

Coleman Supportive Oncology Initiative

Survivorship Training Module

Topic: **Lifestyle and Behavioral Factors**

Presenters: Teresa A. Lillis, PhD and Carol A. Rosenberg, MD

Learning Objectives

By the end of this module you should be able to:

- 1. Explain why it is important for cancer survivors to achieve and maintain a healthy lifestyle following active treatment for cancer**
- 2. Restate what constitutes healthy lifestyle habits for survivorship**
- 3. Describe the benefits/risks of engaging in healthy lifestyle behaviors as part of cancer survivorship**

Importance of Achieving and Maintaining a Healthy Lifestyle in Cancer Survivors

- **Healthy lifestyle habits have been associated with improved health outcomes and quality of life in cancer survivors.**

- **These habits include:**
 - Engaging in daily physical activity. Strive to participate in strength or resistance training at least twice a week.
 - Maintaining a nutritious diet and a healthy weight
 - Limiting alcohol consumption
 - Avoiding tobacco products
 - Limiting sun exposure
 - Having regular follow-up with a primary care physician

- **For some cancers, a healthy lifestyle has been associated with a reduced risk of cancer recurrence and cancer-related death.**

Physical Activity

- **Physical inactivity/sedentary behavior is a risk factor for cancer incidence and mortality, while physical activity has been linked with decreased cancer incidence and recurrence.**
- **Cancer survivors, who have confirmed with their oncologist that it is safe to resume physical activity following active treatment, should be encouraged to engage in daily physical activity, including exercise, recreational activities and activities of daily living.**
- **General recommendations for post-cancer treatment physical activity include:**
 - At least 150 minutes of moderate-intensity activity or 75 minutes of vigorous-intensity activity per week; AND
 - Two to three sessions per week of strength training that include major muscle groups; AND
 - At least 2 sessions per week that include stretching major muscle groups.

	Moderate Intensity Activities	Vigorous Intensity Activities
Exercise and leisure	Walking, dancing, leisurely bicycling, ice and roller skating, horseback riding, canoeing, yoga	Jogging or running, fast bicycling, circuit weight training, swimming, jumping rope, aerobic dance, martial arts
Sports	Downhill skiing, golfing, volleyball, softball, baseball, badminton, doubles tennis	Cross-country skiing, soccer, field or ice hockey, lacrosse, singles tennis, racquetball, basketball
Home activities	Mowing the lawn, general yard and garden maintenance	Digging, carrying and hauling, masonry, carpentry
Occupational activity	Walking and lifting as part of the job (custodial work, farming, auto or machine repair)	Heavy manual labor (forestry, construction, fire fighting)

- **All of the major modalities of cancer treatment (e.g., surgery, radiation and chemotherapy) can significantly change eating habits and interfere with normal digestion and nutrient absorption processes.**

- **Survivors with post-treatment nutritional concerns should be encouraged to follow up with a registered dietician to assess their post-treatment nutritional needs.**
 - For survivors at risk for becoming or maintaining an underweight status, consuming smaller and more frequent meals can help increase food intake.
 - For survivors who cannot meet nutritional needs through foods alone, commercially prepared or homemade nutrient-dense beverages/foods can help improve caloric and nutrient intake.

- **Unless prescribed by a treating oncologist, survivors should avoid the use of vitamins, minerals and other dietary supplements.**
 - Some studies have linked dietary supplement use with *increasing* mortality.
 - A recent systematic review showed that they do *not* improve overall survival rates.
 - Refer patient using multiple and/or unknown supplements to registered dietician, preferably with oncology credentials

Balanced Nutrition

Nutrition Guideline for Cancer Survivors: American Institute of Cancer Research

1. Be as lean as possible without becoming underweight.
2. Be physically active for at least 30 minutes every day.
3. Avoid sugary drinks, and limit consumption of energy-dense foods (particularly processed foods high in added sugar, low in fiber or high in fat).
4. Eat more of a variety of vegetables, fruits, whole grains and legumes such as beans.
5. Limit consumption of red meats (such as beef, pork and lamb) and avoid processed meats.
6. If consumed at all, limit alcoholic drinks to two for men and one for women a day.
7. Limit consumption of salty foods and foods processed with salt (sodium).
8. Do not rely on supplements to protect against cancer

The World Health Organization (WHO) published an update on October 26, 2015 on the consumption of red and processed meat. According to this update, data suggests that the risk of colorectal cancer could increase by 18% for every 50 gram portion of processed meat eaten daily. Their recommendation: Individuals who are concerned about cancer could consider reducing their consumption of red meat or processed meat until updated guidelines related specifically to cancer have been developed.

American Institute for Cancer Research/World Cancer Research Fund: Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective. Washington DC, American Institute for Cancer Research, 2007. <http://wcrf.org/int/research-we-fund/continuous-update-project-cup/second-expert-report>. pdf available <http://wcrf.org/sites/default/files/Second-Expert-Report.pdf>.

International Agency for Research on Cancer, World Health Organization (WHO). <http://www.aicr.org/patients-survivors/aicrs-guidelines-for-cancer.html>

International Agency for Research on Cancer, World Health Organization (WHO). https://www.iarc.fr/en/media-centre/pr/2015/pdfs/pr240_E.pdf

WHO, Q&A on the carcinogenicity of the consumption of red meat and processed meat. <http://www.who.int/features/qa/cancer-red-meat/en/>

- **Throughout the cancer continuum, individuals should strive to achieve and maintain a healthy body weight as defined by a body mass index (BMI) between 18.5 kg/m² and 25 kg/m² and strive for metabolic health.**
- **Survivors who are malnourished or underweight following completion of active treatment are at risk for post-treatment health complications.**
 - These individuals should address potential changes in their diet and overall energy expenditure to avoid further weight loss.
- **Survivors who are overweight or obese following completion of active treatment are also at further risk of post-treatment health related complications.**
 - Pending the approval of the treating oncologist, these individuals should be encouraged to engage in modest, intentional weight loss (i.e., no more than 2 lbs./week, no more than 1 lb/week in survivors over 64 years) through eating a nutritious, lower calorie diet and increasing physical activity.

Limiting Alcohol Consumption/Avoiding Tobacco Products

Alcohol Consumption

- Survivors should limit alcoholic drinks to < 2 drinks/day for men and < 1 drink/day for women.
- High levels of alcohol consumption (> 2 drinks/day) may increase survivors' risk of developing new primary cancers, including oral, liver, breast and colon cancers.
 - Survivors should be encouraged to limit or abstain from alcohol following active treatment.

Tobacco Avoidance/Cessation

- Survivors are advised to completely avoid tobacco products following active treatment. Current users should completely stop using tobacco products, including smokeless tobacco.
 - Tobacco use following active treatment increases the risk for cancer recurrence.
 - Survivors should also avoid second-hand smoke exposure.

Sun Safety

Cancer survivors, especially those with a history of skin cancer, are more at risk for developing future skin cancer from too much sun exposure and/or too little sun protection.

- Survivors should limit their sun exposure between 10 AM and 2 PM (when UV rays are the strongest).
- Survivors should liberally apply broad spectrum sunscreen (SPF 30 or higher) every 2 hours on sun-exposed skin.
- Survivors should wear protective clothing during sun exposure, including long-sleeve shirts, wide brim hats and sunglasses.
- Survivors should check with prescribing physicians about any medications they are taking that might make them more sensitive to the sun.
- Survivors should **never** use tanning beds.

Regular Follow Ups with Primary Care Physician

Survivors should be encouraged to follow up with a PCP regularly for:

- Adherence to age- and risk- appropriate health screenings for early cancer or pre-cancerous conditions
- Preventive healthcare screenings and measures including age- and risk- appropriate immunizations
- Assessment and treatment of medical and psychosocial late effects of cancer and its treatment
- Assessment of weight and health behaviors that can modify cancer risk
- Assessment, treatment and coordination of care for all co-morbidities

Summary of Points Covered

In this training module we addressed:

- **The importance of cancer survivors achieving and maintaining a healthy lifestyle following active treatment for cancer**
- **Knowing what constitutes healthy lifestyle habits for survivorship**
- **The benefits/risks of engaging and not engaging in healthy lifestyle behaviors following active cancer treatment**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Survivorship](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)
http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf
- [NCCN Clinical Practice Guidelines in Oncology](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp)
http://www.nccn.org/professionals/physician_gls/f_guidelines.asp

American Cancer Society

- [Nutrition and Physical Activity Guidelines for Cancer Survivors](http://www.cancer.org/healthy/informationforhealthcareprofessionals/acsguidelines/nupaguidelinesforcancersurvivors/)
<http://www.cancer.org/healthy/informationforhealthcareprofessionals/acsguidelines/nupaguidelinesforcancersurvivors/>

A Cancer Journal for Clinicians

- [Online Continuing Education Activity, Practical Clinical Interventions for Diet, Physical Activity, and Weight Control in Cancer Survivors](http://onlinelibrary.wiley.com/doi/10.3322/caac.21265/pdf)
<http://onlinelibrary.wiley.com/doi/10.3322/caac.21265/pdf>

American Institute for Cancer Research

- [Reduce Your Cancer Risk](http://www.aicr.org/reduce-your-cancer-risk/)
<http://www.aicr.org/reduce-your-cancer-risk/>

Faculty Bio for Teresa A. Lillis, PhD

Dr. Lillis is an Assistant Professor of Behavioral Sciences at Rush University Medical Center. She received her Ph.D. in Clinical Psychology with an emphasis in Health Psychology in 2015 and completed a research fellowship in Supportive Oncology in 2016. She has worked in the Rush Cancer Center on the Coleman Supportive Oncology Initiative for the past three years and has ongoing research related to the roles of trauma, sleep disturbance, and pain among cancer patients.

For additional information:

http://www.researchgate.net/profile/Teresa_Lillis

Faculty Bio for Carol A. Rosenberg, MD, FACP

Carol A. Rosenberg, MD, FACP, is the Founder and Program Director of the Living in the Future (LIFE) Cancer Survivorship Program at NorthShore University HealthSystem (NorthShore) of Illinois; a 4 hospital health system in greater Chicagoland and its Northern and Northwestern Suburbs. She implemented the LIFE Program in 2006 with a community education grant from the LIVESTRONG Foundation and has sustained and evolved the program with multiple additional grant awards from other philanthropic agencies as well as institutional support. www.northshore.org/LIFE. Dr. Rosenberg is NorthShore's Director of Preventive Health Initiatives, a board certified internist, a Fellow of the American College of Physicians and an clinical associate professor of medicine at the University Of Chicago Pritzker School Of Medicine. <http://www.northshore.org/kellogg-cancer-center/support-services/survivorship/program-director/>

Dr. Rosenberg has served the NorthShore University HealthSystem community for over 30 years as a clinician, medical educator, and administrative physician while holding an active position in national women's health clinical research. She served as a Principal Investigator, Clinical Medical Director and a Lead Investigator for the landmark Women's Health Initiative Study from the National Institute of Health wherein she designed, directed and authored original investigations regarding second cancer risk in women.

Dr. Rosenberg created the first regional health professional curriculum regarding the science of survivorship and is the creator, author and principal provider of the "Living in the Future Survivorship Course" a curriculum targeting internal medicine and family medicine post graduate resident trainees. The curriculum is a framework for the dissemination of the science of survivorship and provides emerging health professionals as well as those in long standing practice, with a foundation of knowledge, attitudes and skills related to survivorship care. Dr. Rosenberg is the author of the *NorthShore Living in the Future (LIFE) Cancer Survivorship Manual: A Resource for Healthcare Professionals Involved with Late Treatment or Post Treatment Cancer Survivors*. www.northshore.org/LIFE-ed

Dr. Rosenberg also serves as a regional Liaison for Adult Healthcare Resources for childhood cancer survivors, and is on the consulting staff of Ann and Robert H. Lurie Children's Hospital in Chicago.

For additional information:

<http://www.northshore.org/kellogg-cancer-center/support-services/survivorship/program-director/>

<http://www.ncbi.nlm.nih.gov/sites/myncbi/collections/bibliography/48985355/>

References

- American Institute for Cancer Research, AICR'S Guidelines For Cancer Survivors. Available at: <http://www.aicr.org/patients-survivors/aicrs-guidelines-for-cancer.html>.
- Bairati I, Meyer F, Jobin E, et al. Antioxidant vitamins supplementation and mortality: a randomized trial in head and neck cancer patients. *Int J Cancer*. 2006; 119: 2221-2224.
- Baron JA, Cole BF, Mott L, et al. Neoplastic and antineoplastic effects of beta-carotene on colorectal adenoma recurrence: results of a randomized trial. *J Natl Cancer Inst*. 2003; 95: 717-722.
- Barrera S, Demark-Wahnefried W. Nutrition during and after cancer therapy. *Oncology (Williston Park)*. 2009; 23(2 suppl Nurse Ed):15-21.
- Davies AA, Davey Smith G, Harbord R, et al. Nutritional interventions and outcome in patients with cancer or preinvasive lesions: systematic review. *J Natl Cancer Inst*. 2006; 98: 961-973.
- Demark-Wahnefried W, Rogers L, Alfano C et al (2015). Practical Clinical Interventions for Diet, Physical Activity, and Weight Control in Cancer Survivors. *CA Cancer J Clin* 65:167-189.
- Fortmann SP, Burda BU, Senger CA, Lin JS, Whilock EP. Vitamin and mineral supplements in the primary prevention of cardiovascular disease and cancer: an update systematic evidence review for the U. S. Preventive Services Task Force. *Ann Intern Med*. 2013;159:824-34.
- Hanna, N., Mulshine, J., Wollins, D. S., Tyne, C., & Dresler, C. (2013). Tobacco cessation and control a decade later: American Society of Clinical Oncology policy statement update. *Journal of Clinical Oncology*, 31(25), 3147-3157.
- Jones, L. W., & Alfano, C. M. (2013). Exercise-oncology research: past, present, and future. *Acta oncologica*, 52(2), 195-215.
- Klein EA, Thompson IM Jr, Tangen CM, et al. Vitamin E and the risk of prostate cancer: the Selenium and Vitamin E Cancer Prevention Trial (SELECT). *JAMA*. 2011; 306: 1549-1556.
- Kronke CH, Fung TT, Hu FB, Holmes MD. Dietary patterns and survival after breast cancer diagnosis. *J Clin Oncol*. 2005; 23: 9295-9303.
- Ligibel JA, Alfano CM, Courneya, KS, Demark-Wahnefried W, Burger RA, Chlebowski RT, Fabian CJ, et al. American Society of Clinical Oncology Position Statement on Obesity and Cancer. *J Clin Oncol*. 2014;32:3568-3574.
- McMahon K, Brown JK. Nutritional screening and assessment. *Semin Oncol Nurs*. 2000; 16: 106-112.
- National Comprehensive Cancer Network. NCCN guidelines for Survivorship Version 1.2018. available at http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf
- Nielsen SF, Nordestgaard BG, Bojesen SE. Associations between first and second primary cancers: a population-based study. *CMAJ*. 2012; 184: E57-E69.
- Pocobelli G, Peters U, Kristal AR, White E. Use of supplements of multivitamins, vitamin C, and vitamin E in relation to mortality. *Am J Epidemiol*. 2009; 170: 472-483.
- Ravasco P, Monteiro-Grillo I, Vidal PM, Camilo ME. Dietary counseling improves patient outcomes: a prospective, randomized, controlled trial in colorectal cancer patients undergoing radiotherapy. *J Clin Oncol*. 2005; 23: 1431-1438.
- Rock, C. L., Doyle, C., Demark-Wahnefried, W., Meyerhardt, J., Courneya, K. S., Schwartz, A. L., ... & Gansler, T. (2012). Nutrition and physical activity guidelines for cancer survivors. *CA: a cancer journal for clinicians*, 62(4), 242-274.
- Rosenberg, C. Living in the Future (LIFE) Cancer Survivorship Manual: A Resource for Healthcare Professionals involved with Late Treatment or Post Treatment Cancer Survivors www.northshore.org/LIFE-ed
- Schattner M, Shike M. Nutrition support of the patient with cancer. In: Shils ME, Shike M, Ross AC, Cabellero B, Cousins RJ, eds. *Modern Nutrition in Health and Disease*. 10th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2006: 1290-1313.
- Schmitz, K. H., Courneya, K. S., Matthews, C., Demark-Wahnefried, W., Galvao, D. A., Pinto, B. M., ... & Schwartz, A. L. (2010). American College of Sports Medicine roundtable on exercise guidelines for cancer survivors. *Medicine and Science in Sports & Exercise*, 42(7), 1409-1426.
- Seagle HM, Strain GW, Makris A, Reeves RS, American Dietetic Association. Position of the American Dietetic Association: weight management. *J Am Diet Assoc*. 2009; 109: 330-346.
- WHO, Q&A on the carcinogenicity of the consumption of red meat and processed meat, October 2015. Available at: <http://www.who.int/features/qa/cancer-red-meat/en/>.

Coleman Supportive Oncology Initiative

Survivorship Training Module

Topic:

Common Psychosocial Challenges of Survivors / Psychosocial Sequelae of Cancer

Presenters: Teresa A. Lillis, PhD & Frank J. Penedo, PhD

Version: 08282018

Learning Objectives

By the end of this module you should be able to:

- 1. Identify common psychosocial experiences and concerns of cancer patients and survivors**
- 2. Discuss experiences of depression, emotional distress and fear of cancer recurrence**
- 3. Recognize financial concerns and considerations for return to work**

Common Psychosocial Experiences & Concerns of Cancer Patients and Survivors

- **Depression is the most common psychological problem among cancer patients:**
 - 30% to 40% of oncology, hematology, and palliative care patients experienced some combination of mood disorder, including depression, anxiety, adjustment disorder, or dysthymia.
 - Severe symptoms of depression are often associated with prolonged hospital stays, poorer quality of life and decreased treatment compliance. In some cases, depressive symptoms may lead to suicide.

- **Fear of recurrence is the most common concern among cancer survivors:**
 - Even in the absence of physical symptoms that would indicate disease recurrence, fear of recurrence is relatively stable and may persist several years after treatment has ended.
 - Some studies note that fear of recurrence may actually be higher in family members and/or caregivers of cancer survivors than in survivors themselves.

Common Psychosocial Experiences & Concerns of Cancer Patients and Survivors

- **Cancer diagnosis and treatment can lead to significant emotional distress:**
 - Distress symptoms can range from normal feelings of sadness and fear to more severe problems, such as depression, anxiety and panic.
- **Financial and employment-related difficulties are common across the cancer diagnostic and treatment trajectory:**
 - Financial hardship is common due to the long-term nature of treatment, expense of effective and potentially life-saving drugs and the loss of employment during treatment.
 - Cancer survivors who return to work may experience both positive and negative effects associated with their transition back to work.

Experiences of Depression

- **For patients in active cancer treatment:**
 - Prevalence rates for depression in patients with cancer ranges from 23% to 60%.
 - Partners and other family members also experience significant anxiety and distress in the wake of a loved one's cancer diagnosis.

- **For cancer survivors**
 - The prevalence of depression is 11.6% while the prevalence of anxiety is 17.9%.
 - Although the majority of survivors' family members and caregivers report few ongoing psychosocial issues, a small subset may experience persistent anxiety and emotional distress following a loved one's active treatment

Experiences of Emotional Distress

- **When distress is high and endures over time, survivors may experience symptoms of posttraumatic stress disorder, including:**
 - Becoming hypervigilant to potential physical/psychological indicators of disease recurrence.
 - Having intrusive thoughts or memories related to diagnosis/treatment.
 - Avoiding situations/places/people that trigger thoughts or memories of diagnosis/treatment.
 - Reliving distressing aspects of diagnosis/treatment (via either dreams or “flashbacks”).

- **Prevalence of emotional distress varies by cancer type:**
 - The highest prevalence was found among patients with breast cancer (42%), head and neck cancer (41%) and malignant melanoma (39%).
 - The lowest prevalence was seen among patients with prostate cancer (22%), stomach cancers (21%), and pancreatic cancer (20%).

Experiences of Fear of Cancer Recurrence

- **The perception that cancer may return at any time, even in the absence of physical symptoms**
 - Innocuous physical symptoms (e.g., headache, muscle pain, etc.) may be interpreted as indications that cancer has returned.
 - Treatment-related physiological/psychological effects (e.g., fatigue, weight loss, and/or cognitive slowing) may be interpreted as indications of disease recurrence.
 - Some studies note that fear of recurrence may actually be higher in family members and/or caregivers of cancer survivors than in survivors themselves.

Experiences of Fear of Cancer Recurrence

Stability and Persistence of Recurrence Fear:

- This fear may persist 5-20 years after completion of active treatment.

Living with Uncertainty:

- The potential for the identification of recurrent disease can cause a survivor to view his/her future in terms of insecurity and perceived loss.
- Survivors and their families must again confront the issue that the cancer may not be cured and the patient's life may be shortened.

Financial Concerns and Return to Work and/or Other Roles

Financial concerns among survivors and patients undergoing active treatment for cancer are common:

- Financial hardship is common due to the long-term nature of treatment, expense of effective and potentially life-saving drugs, and the loss of employment during treatment.
- Between 14.8 and 78.8 % of studies of cancer patients reported some degree of perceived financial burden due to cancer treatment-related costs.

Risk Factors for Increased Financial Burden:

- Low-income households and single-parent households
- Living longer distances from hospitals or treatment centers
- Younger age and lower social-emotional and physical functioning
- Male

Financial Concerns & Return to Work and/or Other Roles

Consequences of Financial Burden to Cancer Patients and Survivors:

- Other family members, and in particular, the spouses/partners of the patient/survivor, may have to engage in new or increased labor-market participation to compensate for these financial losses.
- Patients may discontinue active treatment.
- Patients may forgo treatment altogether.
- Patients may fall below the poverty line due to paying for treatment.
- One study recently found that the degree of cancer-related financial problems was **the strongest independent predictor of quality of life** among a population of adult cancer survivors.

Return to Employment Following Active Treatment:

- Approximately 62% of cancer survivors re-enter the workplace 1-2 years after diagnosis.

Financial Concerns and Return to Work and/or Other Roles

Cancer survivors report both wanting and needing to return to work for financial stability, productivity, continued recovery, and a return to normalcy:

Perceived Benefits of Returning to Work:

- Distraction from painful and difficult aspects of cancer treatment
- Keeping mind occupied to decrease depressive feelings
- Feeling competent and in control
- Providing daytime structure
- Relieved feelings of boredom or isolation
- Financially supporting their families again

Prior treatment burden and ongoing physical/psychological symptoms may impact work-related functioning for survivors:

Common symptoms include:

- Fatigue
- Depressive or anxious mood, pain, or menopausal complaints
- Changes in cognitive functioning, such as working memory, organization, and multitasking

Summary of Points Covered

In this training module we addressed:

- **Common psychosocial experiences and concerns of cancer patients and survivors**
- **Experiences of depression and emotional distress in cancer patients and survivors, as well as fear of cancer recurrence in cancer survivors**
- **The financial concerns and employment-related considerations of cancer patients and survivors**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

- [Patient and Caregiver Resources, Cancer and Work](http://www.nccn.org/patients/resources/life_with_cancer/work.aspx)
http://www.nccn.org/patients/resources/life_with_cancer/work.aspx
- [Patient and Caregiver Resources, Managing Stress and Distress](http://www.nccn.org/patients/resources/life_with_cancer/distress.aspx)
http://www.nccn.org/patients/resources/life_with_cancer/distress.aspx
- [Patient and Caregiver Resources, Cancer and Family](http://www.nccn.org/patients/resources/life_with_cancer/family.aspx)
http://www.nccn.org/patients/resources/life_with_cancer/family.aspx

American Society of Clinical Oncology, ASCO®

- [Institute for Quality™, Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer: An American Society of Clinical Oncology Guideline Adaptation](http://www.instituteforquality.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society)
<http://www.instituteforquality.org/screening-assessment-and-care-anxiety-and-depressive-symptoms-adults-cancer-american-society>

Faculty Bio for Teresa A. Lillis, PhD.

Dr. Lillis is an Assistant Professor of Behavioral Sciences at Rush University Medical Center. She received her Ph.D. in Clinical Psychology with an emphasis in Health Psychology in 2015 and completed a research fellowship in Supportive Oncology in 2016. She has worked in the Rush Cancer Center on the Coleman Supportive Oncology Initiative for the past three years and has ongoing research related to the roles of trauma, sleep disturbance, and pain among cancer patients.

For additional information:

http://www.researchgate.net/profile/Teresa_Lillis

Faculty Bio for Frank J. Penedo, PhD

Dr. Frank J. Penedo is the Roswell Park Professor of Medical Social Sciences, Psychology and Psychiatry and Behavioral Sciences. He is also the Program Leader of the Cancer Control and Survivorship Program in the Lurie Cancer Center and the Director of the Cancer Survivorship Institute at Northwestern Medicine. He is trained in clinical psychology and behavioral medicine and his research has focused on evaluating the role of psychosocial, sociocultural and biobehavioral processes in adjustment, health related quality of life (HRQOL) and health outcomes in chronic disease populations with a major emphasis on diverse cancer survivors in regard to race, ethnicity and socio-economic status. Dr. Penedo has served as PI, co-PI or project leader on multiple NIH-funded studies addressing psychosocial and biobehavioral correlates of adjustment and the efficacy of psychosocial interventions in improving HRQOL, symptom burden and health outcomes in chronic disease populations. He has significant expertise in community based, cohort and intervention studies that target cancer survivors and involve collection and analyses of psychosocial and biological data. He has over 110 peer-reviewed publications, has served as associate editor of two major journals in his field, and some of his translational work has been disseminated as clinical intervention tools. Dr. Penedo currently serves as a standing member of the NIH BMIO study section and on the editorial board of several major journals in his field. He is the president elect of the International Society of Behavioral Medicine, a fellow of the Society of Behavioral Medicine and a member of the Academy of Behavioral Medicine Research. He has received numerous awards and also served on the advisory boards of community organizations such as the Wellness Community, the Intercultural Cancer Council and Salud America.

Link to website with additional information about the faculty member:

<http://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=24719>

References

- Azzani, M., Roslani, A. C., & Su, T. T. (2015). The perceived cancer-related financial hardship among patients and their families: a systematic review. *Supportive Care in Cancer*, 23(3), 889-898.
- Baker F, Denniston M, Smith T, et al. Adult cancer survivors: how are they faring? *Cancer*. 2005;104(11 Suppl):2565-76.
- Bona K et al (2013) Economic impact of advanced pediatric cancer on families. *J Pain Symptom Manag* 47(3):594-603.
- Bowman KF, Rose JH, Deimling GT. Appraisal of the cancer experience by family members and survivors in long-term survivorship. *Psycho-Oncology* 2006;15:834-845.
- Cliff AM, MacDonagh RP. Psychosocial morbidity in prostate cancer: II. A comparison of patients and partners. *BJU Int* 2000;86:834-839.
- Colleoni M, Mandala M, Peruzzotti G, Robertson C, Bredart A, Goldhirsch A. Depression and degree of acceptance of adjuvant cytotoxic drugs. *Lancet*. 2000 Oct 14;356(9238):1326-7.
- Deimling GT, Bowman KF, Sterns S, Wagner LJ, Kahana B. Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psycho-Oncology* 2006;15(4):306-320.
- Fenn, K. M., Evans, S. B., McCorkle, R., DiGiovanna, M. P., Puszta, L., Sanft, T., ... & Chagpar, A. B. (2014). Impact of Financial Burden of Cancer on Survivors' Quality of Life?. *Journal of Oncology Practice*, JOP-2013.
- Gandubert C, Carriere I, Escot C, et al. Onset and relapse of psychiatric disorders following early breast cancer: a case-control study. *Psycho-Oncology* 2009;18(10):1029-1037.
- Gotay C.C. & Muraoka M.Y. (1998) Quality of life in long-term survivors of adult-onset cancers. *Journal of National Cancer Institute* 90, 656-667.
- Grassi L, Rosti G. [Psychosocial morbidity and adjustment to illness among long-term cancer survivors. A six-year follow-up study.](#) *Psychosomatics*. 1996 Nov-Dec;37(6):523-32.
- Heath JA et al (2006) Childhood cancer: its impact and financial costs for Australian families. *Pediatr Hematol Oncol* 23(5):439-448
- Kattlove H, Winn RJ. Ongoing care of patients after primary treatment for their cancer. *CA Cancer J Clin* 2003;53(3):172-196.
- Kodama Y et al (2012) Increased financial burden among patients with chronic myelogenous leukaemia receiving imatinib in Japan: a retrospective survey. *BMC Cancer* 12:152
- Koenig HG, Cohen HJ, Blazer DG, Meador KG, Westlund R. [A brief depression scale for use in the medically ill.](#) *Int J Psychiatry Med*. 1992;22(2):183-95.
- Kornblith A.B., Herndon J.E., Weiss R.B., Zhang C., Zuckerman E.L., Rosenberg S., Mertz M., Payne D.K., Massie M.J., Holland J.F., Wingate P., Norton L. & Holland J.C. (2003) Long-term adjustment of survivors of early-stage breast carcinoma, 20 years after adjuvant chemotherapy. *Cancer* 98, 679-689.
- MacBride S.K. & Whyte F. (1998) Survivorship and the cancer follow-up clinic. *European Journal of Cancer Care* 7, 47-55.
- Markman M, Luce R (2010) Impact of the cost of cancer treatment: an internet-based survey. *Am Soc Clin Oncol* 6(2):69-73.
- Mitchell, A.J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C. & Meader, N. (2011). Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: A meta-analysis of 94 interview-based studies. *Lancet Oncology*, 12, 160-174.
- Mehnert, A., Brähler, E., Faller, H., Härter, M., Keller, M., Schulz, H., ... & Koch, U. (2014). Four-week prevalence of mental disorders in patients with cancer across major tumor entities. *Journal of Clinical Oncology*, JCO-2014.
- Mellon S, Northouse LL, Weiss LK. A population-based study of the quality of life of cancer survivors and their family caregivers. *Cancer Nurs* 2006;29:120-131.
- Newport, D.J. & Nemeroff, C.B. (1998). Assessment and treatment of depression in the cancer patient. *Journal of Psychosomatic Research*, 45, 215-237.
- Newport, D.J. & Nemeroff, C.B. (1999). Treatment of depression in the cancer patient. *Clinical Geriatrics*, 7, 40-55.
- Northouse LL. [The impact of cancer in women on the family.](#) *Cancer Pract*. 1995 May-Jun;3(3):134-42. Review.
- Prieto JM, Blanch J, Atala J, Carreras E, Rovira M, Cirera E, Gastó C. [Psychiatric morbidity and impact on hospital length of stay among hematologic cancer patients receiving stem-cell transplantation.](#) *J Clin Oncol*. 2002 Apr 1;20(7):1907-17.
- Rogers SN et al (2012) Patients' perception of the financial impact of head and neck cancer and the relationship to health related quality of life. *Br J Oral Maxillofac Surg* 50:410-416
- Spelten ER, Sprangers MA, Verbeek JH. Factors reported to influence the return to work of cancer survivors: a literature review. *Psycho-Oncology* 2002;11(2):124-131.
- Stergiou-Kita, M., Grigorovich, A., Tseung, V., Milosevic, E., Hebert, D., Phan, S., & Jones, J. (2014). Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *Journal of Cancer Survivorship*, 8(4), 657-670.
- Taskila T, Martikainen R, Hietanen P, Lindbohm ML. Comparative study of work ability between cancer survivors and their referents. *Eur J Cancer* 2007;43(5):914-920.
- Turner, D., Adams, E., Boulton, M., Harrison, S., Khan, N., Rose, P., ... & Watson, E. K. (2013). Partners and close family members of long-term cancer survivors: health status, psychosocial well-being and unmet supportive care needs. *Psycho-Oncology*, 22(1), 12-19.
- Yabroff K.R., Lawrence W.F., Clauser S., Davis W.W. & Brown M.L. (2004) Burden of illness in cancer survivors: findings from a population-based national sample. *Journal of the National Cancer Institute* 96, 1322-1330.
- Vivar, C. G., Canga, N., Canga, A. D. and Arantzamendi, M. (2009), The psychosocial impact of recurrence on cancer survivors and family members: a narrative review. *Journal of Advanced Nursing*, 65: 724-736.
- Wagner LI, Cella D. Fatigue and cancer: causes, prevalence and treatment approaches. *Br J Cancer* 2004;91(5):822-828.
- Wefel JS, Lenzi R, Theriault RL, Davis RN, Meyers CA. The cognitive sequelae of standard-dose adjuvant chemotherapy in women with breast carcinoma: results of a prospective, randomized, longitudinal trial. *Cancer* 2004;100(11):2292-2299.
- Wilt TJ. Clarifying uncertainty regarding detection and treatment of early-stage prostate cancer. *Semin Urol Oncol* 2002;20(1):10-17.
- Zajacova, A., Dowd, J. B., Schoeni, R. F., & Wallace, R. B. (2015). Employment and income losses among cancer survivors: Estimates from a national longitudinal survey of American families. *Cancer*.

Coleman Supportive Oncology Initiative

Survivorship Training Module

Topic: **Common Late and Long-Term Effects**

Presenters: Patricia Robinson, MD and Sara M. Goetzman, BA,
updated by Christine B. Weldon, MBA and Betty Roggenkamp, BA

Learning Objectives

By the end of this module you should be able to:

- 1. Discuss the definition of late and long-term complications and effects of cancer treatment**
- 2. Describe the major categories in which the complications fall**
- 3. Explain common late and long-term complications**

Late and Long-Term Effects

- There is limited information on the prevalence of late effects, but there is a general recognition that they have become more common largely due to more frequent use of complex cancer interventions including combinations of surgery, chemotherapy, radiation and hormone treatments.
- Long-term effects refer to any side effects or complications of treatment for which a cancer patient must compensate. Also known as persistent effects, they begin during treatment and continue beyond the end of treatment.
 - E.g., neuropathy, sexual morbidity, fatigue, pain
- Late effects refer to unrecognized toxicities that are absent or sub-clinical at the end of therapy and manifest later with the unmasking of unseen injury because of any of the following factors:
 - Developmental processes
 - Failure of compensatory mechanisms with the passage of time
 - Organ senescence
 - Other examples such as cardiomyopathy and secondary cancers

Survivorship Issue Categories

- **Cancer survivors have a substantial number of issues and concerns that are currently being researched.**
- **Issues can be grouped into these categories:**
 - Management of long-term treatment toxicities
 - Psychological needs
 - Employment issues
 - Appropriate surveillance

Cardiac Issues

- Patients with signs of cardiac dysfunction, such as shortness of breath, volume overload, or chest pain, should be assessed.
- Treatment-associated cardiac issues may take years to develop.
- A history of anthracycline exposure or radiation therapy plus additional cardiovascular risk factors increases one's risk for progressive heart failure.

Cardiovascular risk factors:

- Smoking
- Alcoholism and/or other substance use
- Obesity
- Family history of cardiomyopathy
- Exposure to anthracyclines, HER2 targeted agents and/or chest radiation therapy

Based on patient's symptoms, may include echocardiogram, integrated management with primary care physician and/or referral to cardiology.

Cognitive Dysfunction

Cognitive dysfunction is described as difficulty concentrating or finishing tasks, short-term memory problems, confusion, and an inability to think clearly.

Assessment of cognitive function should include:

- Identification of focal neurologic deficits
- Timing of onset of symptoms and pace of symptom progression
- Cancer treatment history
- Prescription medication, over-the-counter medication and supplement use
- Menopausal status
- Fatigue and/or depression level

General strategies for management of cognitive dysfunction

- Review organization techniques
- Encourage routine physical activity
- Minimize alcohol intake
- Provide guidance for sleep disturbance and fatigue
- Educate on the potential influence of comorbidities, including hormone levels
- Consider Meditation, yoga, mindfulness-based stress reduction and brain games

Pain

- Cancer pain comes in many forms. It may be the by-product of a surgery such as an amputation, neck dissection, mastectomy or thoracotomy. Pain may also occur following radiation. Neuropathy is a commonly experienced form of pain following chemotherapy. Patients may also experience pain from lymphedema.
- It is important to assess pain at each clinic visit.
- As part of comprehensive pain assessment, it is critical to identify its cause and impact on quality of life, as well as the patient's management goals.

Treatment may include:

○ Non-pharmacologic interventions

- Physical modalities including heat, cold, massage, physical therapy or occupational therapy
- Acupuncture
- For muscle cramps or spasms, check levels of electrolytes, magnesium and calcium and hydration status.

○ Pharmacologic interventions

- Nonsteroidal anti-inflammatory drugs
- Anti-epileptic drugs (e.g., gabapentin)
- Tricyclic antidepressants
- Serotonin-norepinephrine reuptake inhibitors
- Opioids, weighing risks/benefits in long-term survivors

○ Referral to pain management specialist or palliative care

Fatigue

- Fatigue can persist for a long time after treatment.
- Assessment should include identifying variables that influence intensity of fatigue, interference with function, comorbidities such as alcohol use, endocrine dysfunction (e.g., hypothyroidism) and anemia.
- Document the use of medications, including prescription or over-the-counter sleep aids
- Query sleep disturbance (e.g., sleep apnea, hot flashes and bathroom use)
- Make use of local resources to help patients increase exercise (e.g.; aerobics, strength training, yoga/stretching)

Sexual Morbidity

- In women, sexual morbidity may be defined as premature menopause, infertility, vaginal dryness, loss of libido, pain during sexual intercourse and the inability to reach climax.
- In men, sexual morbidity may be defined as impotence, infertility and incontinence.
- Patients should be referred to specialists including primary care physicians, gynecologists or urologists.

Lymphedema



NCCN Guidelines Version 1.2018 Lymphedema

[NCCN Guidelines Index](#)
[Table of Contents](#)
[Discussion](#)

DEFINITION AND STAGES OF LYMPHEDEMA^{a-c}

- **Definition:** Lymphedema occurs when lymph fluid accumulates in the interstitial tissue, causing swelling of the limb or other areas such as the neck, trunk, or genitals. It is a common side effect of cancer treatment, occurring on the same side of the body as the cancer treatment, as a result of dysfunction of the lymphatic system.
- **Stage 0 (latent/subclinical):** Lymphatic dysfunction without swelling; subtle symptoms, such as a feeling of heaviness or fatigue in the limb, may be present.
- **Stage 1 (spontaneously reversible):** Accumulation of fluid and protein causing swelling; pitting edema may be evident; increased girth, heaviness, and/or stiffness of affected area. For the limbs, swelling is relieved with elevation.
- **Stage 2 (irreversible):** Spongy tissue consistency, with pitting edema that becomes less evident as swelling increases; tissue fibrosis causing hardness and increase in size. For the limbs, swelling is not relieved with elevation.
- **Stage 3 (lymphostatic elephantiasis):** Severe dry, scaly, thickened skin; increased swelling and girth of affected area; can be debilitating. In the limbs, fluid leakage and blisters are common.

- Lymphedema is swelling caused by extra fluid in the tissue, usually in the arms or legs.
- The severity of lymphedema is influenced by the number of lymph nodes dissected, radiation therapy and obesity.
- Recommend good skin care with skin moisturizers, minimizing weight bearing in the affected extremity, weight management, referral to a lymphedema specialist and fitting for a compression garment.

NOTE: See page SLYMPH-3 in NCCN Guidelines for Survivorship for workup and treatment guidelines.

Neuropathy¹

- Neuropathy is tingling or numbness in the hands or feet.
- Several types of chemotherapy, including vinc alkaloids, platins and taxane therapy are known to cause neuropathy. It may improve over time or remain chronic.
- Grading the toxicity may be of benefit.
- Patients may benefit from local therapies and analgesics such as gabapentin.

Osteoporosis²

- Osteoporosis, a condition in which the bones become weak and brittle, is common in survivors treated with hormone therapies (as in breast and prostate cancers).
- Surveillance bone mineral densities, supplemental calcium and vitamin D, as well as bisphosphonates, and RANK ligand inhibitors may be indicated.

¹Hershman DL, Lacchetti C, Dworkin RH, et al. Prevention and management of chemotherapy-induced peripheral neuropathy in survivors of adult cancers: American Society of Clinical Oncology clinical practice guideline. J Clin Oncol 2014;32:1941-1967.

²Van Poznak CH, Bone Health in Adults Treated with Endocrine Therapy for Early Breast or Prostate Cancer, 2015.

Second Cancers and Psychosocial Effects

- Patients are at risk for second malignancies due to radiation therapy, chemotherapy (in particular, alkylating and anthracycline therapy), gene mutations and environmental exposures.
- Screening for second primary cancers should include standard recommended cancer screenings such as colon, breast, cervical and lung; treatment related secondary cancers such as dermatology (skin); surveillance CBCs (leukemia); a thorough physical examination and review of symptoms.
- Cancer screening recommendations should be modified in high-risk patients or gene mutation carriers.
- Individuals with cancer may also experience emotional distress as a result of the cancer or treatment, or they may experience an exacerbation of a prior psychiatric disorder.
- Major depression and depressive symptoms occur frequently in cancer patients.
- According to a review of the literature, prevalence rates varied 10 to 25 % for major depressive disorders, a rate at least 3 times higher than in the general population.
- All survivors should be periodically evaluated for distress, anxiety and depression, with appropriate referrals made to mental health experts as needed.

General Survivorship Care

- **All survivors should be evaluated at least yearly for symptoms related to cancer and prior cancer treatment.**
- **Care providers should assess the following:**
 - Current disease status
 - Functional status
 - Current medications, including supplements
 - Co-morbidities including weight, tobacco use and alcohol use
 - Physical activity including aerobic, strength/resistance training, and yoga / stretching
 - Updated family history to reassess hereditary risk to include recent family diagnosis and new evidence in the field of cancer genetics

Summary of Points Covered

In this training module we addressed:

- **The definition of late- and long-term complications and effects of cancer treatment**
- **Reviewed the major categories to which complications fall**
- **Reviewed the common late- and long-term complications**

Next Steps

For more detailed training on this topic, you can go to the following resources:

National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Survivorship](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)
http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf
- [NCCN Guidelines for Detection, Prevention, & Risk Reduction](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#detection)
http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#detection

American Society of Clinical Oncology

- [Cancer Survivorship](http://www.asco.org/practice-research/cancer-survivorship)
<http://www.asco.org/practice-research/cancer-survivorship>

George Washington Cancer Institute, Guide for Delivering Quality Survivorship Care

- <https://smhs.gwu.edu/gwci/survivorship/ncsrc/guidequalitycare>

MD Anderson Cancer Survivorship Training Series

- <http://www.mdanderson.org/education-and-research/resources-for-professionals/professional-educational-resources/professional-oncology-education/survivorship/index.html>

Faculty Bio for Patricia Robinson, MD

Institution/title: Cardinal Bernardin Cancer Center, Loyola University

Roles: Director, Cancer Survivorship Clinic; Associate Professor, Department of Hematology and Medical Oncology, Loyola University Medical Center

Area of Expertise: Breast oncology, Cancer survivorship, Cancer Disparities

Practice type: Academic Medical Center/ University

Organization/Association Memberships: Member, Health Disparities Committee 2014-2017

Bio: Dr. Robinson is an Associate Professor of Medicine at Loyola University. She specializes in breast oncology. She graduated from the University of Michigan with a B.S. and received her M.D. from Michigan State University. Dr. Robinson completed her residency at Loyola University and Fellowship in Hematology-Oncology at Fox Chase Cancer Center. Dr. Robinson serves as the Director of the Cancer Survivorship Clinic at the Cardinal Bernardin Cancer Center. She serves on the Cancer Survivorship Committee and Breast Committee of the Southwest Oncology Group. In addition to clinical research, Dr. Robinson has several roles in the medical school. She serves as the assistant director for the Internal Medicine clerkship.

For additional information:

<https://www.loyolamedicine.org/doctor/patricia-robinson>

Faculty Bio for Sara M. Goetzman, BA

Sara M. Goetzman is the Program Manager of the Biopsychosocial Mechanisms and Health Outcomes (BMHO) Research Program directed by Dr. Frank J. Penedo within the Department of Medical Social Sciences of Northwestern University, Feinberg School of Medicine.

As manager of the BMHO Research Program, Ms. Goetzman oversees all research activity for Dr. Penedo's NIH-funded studies, which are focused on evaluating the role of psychosocial, sociocultural and biobehavioral processes in adjustment, health related quality of life and health outcomes in chronic disease populations with a major emphasis on ethnically diverse cancer survivors. She has also served as The Coleman Foundation Supportive Oncology Initiative (CSOI), Distress and Survivorship Project Coordinator since the inception of the initiative in December 2014.

References

- Agency for Healthcare Research and Quality publication No 02-E032. Rockville, MD. Agency for Healthcare Research and Quality. July 2002.
- American Society of Clinical Oncology, Cancer Survivorship. <http://www.asco.org/practice-research/cancer-survivorship>. Accessed 01/13/2016.
- American Society of Clinical Oncology-Self Evaluation Program, Third Edition. <http://university.asco.org/asco-sep-third-edition>. Accessed 01/13/2016.
- American Cancer Society. <http://www.cancer.org>. Accessed 01/13/2016.
- Aziz, N. M., and J. H. Rowland, 2003, Trends and advances in cancer survivorship research: challenge and opportunity: Semin Radiat Oncol, v. 13, p. 248-66.
- Carr D, Goudas L. Lawrence D, et al. Management of Cancer Symptoms: Pain, Depression and Fatigue Evidence Report/Technology Assessment No. 61 (prepared by the New England Medical center Evidence based practice Center under contract No 290-97-0019.
- Loprinzi CL. (2015) American Society of Clinical Oncology-Self Evaluation Program (ASCO-SEP®), Medical Oncology Self-Evaluation Program, 4th Edition. <http://university.asco.org/asco-sep%C2%AE-fourth-edition>. Accessed 01/14/2016.
- National Cancer Institute [National Cancer Institute Lymphedema \(PDQ®\)–Patient Version](#) May 29, 2015. Accessed 08/02/2017.
- National Comprehensive Cancer Network®, NCCN Guidelines® for Survivorship. http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf.
- Plana JC, Galderisi M, Barac A, et al. Expert Consensus for Multimodality Imaging Evaluation of Adult Patients during and after Cancer Therapy: A Report from the American Society of Echocardiography and the European Association of Cardiovascular Imaging. J Am Soc Echocardiogr 2014;27:911-939. Available at: <http://www.ncbi.nlm.nih.gov/pubmed/25172399>.
- Van Poznak, C. H. Bone Health in Adults Treated with Endocrine Therapy for Early Breast or Prostate Cancer. American Society of Clinical Oncology, Meeting Library. 2015