Meeting the Emotional Needs of Long-term Lung Cancer Survivors

“Turquoise Takeover” LUNG FORCE EVENT

National Women's Lung Health Week May 12-18, 2019

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Introduction

Nurses protect, promote, and improve health for all ages. Responsibilities include providing health promotion, counseling, and education to individuals and to groups.

“A planning committee came up with the topic. The conversation was that basically, people are surviving longer (yay!) – and surviving things that used to be terminal (i.e. cancer). While providers know how to medically treat patients, they cannot be the stand alone support for their patients emotional support. It takes a comprehensive team approach to meet the emotional needs of long term survivors. So, there needs to be education on both sides. Improved understanding by providers of the emotional needs of survivors – and the importance of understanding the need to reach out for support (by patients and caregivers) – and the resources that are available to help them.

Kimberly Rogers, Manager, Health Promotions American Lung Association NV

This presentation is applicable for survivors, loved ones, caregivers, health care providers. Please have patience with terminology because of the mixed group.

Take a deep breath, then exhale slowly; relax = parasympathetic system activation
Learner Outcomes

• Identify common emotional needs of long-term lung cancer survivors
• Describe interventions for the survivor
• Review communication skills
• Identify resources to prepare for survivorship and end-of-life
Warning

This presentation contains health information for educational purposes. It is not meant to diagnose any medical or mental health condition. You should always consult a health care practitioner for examination, diagnosis, treatment, and personal advice.

No financial attachment to health care providers or facilities, researchers, resources, or references.
Lung Cancer Stats

• Lung cancer = leading cause of cancer-related deaths for men and women in the US -- 28% all deaths; mostly 40-75 age group
• Overall 5-year survival rate = 15%
• Cigarette smoke = chronic respiratory irritant = greatest risk factor = 80-90% of all cases; cigarette and secondhand smoke contain PAHs
• Sidestream smoke = same 60 carcinogens as mainstream smoke
• Pipe / cigar – slightly higher risk than nonsmokers
• Occupational / environmental major risk factors are radon, polycyclic aromatic hydrocarbons (PAHs), asbestos
Who is a Survivor?

The National Coalition for Cancer Survivorship defined the terms “survivor” and “survivorship” as they are now widely understood and accepted:

- Whether treatment is being received or has been completed, anyone who has received a cancer diagnosis is a cancer survivor.
- Survivorship is the total experience of living with, through, and beyond cancer.
- Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.

Resources:
The Cancer Patient’s Guide To Talking With Your Doctor, Fifth Edition
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LCA Survey Results Show Unmet Emotional Needs of Long-Term Survivors

ANXIETY is the major emotion

Resources:  “Survey Data from Lung Cancer Alliance Highlights the Unmet Emotional Needs of Long-Term Lung Cancer Survivors”  https://lungcanceralliance.org/blog/lca-survey-results-show-unmet-emotional-needs-of-long-term-survivors/

MA07.01 No Longer Outliers: Understanding the Needs of Long-Term Lung Cancer Survivors
https://www.jto.org/article/S1556-0864(18)31325-X/fulltext
Signs of Anxiety

Anxiety is an emotion characterized by feelings of tension, worried thoughts and physical changes like increased blood pressure, perspiration, and rapid heartbeat.

May also have:
• Sleep disturbances
• Appetite changes
• Fears
• Feeling hopelessness, helplessness guilt, despair, inadequate, emotionally disconnected, lack of interest especially in family and friends, obsessive behavior
• Feeling overwhelmed by loss & grief
Anxiety (& fear)
Quality of Life (QOL) as patient knows it... ends

- Various aspects tx & side effects; repeated venipuncture & tests; fatigue; chemobrain; nausea; diarrhea
- Dependency issues; loss of freedoms, roles, social standings, abilities
- Side effects distort body image
- Cost of care; loss of income; insurance
- Poor outcomes / fear of reoccurrence / infection
- Scanxiety
- Ongoing clinical visits & hospitalizations
- New / continuing Rx with side effects
- Unsure about CAM (Complementary & Alternative Medicine)
- Conflicting advice from family, friends, Dr. Google
- Caregiving issues
- Have to face end-of-life issues
Emotion

“a complex reaction pattern, involving experiential, behavioral, and physiological elements, by which an individual attempts to deal with a personally significant matter or event. The specific quality of the emotion (e.g., fear, shame) is determined by the specific significance of the event. For example, if the significance involves threat, fear is likely to be generated; if the significance involves disapproval from another, shame is likely to be generated. Emotion typically involves feeling but differs from feeling in having an overt or implicit engagement with the world”

Resource: https://dictionary.apa.org/emotion
Feeling

“a self-contained phenomenal experience. Feelings are subjective, evaluative, and independent of the sensations, thoughts, or images evoking them. They are inevitably evaluated as pleasant or unpleasant, but they can have more specific intrapsychic qualities, so that, for example, the affective tone of fear is experienced as different from that of anger. The core characteristic that differentiates feelings from cognitive, sensory, or perceptual intrapsychic experiences is the link of affect to appraisal. Feelings differ from emotions in being purely mental, whereas emotions are designed to engage with the world.

2. any experienced sensation, particularly a tactile or temperature sensation (e.g., pain, coldness).”

Resource: https://dictionary.apa.org/feeling
Factors that affect emotions & feelings

meds RX disease meds RX co-morbidities meds RX pain meds OTC herbs/tea sleep or lack of weather light intensity level of activity BP glucose $$$$ diet caffeine other non-CA health issues level of social interaction privacy level of care body processes constipation, etc menopause desired sex/ lack of intimacy self-medicating ETOH/Rx not yours/ MJ MMJ pets media & advertising influences self-image fatigue ADL limitations perceived injustices family conflicts threats language barriers

This is overwhelming.
But let’s be more practical here....
How to recognize the moods of an Irish setter
Since most lung ca is linked to cig smoking... perception could be that the disease is self-inflicted.
Survivor can feel guilty; feel defensive; feel shame. Others can blame.

Unknown or unexpected lung ca, perhaps from radon.

What about workplace exposure and inhaled occupational carcinogens? Feel helplessness, conflicted -- health risk vs providing for family. Others can feel pity. “Whys” again
Stigma

• Stigma is defined as a mark or a brand of disgrace associated with a particular circumstance or quality.
• Fear of being denied treatment, concealment of their condition and psychosocial distress such as anxiety, depression and isolation are all negative impacts of stigma that affect lung cancer patients.
• There is little direct evidence that providers withhold treatment, however lung cancer patients clearly perceive bias, judgment and differential treatment from their providers.
• **Resource: REQUIRED READING!!**
Survivor Guilt

Although happy to be alive, cancer survivors may feel guilty that they survived while fellow patients they became friendly with during treatment or as part of a support group did not. (Early after a diagnosis of cancer, people first ask, “Why me?” When survivors think about those who have died, they tend to ask, “Why not me?”)

Both Survivor and Caregiver Supportive Behavior

- Honest communication skills “I feel”
- Boundaries
- Loss = opportunities for growth and to redefine oneself
- Changed roles; fluctuating roles
- Don’t define oneself or others by illness, injury, disability, or disease!!
- Post traumatic growth
- Self help programs promoted by cancer centers
Health Care Provider Supportive Behavior

• Nursing Assessment – “The nurse can assess the level of anxiety experienced by the patient, and the support provided and needed by the patient’s significant others”

• Communicate “You will be followed. We are a team treating you and your loved ones. Here is available support” Ask the survivor and caregiver to repeat back in their own words what you are communicating.

• Honesty, Trust, Acknowledge anxieties
• Empathy; Non-judgmental attitude
• Have resources available
• Encourage use of support and survivorship plans
• Refer for co-morbidities & other health concerns
"Do you want to talk about what this means?"

**Survey: Half of Cancer Patients Don't Know Their Stage**

"Patients struggle both with interpretation of jargon (e.g., what does stage IIb mean) as well as contextualization (e.g., what does "the cancer is in the liver" mean)," he told Medscape Medical News in an email.

Dr Campbell, who was not involved with the study, cited previous research that "has taught us that there is cognitive (and probably emotional) resistance to the information and the prognostic implications." The end result is that "the information has a more difficult time being incorporated" by patients.

Dr Campbell has a simple way to work around resistance. He asks patients, That is "a prompt which creates space to discuss prognostic information if the patient/family invite it," he said.

**Resource:** Survey: Half of Cancer Patients Don't Know Their Stage - *Medscape* - Sep 06, 2017. Oncology News
“Good doctor-patient communication has the potential to help regulate patients' emotions, facilitate comprehension of medical information, and allow for better identification of patients' needs, perceptions and expectations. Patients reporting good communication with their doctor are more likely to be satisfied with their care, and especially to share pertinent information for accurate diagnosis of their problems, follow advice, and adhere to the prescribed treatment. Patients' agreement with their doctors about the nature of the treatment and need for follow-up is strongly associated with their recovery.”

Survivorship Care Plans

Resources:
National Coalition for Cancer Survivorship
  https://www.canceradvocacy.org/cancer-advocacy/elevating-survivorship/
  https://www.canceradvocacy.org/resources/cancer-survival-toolbox/
Office of Cancer Survivorship
  https://cancercontrol.cancer.gov/ocs/
American Cancer Society
Survivorship Care Plans

• Dana-Farber Cancer Institute
  https://www.dana-farber.org/for-patients-and-families/for-survivors/

• Memorial Sloan Kettering Cancer Center
  https://www.mskcc.org/experience/living-beyond-cancer
  https://www.mskcc.org/cancer-care/types/lung/survivorship
  https://www.mskcc.org/cancer-care/types/lung/treatment/follow
Nursing Perspective & Diagnoses

- **Nursing DX (for example)**
  - Ineffective airway clearance related to increased trachea-bronchial secretions and presence of tumor
  - Anxiety related to lack of knowledge of diagnosis or unknown prognosis and treatments
  - Risk for infection related to decreased pulmonary function
  - Acute pain related to pressure of tumor on surrounding structures and erosion of tissues
  - Imbalanced nutrition: less than body requirements related to increased metabolic demands, increased secretions, weakness, and anorexia
  - Ineffective health maintenance related to lack of knowledge about the disease process and therapeutic regimen
  - Ineffective breathing pattern related to decreased lung capacity
Nursing Goals/Outcomes

The patient with lung cancer will have:
1. effective and/or adequate breathing patterns
2. adequate airway clearance
3. adequate oxygenation of tissues
4. minimal to no pain
5. realistic attitude toward treatment and prognosis
Phone Check & Take a Deep Breath
The Tough Talk
Stop It!

Stop smoking!! For your benefit and those around you!!

A combination of behavioral techniques and nicotine replacement products is the most effective strategy to help smokers quit. Continue the cessation attempt even if slip or relapse.

Resources:
- [https://gethealthyclarkcounty.org/live-tobacco-free/quit-smoking/](https://gethealthyclarkcounty.org/live-tobacco-free/quit-smoking/)
- [http://www.tobaccofreenv.org/tobacco-information/quit-smoking/](http://www.tobaccofreenv.org/tobacco-information/quit-smoking/)
- [https://truthinitiative.org/tobacco-use-nevada](https://truthinitiative.org/tobacco-use-nevada)
- [https://gethealthyclarkcounty.org/live-tobacco-free/quit-smoking/](https://gethealthyclarkcounty.org/live-tobacco-free/quit-smoking/)
- [http://www.tobaccofreenv.org/tobacco-information/quit-smoking/](http://www.tobaccofreenv.org/tobacco-information/quit-smoking/)
Stop it!

Stop It! Do not be a victim of your disease!
Do not use your disease as a way to manipulate others! Use “cancer card” judiciously; only when you really need help!
Stop it!

Stop It! Do not use the disease of the one you are caring for as an opportunity for exploiting patient!

Beware of Caregiver Fatigue! Don’t take your frustrations out on the medically vulnerable!

Take a break if you need it.

**Resources:** most major cancer centers websites have information regarding this topic
Stop it!

Stop Abuse!
• Mandated reporter = health care providers
• Report intentional harm to others or self; self-neglect
• Beware of Compassion Fatigue! Take a break if you need it!

Resources:
your professional or licensure organization;
https://nevadaadrc.com/lib/sections/eapt/elder_abuse_training.pdf
Definitions of Elder Abuse   NRS 200.5092
Mandated Reporting Guidelines   NRS 200.5093
Marijuana & Medical Marijuana; CBD

Recreational & medical marijuana & products are legal in Nevada, in case you haven’t heard....

Some reasons for use are:

• Pain and/or anxiety control
• Opioid avoidance
• Symptom control (nausea, appetite)
• Patient empowerment
• Support of CAM - home remedies - “grassroots” medicine – natural – anti big Pharma

However -- some consider it Biggest Public Health experiment of this century!
Please consider—

- Tell your HCP (or ask your patient) off the record if using cannabis products. Why? MJ is a chemically complex plant. Interactions with Rx and cancer treatments are not well researched.
- Natural does not = safe
- Lack of evidence & research does not = safe
- Heavily advertised / promoted cure-all; especially CBD products
- Budtenders & MJ advocates are generally not licensed HCPs responsible for their diagnoses, treatments, or licenses
- Smoke? Really want lung irritant? Some claim that MJ smoke does not cause lung problems because of “healing properties” of plant.
- Smoke easier to titrate dose due to rapid onset of effects. Edibles are responsible for most ERs admissions= difficult to titrate dose lag time between consumption and effect
- Only slightest overlap between cannabis, EBP. well-controlled research
"[A]lthough less frequent overall, edible products lead to more acute psychiatric events and cardiovascular symptoms than inhaled exposure”

“Edible cannabis has been considered to be more toxic than inhalable cannabis, particularly in light of accumulating poison center data on its associated adverse events (AEs) and anecdotal reports from adult users. In addition, the only deaths in Colorado that have been conclusively linked to cannabis use have involved edible products.”

Rick Simpson Oil: Cancer Cure or Pipe Dream?

The story of Rick Simpson and his namesake cannabis oil has made him a hero to some and a menace to others. Simpson's claim that he used the oil to cure his own skin cancer has spread online like a viral tidal wave. The recipe for Rick Simpson oil (RSO), which he says he has never sold, is translated in 72 languages on his website, which also carries first-person stories extolling the product's "miraculous" properties.

But clinicians familiar with Simpson and his cult-like following take a different view. "It's terrifying," said Adam Friedman, MD, professor of dermatology at the George Washington School of Medicine & Health Sciences in Washington, DC. "This guy's gotta be stopped." In fact, for those who believe that randomized, double-blind, placebo-controlled studies should guide evidence-based medicine, this is the kind of story that makes you want to pull your hair out.

• **Resource:** Rick Simpson Oil: Cancer Cure or Pipe Dream? - *Medscape* - Feb 20, 2019.
Nursing Interventions/Spirituality

“Pts may feel guilty about their cig smoking having caused the ca and need to discuss this feeling with someone who has a nonjudgmental attitude.... Additional counseling from a social worker, psychologist, or member of the clergy may be needed. Nursing research focusing on the effects of spirituality on the sense of well-being of people with lung cancer found that people with more meaning in their live had decreased symptom distress.”

“Additionally, prayer was associated positively with psychologic well-being. This validates the impact of spiritual care for these patients and helps guide the nurses’ practice in spiritual needs. Research on the role of the family found that family disagreements about treatment decisions for patients with advanced lung cancer were common. For nurses, these finding suggest the need to be aware of differences of opinions in order to facilitate family communication and improve patient satisfaction with treatment decisions.” Med-Surg Nursing
Dying & Death

Death— conflict (afraid of it) or peace (prepared for it)?

“Getting older or being debilitated by disease is all about losing control. You lose physical abilities, your driving privileges, the ability to get about on your own and frequently even control of bodily functions. That's scary for all of us and what often matters most to those at this stage in life is regaining some sense of control. Helping people understand and connect to the options available in each jurisdiction, be that palliative sedation, comfort care or medical assistance in dying, can relieve the distress patients feel in this situation allowing them to make the very best use of whatever time remains. In my 52 years of practice the issue of control outweighs every other consideration in the majority of cases and restoring whatever control we can for these patients affords respect, dignity and comfort to them often allowing them to address other matters of importance to them with their sense of control restored.” Dr. George Harpur | (Family Medicine) 04/22/18

We will all die. We may die:

1. From it -- original cancer diagnosis, or return of lung cancer, or metastasis to different cancer
2. With it -- die of something unrelated to lung cancer
   - Accidents
   - Co-morbidities
   - Suicide or assisted suicide
   - Sleep
   - Infection – measles, zika virus, etc.
Dying & Death

Spiritual considerations -

• Time to revisit faith you were raised in
• Time to explore new faith expressions and worldviews
• Chaplains available from healthcare facilities or houses of worship
• Pray to God as you understand God
Dignity Talk

Dignity Talk - a series of research-designed questions providing a “gentle means of facilitating end-of-life conversations”

Resources:


Dying & Death

Assisted Suicide

• Known by such terms as “Aid-in-dying” etc.
• SB 165, the Nevada Death with Dignity Act, passed out of the State Senate Health Committee and did not meet the legislative deadline for passage in the full Senate.
• It may not be like watching your pet being euthanized
• Advocates for vulnerable persons are against assisted suicide, as are many health organizations

Resource: www.patientsrightscouncil.org
Phone Check & Take a Deep Breath
Practical Considerations

Lung cancer diagnosis is like “Accelerated” aging

- Sex
- Pain
- Life review
- Stages of grieving
- Palliative care & hospice care
- Advance Care Planning & legal issues
- Support Groups- Local, BBC, Online
- Dr. Google
- Communication skills
- Best Medicine
"So how is your sex life?“ That is a question that a great many cancer patients would love to hear from their oncologists, but unfortunately, sexuality is not a topic that gets much attention.


--Good question to ask --“Who would you prefer to talk to about intimacy and sexual issues?”
Pain

What so many of those who are diagnosed with cancer fear... pain and uncontrolled pain.

And now, in 2019, a second fear—opioid dependence and/or overdose.

Please have in-depth discussions regarding pain control and palliative care with the survivor! Include all team members and caregivers!

Resources:  https://www.nhpco.org/resources/end-life-care--resources
National Hospice and Palliative Care Organization

https://www.cancercare.org/tagged/pain
Life Review

• Fully engage this most important time of life.
• Can do this privately or with loved ones
• Oral, written, visual (photo/video), media, meditative, music, arts
• Based on Erikson’s Stages of Psychosocial Development: Ego integrity vs. Despair (late adulthood, 60 years and above; also when facing life-limiting illness)—a time for reflection on own life, met and unmet goals and desires
Stages of Grieving

Stages of grieving are a complex, fluctuating mix of emotions & behavior

• Kubler-Ross (1969)
  – Denial
  – Anger
  – Bargaining
  – Depression (DX) Despair (em
  – Acceptance

• Ask you survivor how he or she is feeling!
“For patients with terminal cancer, one of the primary barriers to earlier hospice enrollment has been termed "the terrible choice" of having to give up curative treatments in order to be eligible for hospice care. This is the stark situation for Medicare beneficiaries in the United States — they cannot receive Medicare hospice benefits and active cancer treatment at the same time — they have to make a choice.

"However, the reality of terminal disease, with prognostic uncertainties and ever-expanding therapeutic modalities that hold possibility of benefit, can often be incongruent with such an either/or model," comments Tracy A. Balboni, MD, MPH, of the Dana-Farber Brigham and Women's Cancer Center in Boston, Massachusetts.

"This reality leaves many patients turning to hospice care only when death is days to a few weeks away, or not at all." March 28, 2019  JAMA Oncology.
Advance Directives refer to some or all:
Health Care Power of Attorney (state specific)
Living Will
POLST order (Provider Order for Life Sustaining Treatment)

Resources:
The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care
https://theconversationproject.org/
NV Secretary of State Lockbox
https://www.nvsos.gov/sos/online-services/nevada-lockbox
Nevada Cancer Coalition
https://nevadacancercoalition.org/resources-directory/nevada-polst
Local In-Person Support

Better Breathers Clubs  “The goal of support groups is to improve the quality of life and functional status for members by providing disease-specific education and emotional connection which may prevent exacerbations requiring medical care, thereby reducing the health, economic and social burden of lung disease.

The Caring Place  The Caring Place is dedicated to easing the journey of those touched by cancer. An oasis away from medical facilities, The Caring Place provides no-cost programs and services to support, educate and empower those who have or have had cancer, their family members, friends, and caregivers. Our programs and services are intended to assist in healing mind, body and soul and are not a replacement for medical care.  www.thecaringplacenv.org

Senior Peer Counseling  https://www.dignityhealth.org/las-vegas/classes-and-events/support-groups/senior-peer-counseling
Better Breathers Clubs

**Purpose and Goal**

The **goal** of support groups is to **improve** the **quality of life** and **functional status** for members by providing disease-specific **education** and **emotional connection** which may prevent exacerbations requiring medical care, thereby reducing the health, economic and social burden of lung disease.
Online Support

**Resource:** Inspire’s Lung Cancer Survivors community is offered in partnership with the American Lung Association. It is the largest lung cancer support group for patients and caregivers living with lung cancer.

Providers of online health information:
Dr. Google, Alexa & Siri know everything, right?

Instead, for more accurate and up-to-date information, look for websites that:
- Have .edu or .gov extensions
- Provide continuing education for health care professionals such as https://www.pesi.com and Institute for Brain Potential https://www.ibpceu.com
- Have the HON certification
Communication skills

• “I” messages  I feel, I need, I appreciate you asking, “How am I doing, but I prefer you ask __________.”
• “Please don’t ask that question; I feel uncomfortable about it. Let’s talk about __________.”
• Focus not on the disease, but the person!
• Choose communication over isolation. Take the communication initiative with open-ended questions
• Boundaries – what you can do & what others can do realistically and speak up to define those boundaries
What we say to dogs
Okay, Ginger! I've had it!
You stay out of the garbage!
Understand, Ginger? Stay out of the garbage, or else!

What they hear
blah blah GINGER blah
blah blah blah blah blah
blah blah GINGER blah
blah blah blah blah
Best Medicine – laugh!

Boldly laugh in face of death!

• Journalist Norman Cousins seminal 1979 book *Anatomy of an Illness as Perceived by the Patient* recounts bouts of laughter brought on watching comedy television and movies. "I made the joyous discovery that ten minutes of genuine belly laughter had an anesthetic effect and would give me at least two hours of pain-free sleep. When the pain-killing effect of the laughter wore off, we would switch on the motion picture projector again and not infrequently, it would lead to another pain-free interval."
Testing whether laughter is the best medicine
Live Life Love

- Emotional support is a complex, extensive topic
- Everyone needs purpose, hope, goal, need to be needed – even at the end of life
- Many kinds of love, do you practice “brotherly love”? • How can HCP show love to caregiver? Survivor?
  • How can survivor show love to caregiver? HCP?
  • How can caregiver show love to survivor? HCP?
- Let go of bitterness, despair, resentment, anger, unforgiveness, self-importance, and go to Grand Canyon for perspective
Review Learner Outcomes

• Identify common emotional needs of long-term lung cancer survivors
• Describe interventions for the survivor
• Review communication skills
• Identify resources to prepare for survivorship and end-of-life
Do these too!

- Laugh frequently
- Feel fearlessly
- Breathe deeply
- Speak clearly
- Forgive quickly
- Share generously
- Receive thankfully
- Think broadly
- Live humbly
- Love boldly
Conclusion

Thank you for participating!

American Lung Association
1-800-LUNGUSA
https://www.lung.org/

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