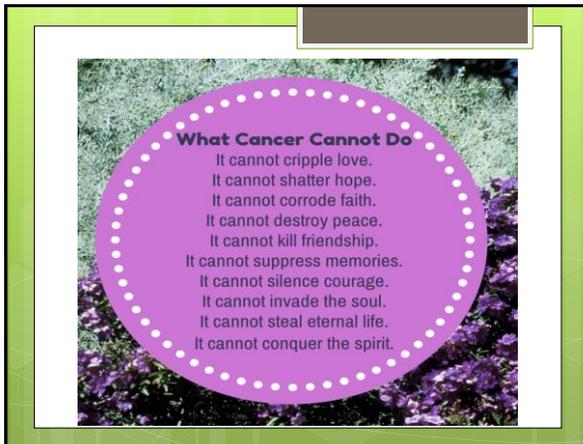


Oncology Care

The Psycho-Social Dimensions of caring for patients and caregivers with cancer

Toni Black, BSN RN, OCN

- Started nursing in a neuro-ICU first in a rural setting then a large urban medical center for 5 years
- Transitioned to L&D for 5 years to experience other end of life spectrum
- Joined oncology team 5 years ago and found perfect blend of interpersonal relationships and technical nursing



What Cancer Cannot Do

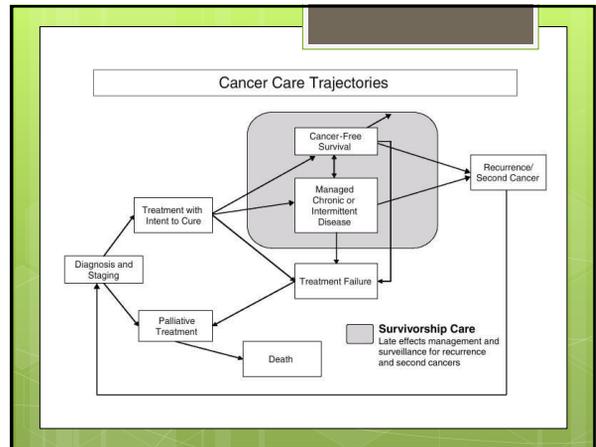
- It cannot cripple love.
- It cannot shatter hope.
- It cannot corrode faith.
- It cannot destroy peace.
- It cannot kill friendship.
- It cannot suppress memories.
- It cannot silence courage.
- It cannot invade the soul.
- It cannot steal eternal life.
- It cannot conquer the spirit.

“Cancer is a completely devastating disease that leaves heartbreak and loss in the lives of those left behind. Someday I believe there will be a cure. Until that day comes, I will reach out with love and support to the ones left hurting. In that way we celebrate little victories while we actively pursue a cure.”

-Carlene

Cancer Quick Facts:

- **41%** of Americans can expect to be diagnosed with cancer in their lifetimes
- **1.6 million** new cases of cancer per year
- Cancer is now considered a “chronic” condition
- Life-saving therapy often causes permanent disability, leading to inability to manage ADLs
- Patients experience ongoing psychological and social sequelae
- By 2020 there will be **18 million people** struggling with these issues



Who's guiding the psychosocial issues facing cancer patients?

- Commission on Cancer: In 2012, the American College of Surgeons (ACOS) established Standard 3.2: Psychosocial Distress Screening to be monitored starting in 2015. This standard requires **ALL** accredited cancer programs to screen 100% of newly diagnosed patients for their level of distress and then prove they did something to help.

So...what do cancer patients worry about, if not their disease?

Please complete the thermometer and identify areas where you have concerns or needs by checking the box below:

Please fill in the thermometer to show how much distress you have been experiencing in the past month, including today.

10 Extreme Distress
9
8
7
6
5
4
3
2
1
0 No Distress

Practical Assistance

- Financial Difficulties
- No Income
- No Insurance
- Limited Insurance
- Housing
- Help at home
- Treatment Decisions
- Other: _____

Information and Resources

- Transportation
- Work/School
- Advanced directives/legal
- Counseling
- Support Groups
- Naturopathy/Nutrition
- Exercise
- Education

Emotional Health

- Sad
- Anxious
- Angry
- Depression
- Fear
- Fear of dying
- Spiritual/religious concern
- Loss of interest in activities
- Other: _____

Relationships Communication

- Talking with Spouse/Partner
- Spouse/Partner needs support
- Talking with my children
- Age(s)
- Sexuality/intimacy
- Other: _____

Physical Health

Fatigue

Pain

Eating

Sleep

Breathing

Memory/concentration

Getting around

Who's the first line of defense for safeguarding our patients?

- Oncology social workers
- Oncology nurses and navigators
- Oncologists
- Support groups
- Family and friends
- Spiritual Support

How do we help?

- Be prepared to discuss weighty and uncomfortable subjects
- Get their families involved in their care
- Get the patients the resources they need to manage their life outside the clinic
- Talk to your patients about their lives, not just their diagnosis
- Be honest about their treatment pathway, the good and the bad
- Laugh and cry, and mean it!



ANXIETY and DISTRESS!!

- Anxiety: Fear or nervousness about what might happen (Webster dictionary)
- This patient has CANCER – what *might* happen to them?
- Distress: unhappiness or pain that affect the body and mind (Webster dictionary)
- How does distress alter our ability to treat the oncology patient?

Signs and symptoms:

- Tearfulness
 - Depression
 - Panic
 - Isolation
 - Non-compliance
 - Exhaustion
 - Nausea/Vomiting
 - Anorexia
- Who will most likely be affected:
 - Lung, pancreatic, brain cancer
 - Young
 - Female
 - Uneducated
 - Non-white

How do patients cope?

- Normal adjustment - as patients gain knowledge about their disease a feeling of control is reestablished
- Adjustment disorder – these patients have trouble managing their lives and may exhibit emotional, social and behavior changes – get the social worker involved
- Anxiety disorder – extreme anxiety, leading to fear, worry and dread. Panic attacks and isolation may result. In some cases, patients have developed PTSD – the social worker may consult psychiatry for these people

What about depression?

- **“If we can bring the joy back in somebody’s life, then we have accomplished our goal.” – Dr. Anis Rashid (Dept of Psychiatry MD Anderson Cancer Center)**
- Depression is the most OVERLOOKED side effect of cancer and treatment – but should be looked at like any other physical symptom
- Treating depression in the oncology population leads to better overall well-being and therefore better oncology outcomes

Signs and symptoms:

- Trouble sleeping
- Eating too much or not enough
- Feelings of hopelessness
- Loss of interest in life
- Feelings of guilt
- Lack of energy
- Poor memory

Treatment strategies:

- Therapy or support groups – talking helps
- Patient collaboration in treatment goals
- Recollect and focus on good memories
- Medications if needed – psychosis may present in severe cases

These patients may need frequent screening for suicidal ideation – request an assessment by the social worker with any concern

What about social issues?

- Low income
- Uninsured or underinsured
- Lack of social support
- Level of education
- Lack of housing
- Physical age (not chronological...)
- Co-morbidities and functional status
- Personal habits
- Trust in healthcare system
- Language barriers

Cancer patients pick their top issues with life:

1. Managing the home
2. Managing insurance and disability services
3. Finances
4. Employment
5. Legal matters
6. Relationships
7. Sexuality and body image
8. Recreation

British Journal of Cancer, 2002

**“An individual
doesn’t get
cancer...
A family does.”**

Terry Tempest Williams

Relationships and Cancer

- In 2005, the Journal of Clinical Oncology published an article about sexuality...
"The Sounds of Silence: Sexuality Information for Cancer Patients"
- A cancer diagnosis and subsequent treatment affects all aspects of sexuality: sexual activity, body image, physical function, emotions and mental perceptions
- Fatigue, pain and restriction of movement usually contribute to this even if the cancer does not involve a sexual organ

PSSST.....

The truth is....patients are as reluctant to you talk about sex as the staff is to discuss it.... Here's a model to help you: The Ex-PLISSIT model

Stage	Description
Permission	Is it ok to discuss this issue with you?
Limited Information	Correct information to dispel myths, offer basic info to identify issue
Specific Suggestions	Offer specific suggestions to manage sexual side effects
Intensive Therapy	Identify if further support is needed after initial discussion – make referral

And the winner is....

When it comes to issues that patients with newly diagnosed or ongoing cancer have....

THE STRESS OF FINANCES

is the *most* talked about topic utilizing the most staff resources to manage.

If patients have insurance why do they worry about money?

- Most insurance plans have a high deductible – patients are required to pay 20% of their treatments until this is met resulting in thousands of dollars per treatment in bills before 100% coverage kicks in
- No prescription drug plan? Can you afford a \$2,500 monthly co-pay on your oral chemotherapy?
- Most people are already living paycheck to paycheck – they can scarcely afford the life they're living – how can they expect to pay their \$7,500 deductible?
- MANY patients will decline or alter treatment based on financial stressors – even if it meant a CURE!

How we bridge the gap...

- Financial counselors are instrumental in finding \$\$\$ to help patients meet their needs.
 - Patient access foundations
 - Drug replacement
 - Pharmaceutical assistance
 - Better coverage
 - SSDI
 - Charity Care
 - Clinical trials

Financial Solution:	Amount Impacted (YTD):
Insurance applications	\$953,400+
Patient Access Foundations	\$30,000
Pharmaceutical partnerships	\$100,000+
Billing disputes	\$15,000
Reversal of insurance denials	\$261,700
Total:	\$1,360,100+

Conclusion:

- Cancer patients are under tremendous stress. (And we didn't even talk about chemo side effects or hospitalizations.....)
- The Cancer team has the resources and desire to meet the needs of the patient in a holistic fashion
- The key is to bravely approach these topics with your patients