employers and Other Purchasers
Brenna Schebel, National Business Group on Health

1:40 Panel Discussion: Data Gaps in Outcomes and Costs of Care
Session Speakers

2:00 Break

SESSION 4: Dissemination Science and Implementation: Reaching the Ideal

Moderated by Marian Neuhouser, Fred Hutchinson Cancer Research Center

2:30 Dissemination and Implementation of Nutritional Care in Acute Care and Specialized Centers
Barbara Grant, Saint Alphonsus Cancer Care Center

Dissemination and Implementation of Nutritional Care in Community Settings
Colleen Doyle, American Cancer Society
Development of Clinical Practice Guidelines
Joan McClure, National Comprehensive Cancer Network

3:30 Data Gaps in Communication and Dissemination of Oncology Care
Session Speakers

SESSION 5: Facilitated Discussion: Synthesis of the Evidence

4:00 *Discussion Leaders:*
- *Steven Clinton, The Ohio State University*
- *Kim Robien, The George Washington University*
- *Suzanne Dixon, The Health Geek LLC*

Questions for Participant Discussion:
- What is new and creative in oncology nutrition care that will move the field forward?
- How can we make the registered dietitian/registered dietitian nutritionist part of the health care system?
- How can nutrition care become part of routine oncology care in the outpatient setting?
- How will nutrition care in outpatient centers be paid for?
- What is the evidence to justify the need for nutrition care in outpatient oncology?

4:40 Chair's Summary and Recognition of Additional Sponsors
Cheryl Rock, Professor, Department of Family Medicine and Public Health, University of California, San Diego
Recognition of Additional Sponsors:
- OptionCare, *Noreen Luszcz, Nutrition Program Director*
- Medtrition, *Evelyn Phillips, Corporate Clinical Dietitian Consultant*
- Savor Health, *Susan Bratton, Founder and CEO*
- The Annie Appleseed Project, *Ann Fonfa, President*

5:00 Adjourn Meeting

Appendix B

Biographical Sketches of Speakers and Moderators

SPEAKERS

Steven Clinton, M.D., Ph.D., is Professor in the Department of Internal Medicine, Division of Medical Oncology at The Ohio State University. He is the Program Leader for the Molecular Carcinogenesis and Chemoprevention Program of the Comprehensive Cancer Center and serves the James Cancer Hospital as Director of Prostate and Genitourinary Oncology. Dr. Clinton is a faculty member of the campus-wide Ohio State University Nutrition Graduate Program (OSUN) and is Co-director of the Center for Advanced Functional Foods Research and Entrepreneurship. His research examines fundamental mechanisms underlying the development of cancer and studies novel prevention and therapeutic strategies in human clinical trials. His cancer research interests within nutritional sciences include the roles of energy intake, bioactive lipids, vitamin D, carotenoids, and other phytochemicals.

Suzanne Dixon, M.P.H., M.S., RDN, is an epidemiologist and Registered Dietitian, and an author, speaker, and internationally recognized expert in nutrition, chronic disease prevention and management, and health and wellness. She is best known as the creator of the award-winning website CancerNutritionInfo.com (sold in 2005), which was acclaimed by *The New York Times* and named one of *Time* Magazine's 50 Coolest Websites of 2005. She has numerous scholarly and popular literature publications and has received awards from the Academy of Nutrition and Dietetics for Innovative Nutrition Education Programs for the Public and Distinguished Practice in Oncology Nutrition. Ms. Dixon received her training in epidemiology and nutrition at the University of Michigan, School of Public Health, at Ann Arbor, and currently runs her own consulting business in Portland, Oregon.

Colleen Doyle, M.S., RD, is Director of Nutrition and Physical Activity for the American Cancer Society. She is a registered dietitian who has worked in the health promotion field for more than 20 years. In her role as director, she has been instrumental in developing strategies to increase awareness of the importance of diet and exercise for chronic disease prevention and management, and to create changes in schools, worksites, and communities that can help improve healthy lifestyles. Colleen has extensive media and public speaking experience. She has appeared on national broadcasts, including CNN, Headline News, Discovery Health, and the Do It Yourself Network, as well as numerous local news and cable television shows. She is frequently quoted in nationwide publications including *USA Today*, *The Washington Post*, and the *Los Angeles Times* and is a frequent presenter at both scientific and consumer meetings, and has authored numerous scientific and consumer articles on nutrition and physical activity.

Diana Dyer, M.S., RD, is a registered dietitian in Ann Arbor, Michigan, and a two-time breast cancer survivor. She is also a survivor of neuroblastoma, a childhood cancer. After a 20-year career working in the specialty area of critical care nutrition, Ms. Dyer combined her personal experience and professional expertise to focus her efforts on increasing awareness of the benefits of proactively including nutrition as a component of true comprehensive cancer care. Ms. Dyer authored the book *A Dietitian's Cancer Story*, with proceeds contributed to an endowment she established at the American Institute of Cancer Research (AICR) in Washington, DC, that funds research focused on nutrition and cancer survivorship. She has served as a consultant to the University of Michigan's Integrative Medicine Research Center, AICR, and is on the Professional Advisory Board for the Wellness Community of Southeast Michigan. Ms. Dyer has been a board member of the Oncology Nutrition Dietetic Practice Group of the Academy of Nutrition and Dietetics and was the founding chair of their Survivorship Subunit.

Barbara Grant, M.S., RDN, CSO, FAND, is the outpatient oncology dietitian at the Saint Alphonsus Cancer Care Center in Boise and Caldwell, Idaho. Ms. Grant has more than 30 years of experience in cancer nutrition. At Saint Alphonsus she provides individualized nutritional counseling and educational classes for individuals diagnosed with cancer throughout the continuum of care. Ms. Grant is a founding member and past chair of the Oncology Nutrition Dietetic Practice Group of the Academy of Nutrition and Dietetics. She is a contributing editor to the *Clinical Guide to*

Oncology Nutrition and co-author of *Management of Nutrition Impact Symptoms in Cancer and Educational Handouts*, among her many patient and professional publications.

Liz Isenring, Ph.D., is Professor and Head of Program in the Faculty of Health Sciences and Medicine at Bond University, Australia. She is internationally recognized in the areas of oncology nutrition, nutrition in older adults, nutrition screening, and assessment. She supervises higher-degree by research (HDR) students in a broad research program that includes oncology nutrition, nutrition for older adults, managing malnutrition, and developing evidence-based nutrition guidelines for improving the care of patients. Her students have won numerous research awards. Previously, she led the development and contributed to several sets of Australian and international evidence-based guidelines leading to improved nutrition care. She is Nutrition Section Editor for *Current Oncology* and Associate Editor for *Nutrition and Dietetics*.

Jim Lee, M.S., is Vice President and Director, Systems Research and Initiatives Group (SRI), Altarum Institute. Mr. Lee has been with Altarum Institute for more than 20 years. Before his current position, he served as Director of Altarum's Medical Care Systems Group, where he led public health informatics and health quality research programs. Mr. Lee's most recent work focuses on health technology assessments drawing on administrative, financial accounting, and clinical data to support clinical trials, practice guideline development, and program evaluations. His recent studies include evaluation of the cost-effectiveness of alternative diagnostics in lung, breast, and cervical cancer; rapid identification and intervention in severe sepsis; and HIV viral load surveillance protocols.

Rhone Levin, M.Ed., RD, CSO, LD, has been a Registered Dietitian for 24 years and has specialized in oncology nutrition. She is board certified in oncology nutrition. Ms. Levin is an oncology dietitian at the Dell Children's Medical Center. Previously she was at the Mountain States Tumor Institute for St. Luke's Health System. She is currently part of the Academy of Nutrition and Dietetics' Evidence Analysis Library oncology revision of evidence-based nutrition research work group.

Joan McClure, M.S., is Senior Vice President of Clinical Information and Publications at the National Comprehensive Cancer Network (NCCN). Ms. McClure is responsible for the *NCCN Clinical Practice Guidelines in Oncology*, associated guidelines for patients in English and Spanish, the *NCCN Drugs & Biologics Compendium*, and *The Journal of the NCCN*. Ms. McClure also serves as an Associate Editor for *JNCNN*. Updated annually, the clinical practice guidelines are recognized as the standard for clinical policy in the United States and have served as a model for guidelines programs elsewhere in the world. Ms. McClure previously directed investigator and patient recruitment efforts in oncology for a multinational contract research organization where she also managed the technical and scientific effort to identify and develop standards for medical and toxicology data for submission to regulatory authorities in the United States, Europe, and Japan.

Mary Platek, Ph.D., M.S., RD, is Research Assistant Professor at Roswell Park Cancer Institute. Dr. Platek is a nutritionist and clinical epidemiologist with expertise in nutrition interventions for chronic disease management. Her research interests include cancer-related malnutrition and cachexia. She had clinical experience in diverse patient and community settings as well as university teaching. She was responsible for establishing and directing an accredited dietetic internship program for the State University of New York and received the Outstanding Dietetic Educator award from the New York State Dietetic Association. She completed a National Institutes of Health fellowship in the epidemiologic and basic science of cancer prevention at Roswell Park Cancer Institute where she actively examines nutritional status and intervention with outcomes of treatment in various cancer populations.

Cheryl Rock, Ph.D., RD, is Professor in the Department of Family Medicine and Public Health, and the Cancer Prevention and Control Program, University of California, San Diego, School of Medicine. Dr. Rock's research efforts are focused on the role of nutritional and dietary factors in the development and progression of cancer, particularly breast cancer, and healthy weight management in adults. Her research efforts address diet composition and weight management, and how diet, adiposity, and physical activity affect biomarkers and the risk and progression of cancer and other chronic diseases. Dr. Rock has served on numerous National Institutes of Health and U.S. Department of Agriculture review panels and committees, and she has served on editorial boards for several peer-reviewed journals. To date, she is the author of more than 240 scientific papers and book chapters. Dr. Rock completed undergraduate training in nutrition and dietetics at Michigan State University, achieved a Master of Medical Science degree in clinical nutrition at Emory University, and was awarded a doctoral degree in nutritional sciences from the University of California, Los Angeles.

Brenna Haviland Shebel, M.S., is Director of Health Care Cost and Delivery at the National Business Group on Health. Her areas of focus are consumer-directed health care, consumerism, employee communications and engagement, and cancer. She coordinates the operations of the Institute on Health Care Costs and Solutions. In addition, she served as project manager for the Employer's Guide to Cancer Treatment and Prevention, a major, multiyear initiative to help employers address a growing health care challenge—cancer in the workplace. Prior to joining the Business Group, Ms. Shebel worked for Healthy Maine Partnerships in promoting physical activity, nutrition, and tobacco-resistance activities in schools, communities, and workplaces in southern Maine where she led efforts to establish tobacco-free communities, created youth advocacy programs in three school districts, and assisted with workplace wellness initiatives. She is a Certified Health Education Specialist.

MODERATORS

Wendy Johnson-Askew, Ph.D., M.S., is Vice President of Corporate Affairs with Nestlé Infant Nutrition, North America. In this role she leads the Corporate Affairs Function, which includes Medical Advocacy and Public Policy, Nutrition, Health and Wellness and Corporate Communications. Dr. Johnson-Askew is a member of the National Academies of Sciences, Engineering, and Medicine's Food Forum and a member of the International Food Information Council Board of Directors. She is an active member of the American Public Health Association where she is a Past Chair of the Food and Nutrition Section and a member of the Inter-Sectional Council Steering Committee. Prior to joining Nestlé, Dr. Johnson-Askew was employed by the National Institutes of Health, Division of Nutrition Research Coordination, as a public health nutrition and health policy adviser. While there she was actively involved in the development and follow-up actions to the Surgeon General's Call to Action to Prevent and Decrease Overweight and Obesity and the Dietary Guidelines process. She developed scientific symposia on communicating dietary information and determinants of eating behavior that informed the granting process by leading to the development of requests for proposals. Dr. Johnson-Askew's research interests include determinants of eating behavior, racial and ethnic health disparities, and obesity.

Marian L. Neuhouser, Ph.D., RD, is Full Member in the Cancer Prevention Program, Division of Public Health Sciences, at the Fred Hutchinson Cancer Research Center in Seattle, Washington. She is also Core Faculty in Nutritional Sciences and Affiliate Professor of Epidemiology, both in the School of Public Health, University of Washington. Dr. Neuhouser is a nutritional epidemiologist whose primary research focus is nutrition and energy balance and their relationship to cancer prevention and cancer survivorship. She has broad experience and leadership in large clinical trials, including the Women's Health Initiative and the Prostate Cancer Prevention Trial, small-scale controlled dietary interventions, and large observational cohorts. In addition, a portion of Dr. Neuhouser's research portfolio is focused on methods to improve diet and physical activity assessment and numerous aspects of health disparities, which links together nutrition, energy balance, and cancer risk. Dr. Neuhouser was a member of the 2015 Dietary Guidelines Advisory Committee and currently serves as Vice-President of the American Society for Nutrition (2015-2016), and is to be President in 2016-2017.

Nico Pronk, Ph.D., FACSM, FAWHP, is Vice President for Health Management and Chief Science Officer for HealthPartners, a nonprofit, member-governed integrated health system headquartered in Minneapolis, Minnesota. Dr. Pronk is also a senior research investigator at the HealthPartners Institute for Education and Research; adjunct professor for Society, Human Development and Health at the Harvard School of Public Health; visiting research professor in Environmental Health Sciences at the University of Minnesota, School of Public Health; member of the Task Force on Community Preventive Services; and founding and past-president of the International Association for Worksite Health Promotion. His research expertise lies in the areas of population health improvement, the role of physical activity in health, and the impact of multiple health behaviors on health outcomes. Dr. Pronk is particularly interested in improving population health in context of the employer setting, the integration of health promotion with occupational safety and health, and the integration of health promotion, behavioral health, and primary care. Dr. Pronk received a Ph.D. in exercise physiology from Texas A&M University and completed postdoctoral studies in behavioral medicine at the University of Pittsburgh Medical Center and the Western Psychiatric Institute and Clinic in Pittsburgh.

Kim Robien, Ph.D., RD, CSO, FAND, is Associate Professor at The George Washington University in the Milken Institute School of Public Health. She is a registered dietitian, nutrition scientist, and epidemiologist whose research focuses on nutrition in relation to cancer prevention and survivorship. She is a certified specialist in oncology nutrition (CSO), and practiced as an oncology dietitian for more than 10 years prior to beginning her research career. Dr. Robien serves as Program Director for the Master's in Public Health degree program in Public Health Nutrition at The George Washington University. She is a widely published scientific researcher, and also serves as a member of the editorial boards for the *Journal of the Academy of Nutrition and Dietetics* and *Nutrition in Clinical Practice*.

Appendix C

Additional References Used by the Planning Committee to Develop the Workshop

CURRENT KNOWLEDGE AND STATUS OF NUTRITION PRACTICES IN ONCOLOGY OUTPATIENT CARE

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