

UNC Lineberger Cancer Network
PATIENT CENTERED CARE Live Webinar **November 2, 2022**

Welcome to the UNC Lineberger Cancer Network's live webinar

Sound Check 11:55 AM **Start Time** 12:00 PM

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1

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2

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3

OUR PRESENTER



**Patricia Morfeld,
RN, BSN, OCN**

Patti Morfeld, RN, BSN, OCN, is a native Texan and now Carolinian for 13 years. She has been an Oncology Nurse since 2010 and is currently pursuing an MSN in Health Care Leadership and Administration at UNC Chapel Hill.

Patti is a previous member of the Patient and Family Advisory Council, current member of the Lineberger Equity Council, and member of the LGBTQ community.

7

Respond at [PollEv.com/uncfcn](https://poll.ev.com/uncfcn)

Text UNCLCN to 223333 once to join, then A or B

UNC UNIVERSITY OF NORTH CAROLINA
UNC Lineberger Cancer Network

Does heightened acceptance mean increased access or treatment?

Yes **A**

No **B**

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8

DISCLOSURES

This activity has been planned and implemented under the sole supervision of the Course Director, William A. Wood, MD, MPH, 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.

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9

UNC Lineberger Cancer Network logo at the top. The main text asks: "Does heightened acceptance mean increased access or treatment?". Below the text is a vertical axis with "Yes" at the top and "No" at the bottom. A blue line starts at the "Yes" level and drops to the "No" level. At the bottom, it says "Powered by Poll Everywhere" and "Start the presentation to see live content. For screen share software, share the entire screen. Get help at poll.com/app".

10

Dark purple background with white text. Title: "Caring for LGBTQ patients with Cancer". Subtitle: "HOW AND WHY IS IT DIFFERENT AND WHY OUR COMMUNICATION WITH PATIENTS, CAREGIVERS, AND EACH OTHER MATTERS". A pink tab is visible in the top right corner.

11

Dark purple background with white text. Quote: "Comfortable in my skin / Cozy with who I am / Comfortable in my skin (cozy, cozy)". Attribution: "BEYONCÉ KNOWLES-CARTER". A pink tab is visible in the top right corner. At the bottom, there is a small paragraph: "In order to talk openly we have to be honest with ourselves so for at least the next hour I'd ask you to be exactly where you are and OPEN to hearing and learning how to provide LGBTQ friendly care, even awkwardly, as a part of being comfortable with your own self and the people around you."

12

Goals for today

<p>Recognize Vocabulary</p> <ul style="list-style-type: none"> Learn a little more about preferred vocabulary Acknowledge that there is no one size fits all way to identify people or populations of people. 	<p>Create Conversation</p> <ul style="list-style-type: none"> Starting points for conversation with colleagues <ul style="list-style-type: none"> About patient/caregivers About our work About our work environment 	<p>Identify Resources</p> <ul style="list-style-type: none"> UNC Health/Lineberger Resources Local, State, National Resources Electronic Medical Record hints
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13

No more standing in the shadows

Until the AIDS crisis in the 1980's the U.S. LGBTQ population was doing advocating for itself and establishing organizations to protect and advocate for LGBTQ people. The AIDS crisis caused a seismic shift in "public" advocacy and the creation of organizations like ACT UP, Gay Men's Health Crisis.

- This isn't ancient history. Many of the LGBTQ patients we care for were born and raised in a time where identifying as their authentic selves was potentially dangerous, physically, emotionally, personally and professionally.
- The shift in public acceptance can be credited to many things:
 - Advocacy for research and care for all people with HIV/AIDS and related illnesses.
 - Consistent pressure by advocacy groups to demand support, education, and protection for LGBTQ people
 - Public and private LGBTQ persons "coming out."
 - Support and investment by allies to LGBTQ people and allies speaking up and out about the LGBTQ people they love in their own lives.
 - Increased visibility of LGBTQ people in all forms of media and not always as a criminal, pervers, or handy aunt with a hammer and "roommate of 30 years" who just never found a fella.

14

Heightened acceptance does not equal increased access or treatment

"The majority of published research identified through this review on healthcare needs among LGBTQ populations has been focused on family systems, human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) prevention and maintenance, and general health. This review revealed that, to date, there have been limited efforts to systematically identify cancer health care needs across the cancer continuum, including prevention, early detection, diagnosis, treatment, survivorship and end-of-life care." Quinn, G. P., Sanchez, J. A., Turner, S. E., Hildebrandt, S. C., Nguyen, G. T., Green, S., Karaman, P. A., & Schoenbach, M. B. (2018). Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations.

15

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All of the following are barriers to accessing and receiving care except:

- Lack of insurance coverage due to a lack of insurance from domestic partner
- Fear of discrimination
- Lack of coverage for screening exams if they identify as a different gender on their insurance card
- All of the above

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16

Why does this matter?

LGBTQ people face increased barriers to accessing and receiving care:

- ▶ Lack of insurance coverage some due to a lack of insurance for domestic partners, lack of coverage for screening exams if they identify as a different gender on their insurance card
- ▶ Fear of discrimination or ignorance can lead some patients to not disclose their sexual orientation/identity. This is often based on previous negative experiences or negative experiences of their friends.
- ▶ LGBTQ cancer survivors are less likely to participate or feel welcomed in survivorship programs.
- ▶ LGBTQ patients may delay palliative care end of life decisions out of concern their decisions will not be honored.

National LGBT Cancer Network

17

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What organization sets the standard for the hospital to allow a family member, friend, or other individual to be present with the patient for emotional support during the course of stay?

- The Joint Commission
- Center for Medicare and Medicaid Service
- American Hospital Association
- United States Department of Health and Human Services

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18

The Joint Commission also recognizes and set this standard in 2011.

STANDARD RI.01.01.01, EP 28 STATES: THE HOSPITAL ALLOWS A FAMILY MEMBER, FRIEND OR OTHER INDIVIDUAL TO BE PRESENT WITH THE PATIENT FOR EMOTIONAL SUPPORT DURING THE COURSE OF STAY. ADDITIONAL NOTES FURTHER CLARIFY THAT THE SUPPORT INDIVIDUAL:

BE CHOSEN BY THE PATIENT (UNLESS THE INDIVIDUAL'S PRESENCE INFRINGES ON OTHERS' RIGHTS, OR SAFETY, OR IS MEDICALLY OR THERAPEUTICALLY CONTRAINDICATED)

MAY OR MAY NOT BE THE PATIENT'S SURROGATE DECISION MAKER OR LEGALLY AUTHORIZED REPRESENTATIVE

19

Our language doesn't have to be perfect- but it does have to be honest.

Why do we always have to talk about someone's sex life?
Nope. Gender identity and sexual orientation are not equivalent to sexual behavior.

Why do I have to call her by a mans name?
Nope. How does calling another person by their chosen name impact your ability to perform your work?

Why should I have to make this accommodation, I disagree with their "lifestyle"?
Nope. Part of accepting the responsibility of being a health care professional means we care for all people-not the ones that look like or agree with us.

Why does it matter we are just treating their cancer?
Nope. We are treating a whole person and oftentimes the people closest to them. We need to ask so we can fully assess their health needs and risks, and so we can create treatment plan that fits them.

20

"But I'm afraid I'll screw up and say the wrong thing!"

Most patients and caregivers recognize the staff person who is making an effort to get it right. They understand when someone is intentionally trying to use their chosen pronouns, or address their partner as their spouse, and they appreciate it.

21

Make it a **HABIT**

What is your preferred name?

Who are your caregivers?

Do you like staff to call you by your first name or would you prefer Mrs. XXX or Dr. YYY?

If we give patients and caregivers the opportunity to identify themselves we give them an opportunity to be honest about who they are and to build a trusting relationship with us as their chosen healthcare team.

What if I do say the wrong thing?
The same thing you do now when you say the wrong thing or hurt someone's feelings unintentionally. "I apologize, let me start over."

22

There are too many names I know I am going to mess this up.



Maybe-but let's focus on the BIG picture. Don't get stuck in the weeds and stop trying.

- More important than any other identity for our patients and caregivers is that they and we are unique human beings and not one label or umbrella term fits all of us.
- Some patients will quietly introduce their same gender partner and claim a lesbian or gay identity-some patients will introduce their same gender caregiver as their roommate and not wish to answer any other questions about their sexual orientation. Both responses are valid.
- Some patients will arrive dressed as the gender they identify with, regardless of their anatomy- they are wearing clothes-not a political agenda.
- How patients chose to identify may change during the time you provide care for them, having cancer can be very clarifying for many patients and lead to them choosing to change their relationships, professions, or how they like to be identified. This can be true for all patients with cancer.

23

So how does this apply to my work team and the care we provide?

Visibility
 Creating and nurturing a healthcare environment that cares for all kinds of people, means all kinds of people who work here should be nurtured too.

- Leaders should be clear in their acceptance of all kinds of staff and expectations for the same behavior from their staff members.
- Staff who are openly LGBTQ should be supported by their leadership and included in conversation about staff events, holiday planning, etc. Joe should be able to bring Steve to the Christmas potluck, and Janine should be able to celebrate the arrival of a new child with their same gender partner.
- Staff who prefer to be quiet about their LGBTQ status should have their privacy honored.
- When there is discomfort expressed by staff or discriminatory language leaders must engage and address it directly.
- Annual education on LGBTQ healthcare issues should be shared and mandated by organizations.
- Recognize that when these attitudes and behaviors are cultivated in staff that also leads to more welcoming and understanding for patients and caregivers.

24

Assume good intentions
 A coworker complains about having to use they/them when addressing a patient or caregiver

- Ask the why?
- Then offer information-"you know that was actually really brave of that patient to share such an important piece of information about their caregiver. They are actually trusting us to treat them just like you want us to treat someone you love or even you."

A patient states, "I don't want that gay nurse."

- Ask the why?
- Then offer information-"you know we hire all kinds of really good people to care for all kinds patients in some of the hardest moments of their lives but we are happy to help refer you to another clinic if you'd prefer that."

Offer accurate information, expect changed behavior, and if negative behavior continues speak to your leadership. Do not accept discriminatory behavior to change without engagement.

How about patient care?

25

SOGI
 Sexual Orientation and Gender Identification

Collecting this information is an important way to demonstrate our organization commitment to LGBTQ inclusive care

Collecting this information on **every** patient makes it a routine part of their care, and a habit for us as healthcare workers.

Collecting this information helps our institution and those across the U.S. to collect data and drive research for underserved populations.

That's what we do-we research and develop treatments for cancer and we can do it better when the research we conduct and the data we collect represents all kinds of people.
[SOGI.pdf \(unchealthcare.org\)](#)

26

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 Current EMRs are required by the Center for Medicare and Medicaid Service to have the capacity to collect Sexual Orientation and Gender Identification information.

True

False

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27

At **UNC Health** institutions using the electronic medical record(EMR) EPIC the SOGI information is easy to access in patient demographics. [\(link to tip sheet at the end\)](#)

- Current EMRs are required to have the capacity to collect SOGI data and the Center for Medicare and Medicaid Service (CMS) recommends that this data is routinely collected- but it is not required.
- Unfortunately the data requirements and policies can be changed based on the opinions of elected officials. This was widely seen during the initial year of the Covid pandemic with elected officials sharing data to further their agenda.
- This is another reason that healthcare organizations should lead with the science and research and make collecting this information the standard. Once that is the expectation it will be impossible for election year shenanigans to cause this type of disruptive change.

28

“
Trust is not built in big, sweeping moments. It's built in tiny moments every day.
”

DR. BRENÉ BROWN- DARE TO LEAD

Thank you all so much for joining this conversation and committing to creating a work and clinical environment that is welcoming for LGBTQ patients, caregivers, and colleagues.

29

Acknowledgements

My thanks to the many friends who allowed me to figure out who I was, who I am today, and who I may become. Those who have been patient as I learned and most especially my sons, Nick and Henry.

30

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31

Great websites and resources

 **HUMAN RIGHTS CAMPAIGN**
<https://www.hrc.org/resources/healthcare-equality-index>

 **Dana-Farber Cancer Institute**
<https://www.dana-farber.org/for-patients-and-families/becoming-a-patient/patient-safety-and-advocacy/lgbtq-patient-care-and-support/>

 **UCLA Health**
<https://www.uclahealth.org/programs/lgbtq>

32

 **NATIONAL LGBTQIA+ HEALTH EDUCATION CENTER**
A PROGRAM OF THE EDWARDS INSTITUTE
<https://www.lgbtqiatheducation.org/>

 **THE TREVOR PROJECT**
<https://www.thetrevorproject.org/>

 **National Coalition for LGBTQ Health**
<https://healthnlgbtq.org/>

 **WELCOMING SPACES**
Creating Inclusive Health Care Environments
<https://www.welcomingspaces.org/>

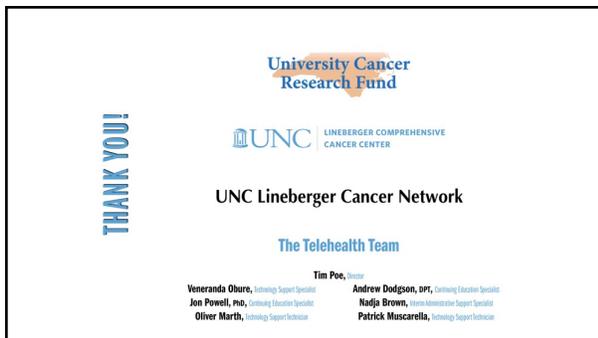
(This one has a great program for education that is 100% free and funded by the Society for Gynecologic Oncology)

[Welcoming Spaces: Treating Your LGBTQ+ Patients | SGO ConnectEd](#)

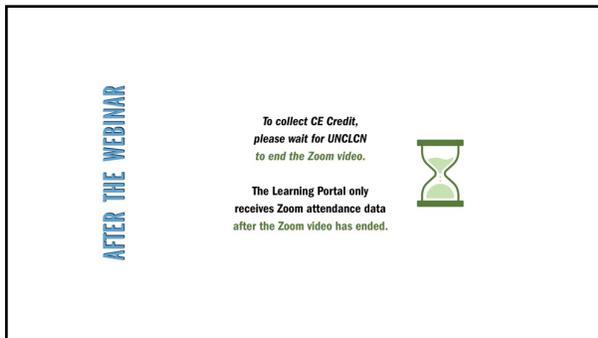
33



34



35



36

UPCOMING LIVE WEBINARS

<p>ADVANCED PRACTICE PROVIDER  November 9 4:00 PM</p>	<p>Acute Radiation Side Effects Lara Novak, PA-C</p>
<p>RESEARCH TO PRACTICE  November 16 12:00 PM</p>	<p>Acute Myeloid Leukemia with Myelodysplasia-Related Changes (AML-MRC): An Evolving Poor-risk Subgroup of High Unmet Need Joshua F. Zeidner, MD</p>
<p>SOUTHEASTERN AMERICAN INDIAN CANCER HEALTH EQUITY PROMOTIONS  November 30 12:00 PM</p>	<p>American Indian Cancer Control & Health Equity Donald Warne, MD, MPH</p>

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37

SELF-PACED, ONLINE COURSES

<p>ADVANCED PRACTICE PROVIDER  What Can VIR Do for You? Katie Riffle, MSN, FNP-BC</p>
<p>RESEARCH TO PRACTICE  Topics in Cancer Pharmacy in North Carolina: Updates for Oral Chemotherapy for 2022 Bianka Patel, PharmD, BCOP, CPP</p>
<p>PATIENT CENTERED CARE  Psycho-Social Complications of Receiving a Cancer Diagnosis and Treatment During the Pandemic Justin Yopp, PhD</p>

Today's webinar will be available in December 2022 as a FREE, Self-Paced, Online Course. Complete details on Self-Paced Online Courses:
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38

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39
