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UNC Lineberger Cancer Network
ADVANCED PRACTICE PROVIDER
April 20, 2022

Cancer Survivorship Care in Primary Care



Helen Tackitt, NP

Progress indicator: 10 columns of 5 squares each. The first 10 squares in the first row are filled with a red circle, indicating 100% completion.

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OUR PRESENTER



Helen Tackitt, NP

Helen Tackitt DNP, RN, FNP-BC graduated from USF in 2002 with her BSN. She then went on to attend Regis University to receive her MSN as a FNP. She has been a board-certified family nurse practitioner for almost 16 years. In 2016 she graduated with her DNP from Regis University.

As a nurse practitioner she spent 10 years working in urology and 5 years in oncology. She has over 11 years of progressive leadership experience including working as the Director of APRN/PA for the Taussig Cancer Institute at the Cleveland Clinic and Director of Clinical Practice and Education at Duke Cancer Network. She has a passion for cancer survivors which led to her opening Direct Primary Care Mebane in January of this year.

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UNC LINCOLN UNIVERSITY
UNCLINICAL COMPETENCY
CANCER CARE

UNC Lineberger Cancer Network

Cancer survivorship starts at diagnosis and continues through and beyond treatment.

True **A**

False **B**

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DISCLOSURES

This activity has been planned and implemented under the sole supervision of the Course Director, Lee Berkowitz, MD, in association with the UNC Office of Continuing Professional Development (CPD). The course director and CPD staff have no relevant financial relationships with ineligible companies as defined by the ACCME.

Greensboro Area Health Education Center is approved as a provider of nursing continuing professional development by the North Carolina Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

The presenter has no relevant financial relationships with ineligible companies as defined by the ACCME.

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Role of the Primary Care Provider in Cancer Survivorship

HELEN TACKITT DNP, RN, FNP-BC, NE-BC

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What is Cancer Survivorship?

A person becomes a cancer survivor at the time of their cancer diagnosis.



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Cancer Survivors

There are over 17 million cancer survivors in the United States. By 2040 the number is estimated to be 26.1 million. The number of cancer survivors is expected to increase due to:

- o Improvements in cancer screening
- o Increases in life expectancy following treatment
- o The aging of the population

Chan, K. & Hesteyden, L. (September 2021). Overview of cancer survivorship care for primary care and oncology providers. Up to Date.

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Cancer Survivorship

There are 3 phases of cancer survivorship

- o Acute phase: Active treatment
- o Extended phase: Treatment recently ended
- o Permanent phase: Rest of life

Kang J, Park E, & Lee J. (2019). Cancer survivorship in primary care. Korean Journal of Family Medicine, 40(9) 333-341

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Phases of Cancer Survivorship

Acute phase: Main concerns are pain, fatigue and emotional distress. On active treatment and lots of support from treatment team.

Extended phase: Treatment is over, but patients face physical, psychological and social readjustments. Usually still being seen by oncologist.

Permanent phase: Patients should have transitioned to Primary Care Provider (PCP). Main struggles are employment, health insurance, fear of secondary cancers and late effects.

Kang J, Park E, & Lee J. (2019). Cancer survivorship in primary care. Korean Journal of Family Medicine, 40(9) 333-341

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Gaps in Primary Care Providers Knowledge

The American Society of Clinical Oncologists (ASCO) reported on a survey from 2019 of 117 PCPs in practices affiliated with a large academic medical center with 4 main areas of focus.

- o Current practices in care of cancer survivors
- o Sense of preparedness to deliver such care
- o Barriers to care of cancer survivors
- o Preferences for shared care and communication between PCPs and oncologists

ASCO (2019) Study finds primary care providers are engaged in cancer survivorship care but report barriers to optimal care delivery

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Gaps in Primary Care Providers Knowledge

The results of the ASCO survey showed:

- o "Primary care physicians are often involved in cancer survivorship, and many do not feel adequately prepared for key components of it."
- o 84% assume responsibility of complications from cancer therapy but only 10% felt prepared to manage complications

ASCO (2019) Study finds primary care providers are engaged in cancer survivorship care but report barriers to optimal care delivery

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Gaps in Primary Care Providers Knowledge

The results of the ASCO survey showed:

- o 65% felt unprepared to screen for late complications
- o 36% felt unprepared to screen for recurrence
- o 94% assume responsibility for managing/making referrals for psychological therapy but only 25% felt prepared to take on this responsibility

ASCO (2019) Study finds primary care providers are engaged in cancer survivorship care but report barriers to optimal care delivery

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Gaps in Primary Care Providers Knowledge

Crabtree et al. (2020) interviewed 38 clinicians in 14 primary care practices with national reputations as "workforce innovators."

The interviews found:

- o PCPs think it is hard to stay current on cancer treatment
- o PCPs described an "uneasy relationship" with oncologists
- o PCPs have a lack of knowledge about cancer survivorship care
- o None of the PCPs interviewed had knowledge of cancer survivorship guidelines

Crabtree et al. (2020). Cancer survivorship care roles for primary care physicians. *Annals of Family Medicine*

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Oncology Care is Complicated

Oncology care is an ever-evolving field, with new treatments and complex therapies as well as evolving genetic implications.

PCPs can't always keep up with these brand-new cutting-edge specialty treatments.

It can be difficult for many providers to identify the side effects and reactions patients experience from chemotherapy or radiation treatments.

15-minute appointment slots limit what a PCP can manage.

Chan, R. & Hethcote, L. (September 2021). Overview of cancer survivorship care for primary care and oncology providers.

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Cancer Treatment is Complicated

Cancer survivorship care requires knowledge of the toxicities, risks and long-term effects of:

- Chemotherapy
- Immunotherapy and targeted therapy
- Hormone therapy
- Radiation
- Surgery



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Cancer Treatment is Complicated

One physician said,

"Cancer treatment kind of happens like in a black box...I feel a little intimidated by it, to be honest with you... I don't feel like I know enough about the long-term side effects of the chemo toxic agents."



Crabbie et al. (2020). Cancer survivorship care roles for primary care physicians. *Annals of Family Medicine*

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Why do PCPs Struggle with Cancer Survivorship Care?

Knowledge/Skills	<ul style="list-style-type: none"> Survivorship not integrated into medical education Few continuing education programs Patients' lack of trust in PCPs role in survivorship care Oncologists' lack of trust in PCPs role in survivorship care Emerging evidence regarding late effects, surveillance
Communication	<ul style="list-style-type: none"> Lack of consistent information from oncologist to PCP Lack of information from patients, dependence on patients as sources for communication exchange Insufficient dissemination of clinical guidelines Variable use of electronic medical records
Financial/Resources	<ul style="list-style-type: none"> Lack of time/clinical priorities Lack of reimbursement incentives Not traditionally targeted population for quality improvement Restrictions of insurance coverage Lack of access to appropriate providers/services

Hesthaven, L., O'Mahy, D., & Rubin, S. (2017). Integrating primary care providers in the care of cancer: Evidence and future opportunities. *Cancer Oncology*, 18 (1) e30-e38

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What are New PCPs Taught About Cancer Survivorship?

Harvard's board review for internal medicine 2021:

- One hour review (30 minutes on guidelines, 30 minutes on psychosocial considerations).
- Breast, Prostate, Colorectal, and Lung
- Basic follow-up labs and imaging for screening recurrence
- Brief mention of most common side effects from radiation, chemotherapy and surgery. Not specific to cancer type

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Survivorship Care Competencies

Table 3
Care Competencies for Cancer Survivorship – American Society of Clinical Oncology

Topic	Care Competencies
Survivorship	<ul style="list-style-type: none"> • Demonstrate how to obtain a cancer and cancer treatment history and how to interpret the health implications of this history. • Differentiate between common uses of the terms “personal care,” “disease-free survival,” “overall survival,” “survivorship,” and “cancer survivor” and how they affect clinical approaches and policymaking. • Identify incidence and prevalence of cancer survivorship overall, and differences by age and gender.
Surveillance	<ul style="list-style-type: none"> • Understand the risk of new primary cancers, local or metastatic recurrences and temporal patterns of recurrences of specific primary cancers. • Be aware of available surveillance methods (e.g. history and physical examination, imaging studies, blood work including tumor markers), and if applicable, their sensitivity and specificity in detecting recurrences and their cost-effectiveness. • Be familiar with data on the impact of surveillance and early detection of recurrences on overall survival. • Recognize treatment options and their effectiveness in the event of a new primary cancer, local or metastatic recurrence.

2020; G. Li, et al. ASCO Care Guidelines for Cancer Survivorship Education. Journal of Oncology Practice, 2016, p. JOP160044F

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What is the Solution?

ASCO recognized the importance to provide survivorship care and in 2004 established a Survivorship Task Force.

As detailed in the Institute of Medicine (IOM)'s 2005 landmark report, "From Cancer Patient to Cancer Survivor: Lost in Transition," cancer survivors have unique health care needs for their well-being.

IOM described survivorship care as a specific approach to monitoring and managing near, long term, and late effects of cancer treatment and promoting health.

The IOM also identified the necessity of a cancer treatment summary and follow-up care plan, or survivorship care plan (SCP).

The ASCO Panel (June 24, 2019). Study Finds Primary Care Providers are Engaged in Cancer Survivorship Care but Report Barriers to Optimal Care Delivery. ASP News Service, LLC

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What is the Solution?

The IOM identified four main parts of survivorship care:

- o Preventing recurrent and new cancers, as well as late effects of treatment
- o Watching for cancer spread and secondary cancers
- o Intervening to manage the consequences of cancer and its treatment
- o Coordinating specialists and primary care

The ASCO Poll (June 24, 2019). Study finds primary care providers are engaged in cancer survivorship care but report barriers to optimal care delivery. HSP News Service, LLC.

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What is the Solution?

In 2011 ASCO developed a committee on survivorship care:

- o Defined statements around survivorship care
- o Developed templates for SCPs
- o Developed guidelines around survivorship care
- o Outlined models of survivorship care
- o Developed a survivorship compendium to promote resources and tools for building and implementing a survivorship program

Blasko, A., Atkinson, P., Forstner, L., & Barlow, S. (2018). Survivorship Care Plans and the Commission on Cancer Standards: The increasing need for better strategies to improve the outcome for survivors of cancer. JCO Oncology Practice, 14(9), 447-450.

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Survivorship Care Plan

A patient specific record that summarizes and communicates what happened during active cancer treatment, recommendations for follow-up care, surveillance testing, referrals for support services, information on short term and long-term care.

ASCO requires at a minimum the SCP must include ASCO's recommended elements describing the treatment summary and a follow-up care plan.

Chen, R. & Haskivoy, L. (September 2011). Overview of cancer survivorship care for primary care and oncology providers. Up to Date.

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Survivorship Care Plan

In 2016 CoC created standard 3.3:

- o This standard required that all patients receive a SCP if they received curative intent for cancer treatment.
- o Programs could lose accreditation if this requirement was not met.
- o All programs were supposed to gradually meet a goal of 100% SCP delivery.
- o Organizations started focusing on providing the care plan instead of delivering the information to the patient and PCP.

Blakes, A., Adamson, P., Fakhri, L., & Shultz, S. (2020). Survivorship Care Plans and the Commission on Cancer Standards: The increasing need for better strategies to improve the outcome for survivors of cancer. JCO Oncology Practice, 16(8), 447-450.

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Survivorship Care Plan

Over-time, several barriers in implementing the SCP emerged
It became clear that the current implementation of the SCP may not be achieving their intended goals.



Blakes, A., Adamson, P., Fakhri, L., & Shultz, S. (2020). Survivorship Care Plans and the Commission on Cancer Standards: The increasing need for better strategies to improve the outcome for survivors of cancer. JCO Oncology Practice, 16(8), 447-450.

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Survivorship Care Plan

98% of PCPs stated they wanted a SCP with follow-up care recommendations from the patient's oncologist.

Only 11% received one



ASCO. (2017). Study finds primary care providers are engaged in cancer survivorship care but report barriers to optimal care delivery.

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Survivorship Care Plan

In 2019 CoC changed standard 3.3 to standard 4.8.

Standard 4.8 no longer requires a SCP to meet accreditation.
Standard 4.8 can be met by:

- Having a survivorship program and survivorship coordinator
- Document a minimum of 3 services offered to cancer survivors which can include the SCP, seminars, referrals for nutritional, psychological and rehabilitation services

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Survivorship Care Plan



Without the survivorship care plan PCPs are left guessing what to do with cancer survivors.

PCPs usually only have 15 minutes with their patients, which is not enough time to research the patient's treatment.

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What are PCPs Supposed to do?

SCP are time consuming and hard to track for reporting to CoC, meaning most programs will give up on SCPs.

NCCN has guidelines for survivorship care, but accessing guidelines requires an NCCN membership.

PCPs don't have memberships to NCCN, and even if they did, the guidelines are an overwhelming 291 pages.

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Comprehensive Patient Care Management by the PCP

Cancer survivors have a higher rate of comorbidities compared to the general population.

Cancer patients need regular scheduled follow-up appointments focused on screening for recurrence and secondary cancers, prevention and assessment of late effects.

Chan, R. & Hethcote, L. (September 2021). Overview of cancer survivorship care for primary care and oncology providers. Up to Date.

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Cancer Survivorship Care

- Screening and treatment for tobacco cessation
- Nutrition support and guidance
- Screening and treatment alcohol and drug dependency
- Sexual health
- Physical functioning
- Depression screening
- Anxiety screening

Chan, R. & Hethcote, L. (September 2021). Overview of cancer survivorship care for primary care and oncology providers. Up to Date.

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Adolescent and Young Adults

- o Body image disturbances
- o Fertility
- o Financial toxicity
- o Peer relationships
- o Work and career
- o Sexuality



Lawrentz, K., Fradette, M., Hwang, E., Sennar, A., Tishler-Epstein, Y., & Gruneir, K. (2021). The diagnosis and psychosocial care of adolescent and young adult (AYA) cancer patients: A review of 12-month prospective longitudinal study. BMC Cancer, 21(1), 1-10. Retrieved from <https://doi.org/10.1186/s12875-021-02074-9>

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Financial Toxicities

Cancer survivors have significant economic burden, even years after diagnosis.

As many as 2 in 3 patients experience some level of financial toxicity.

25% of cancer survivors reported using up all or most of their savings on treatment.

10% have problems paying their personal bills.

8% delay or avoid care due to cost of cancer treatment.

Chan, K. & Haskyrov, L. (September 2021). Overview of cancer survivorship care for primary care and oncology providers. Up to Date.

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Financial Toxicities

Among those filing for bankruptcy, the highest out-of-pocket medical expenses were associated with cancer compared to other diagnoses.

One study suggests that cancer survivors ≤ 65 years old were more likely to forego medical care due to costs.

Another study found that 12% of cancer survivors reported being denied health or life insurance coverage because of their cancer diagnosis.

Chan, K. & Haskyrov, L. (September 2021). Overview of cancer survivorship care for primary care and oncology providers. Up to Date.

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Accessibility

When patients are told they are "cured", and they do not need to keep seeing their oncologist on a regular basis they can feel psychological stress. They do not want to stop seeing the oncologist who they trust and lose support from the care team.

Many do not have a primary care provider and have difficulty establishing with a local PCP.

Even if they find a PCP, they may have to wait months to be seen.

Once established with a PCP, they do not know that providers comfort level with managing a cancer survivors complex care

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How Can Oncology Providers Help PCPs?

- o Complete a SCP and share it with the patient and PCP
- o Educate local PCPs about survivorship guidelines
- o Symposia and continuing education events for PCPs
- o Reach out to local PCP offices and establish collaborative relationships
- o Establish the ability for PCPs to have eConsults with oncologists

Kang J, Park E, & Lee J (2015). Cancer survivorship in primary care. Korean Journal of Family Medicine, 40(2): 153-161

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Direct Primary Care Mebane
Affordable Care that isn't Rushed

- o Direct Primary Care Mebane subspecializes in cancer survivorship
- o All patients are scheduled for 60-minute appointments each visit
- o Cancer survivors are screened for late effects using the NCCN Cancer Survivorship Guidelines

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Direct Primary Care Mebane
Affordable Care that isn't Rushed

- o All cancer survivors are screened for psychosocial distress through use of the PHQ-9 and GAD
- o Direct Primary Care Mebane has relationships with therapists specializing in cancer survivorship for patients who are in psychosocial distress
- o Same day/next day appointments are available to help keep patients out of the emergency department

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Direct Primary Care Mebane
Affordable Care that isn't Rushed

Direct Primary Care Mebane Cancer Survivorship is a non-profit 501(c)(3) which offers free primary care memberships to cancer patients experiencing financial toxicity

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Direct Primary Care Mebane
Affordable Care that isn't Rushed

Direct Primary Care Mebane is here to partner with you and your patients

Patients and providers can schedule a meet and greet at www.DirectPrimaryCareMebane.com

or call 919-568-0004

Helen Tackitt can be emailed at DirectPrimaryCareMebane@gmail.com

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Chan, R. & Nekhlyudov, L. (September 2021). *Overview of cancer survivorship care for primary care and oncology providers*. Up to Date. <https://www.uptodate.com/contents/overview-of-cancer-survivorship-care-for-primary-care-and-oncology-providers>

Crabtree, B., Miller, W., & Howard, J., et al. (May 2020). Cancer survivorship care roles for primary care physicians. *The Annals of Family Medicine*, May/June 2020, 18 (3) 202-209; DOI: <https://doi.org/10.1370/afm.2498>

The Asco Post, (June 24, 2019). *Study finds primary care providers are engaged in cancer survivorship care but report barriers to optimal care delivery*. HSP News Service, LLC.

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Leuteritz, K., Friedrich, M., Nowe, E., Sender, A., Stobel-Richter, Y., & Geue, K. (2017). Life situation and psychosocial care of adolescent and young adult (AYA) cancer patients-study protocol of a 12-month prospective longitudinal study. *BMC Cancer* 17, 82. Retrieved from <http://doi.org/10.1186/s12885-017-3077-z>

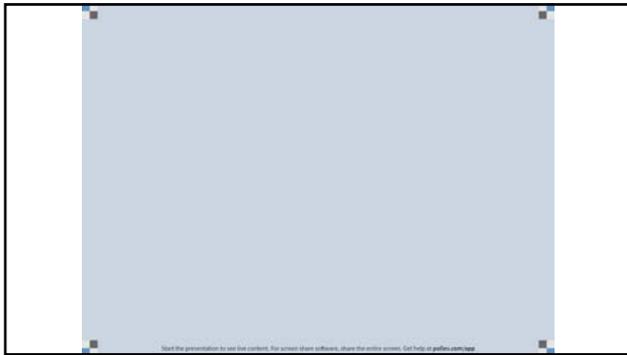
Blaes, A., Adamson, P., Foxhall, L., & Bhatia, S. (2020). Survivorship Care Plans and the Commission on Cancer Standards: The increasing need for better strategies to improve the outcome for survivors of cancer. *JCO Oncology Practice* 16 (8) 447-450

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Nekhlyudov, L., O'Mally, D. & Hudson, S. (2017). Integrating primary care providers in the care of cancer in evidence and future opportunities. *Lancet Oncology* 18 (1) e30-e38

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UNC Lineberger Cancer Network

The Telehealth Team

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UPCOMING LIVE WEBINARS

<p>RESEARCH TO PRACTICE</p> <p>April 27 12:00 PM</p> <p>Advances in Peri-Operative Therapy in Bladder and Kidney Cancer Tracy L. Rose, MD, MPH</p>	<p>ADVANCED PRACTICE PROVIDER</p> <p>May 4 12:00 PM</p> <p>Indigenous Intergenerational Intervention to Address Cancer Among Washington State Tribes Myra Parker, PhD, Ed, MPH Craig Dee, MPH(c)</p>
<p>PATIENT CENTERED CARE</p> <p>May 11 12:00 PM</p> <p>The Vital Role of Primary Care Providers in Breast Cancer Survivorship Care Allison Beam, MPH, Ph.D</p>	<p>ADVANCED PRACTICE PROVIDER</p> <p>May 18 4:00 PM</p> <p>Sex and ATIs with Cancer: Mitigating Risk and Managing Sexual Dysfunction Melissa Matson, MSN, RN, AGPCNP-BC</p>

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SELF-PACED, ONLINE COURSES

<p>ADVANCED PRACTICE PROVIDER</p> <p>Bridging the Bench and Bedside: The Amalgam of Academic Medicine and Its Effect on a Cancer Patient Experience Hannah E. Worlax, MD</p>	<p>ADVANCED PRACTICE PROVIDER</p> <p>Psycho-Oncology: Supporting the Mental Health of Oncology Patients Melissa Holt, DNP, PMHNP-BC, BCNP</p>
<p>RESEARCH TO PRACTICE</p> <p>Lymphoma Management Updates for 2021 Anne W. Beaven, MD</p>	<p>PATIENT CENTERED CARE</p> <p>Testicular Cancer Mary W. Dunn, MSN, RN, OCN, NP-C</p>

Today's webinar will be available in May 2022 as a FREE, Self-Paced, Online Course
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UNC Lineberger Cancer Network

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