FEAR OF RECURRENCE

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Objectives

• Examine emotions and identify triggers related to a cancer diagnosis and fears of reoccurrence
• Understand fear, anticipatory loss and grief and the difference between grief and depression
• Explore coping strategies to improve quality of life
Start of Diagnosis

• What if I die?
• How can I stop working, I have to work!”
• What if I lose my hair?
• Chemotherapy?
• How can I tell my family?
• I am scared!
• Even if it’s cured, what if it comes back?
Fear, Loss and Grief

• Cancer pervades every aspect of your life
• The illness has a profound impact on the way you live your life, which creates feelings of fear loss and grief
• Cancer is usually erratic and unpredictable and our responses need constant readjusting
• Fears about future and not knowing what to expect are normal
Anticipatory Loss (Rando 2008)

• Mourning, coping, interaction, planning psychosocial reorganization stimulated by the awareness of an impending loss

• Recognition of associated losses in the past, present and future

• **Therapeutic Experience:** to balance conflicting demands of simultaneously holding onto, letting go of and drawing close
Anticipatory Loss: Intensified Emotions (Rando 2000)

- Separation Anxiety
- Existential Aloneness
- Denial
- Sadness
- Disappointment
- Anger
- Resentment
- Exhaustion
Anticipatory Loss

- Desperation
- Ambivalence
- Fantasies of escape
- Hypervigilance
- Protectiveness
- Rehearsal of Loss
- Imagined Suffering
- Fluctuation between pain/preciousness
6 Dimensions of Anticipatory Mourning (Rando 2000)

• 1. Recognize the Loss-
  • acknowledge and understand

• 2. React to the Separation
  • experience the pain
  • feel, identify, accept, give expression to
  • the psychological reactions
  • identify and mourn secondary losses
6 Dimensions

3. Recollect and Re-Experience the initial diagnosis and treatment process

4. Relinquish the old attachments to the losses and the old assumptive world
6 Dimensions

• 5. Readjust to move adaptively into the new world without forgetting the old
  • Revise the assumptive world
  • Develop a new relationship with your body and your role
  • Adopt new ways of being in the world
  • Form a new identity

• 6. Reinvest
  • To invest again or anew
LOSS

• WHAT DO WE DO WHEN THE LOSSES WE ANTICIPATE ACTUALLY HAPPEN?

• WHAT ARE THE TYPICAL LOSSES AFTER A CANCER DIAGNOSIS?
Multiple Losses

- Loss of control and power which is part of our self-esteem
- Loss of independence
- Loss of faith
- Loss of confidence
- Loss of financial security
- Loss of income
- Loss of identity
- Change in lifestyle
- Change in hopes and dreams for the future
Role Changes Within Family

• Changes of roles within a marriage and family is another adjustment issue
• Family members experience the same changes and accompanying feelings of fear, loss and grief
• Very important to communicate feelings so relationships maintain
• Usually in crisis, strong relationships strengthen and weak relationships weaken
Loss of Identity

- We often define ourselves within our life roles, when these roles change, it is difficult.
- Daughter, brother, mother, wife, husband, father, mechanic, cook, artist, etc.
- Cancer forces us to reframe ourselves and the way we interact with others.
- It is often difficult to feel good about ourselves until we find ways to adapt ourselves to our new self-image.
Visible and Invisible Losses

- Physical- loss of energy and appetite, functional status
- Mental-less control over our emotions and memory
- Emotional- frustration, uselessness, sadness
- Social- hobbies, sports, travel, dining out, movies, theatre, reading
Reactions to Loss of Independence

• **Fear**-afraid of new vulnerability, “How will I manage on my own? You may want family and friends close by at all times or “I don’t’ need anyone’s help”

• **Anger**-feeling angry about needing help and may take anger out on loved ones

• **Guilt**-Feel guilty about not being the ones who helps others and feeling like a burden

• **Confusion**-confused about needing the help, not knowing what to do and longing for the future
Grief

• There is no time frame for grief—for some it may be lifelong
• As illness progresses or changes, we may find we are faced with new losses
• The losses associated with cancer encompass every aspect of our lives and alter our sense of self
## Grief vs Depression

<table>
<thead>
<tr>
<th>GRIEF</th>
<th>DEPRESSION</th>
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</thead>
<tbody>
<tr>
<td>Identifiable loss</td>
<td>Loss may or may not be identifiable</td>
</tr>
<tr>
<td>Focus is on the loss</td>
<td>Focus is on the self</td>
</tr>
<tr>
<td>Sadness and emptiness</td>
<td>Sadness and emptiness</td>
</tr>
<tr>
<td>Emotions come in waves</td>
<td>Emotions are chronic</td>
</tr>
<tr>
<td>Fluctuating ability to feel pleasure</td>
<td>Inability to feel pleasure</td>
</tr>
<tr>
<td>Closeness of others is reassuring</td>
<td>Prefers to isolate</td>
</tr>
<tr>
<td>Relatively stable self-esteem</td>
<td>Loss of self-esteem, worthlessness</td>
</tr>
<tr>
<td>Some specific guilt/regret</td>
<td>Guilt out of proportion</td>
</tr>
<tr>
<td>Thoughts of wanting to be with deceased</td>
<td>Thoughts of active suicide</td>
</tr>
<tr>
<td>Non-bizarre hallucinations</td>
<td>Hallucinations and/or delusions</td>
</tr>
</tbody>
</table>
How to Cope with Losses

• **Patience**-acknowledge the losses and their impact while recognize adapting takes time

• **Self-Acceptance**-the disease is not a personal failure or something you can control. DON’T judge or blame yourself

• **Non-Judgement**-don’t judge how and when you are feeling or reacting. Loss and grief are very individual experiences. Do not compare yourself to others
How to Cope With Loss

• **Recognize Your Feelings**- allow yourself to feel sad or frustrated regarding your loss. This is not a sign of weakness. It is a normal human reaction

• **Remain Open**- Family and friends may offer suggestions to make this easier. Think about and discuss the options

• **Accept Help**- seek and accept help. It will improve your quality of life and lessen frustration
Emotions After Treatment

Completion of treatment can be stressful and exciting.

Once treatment is over, many cancer survivors have thoughts and feelings and concerns that they did not expect to have.
What is Normal?

• Once treatment has ended, you may feel like you are not “fighting” any more.
• Now what?
• For some, now that the fighting has stopped, emotions that were “put on hold” during treatment are very strong.

• Your routine has changed.

• Can you go back to your old role in your family and in your life in general?
Re-Defining Your “Normal”

• How has your outlook on life changed and how has this impacted your view of yourself and your relationships?
• What is more important to you now?
• What is less important to you now?
• You need to become very important and your emotional well being needs to be the focus.
The What If’s

• You may be paying extra attention to the aches and pains in your body
• You may be wondering:
  • Will it come back?
  • What are the chances it will come back?
  • How will I know if it has come back?
  • When will it come back?
Fear

• The “What Ifs” are questions related to very normal fears.
• These fears can be paralyzing.
• They may impact your ability to sleep, eat, concentrate, make simple decisions or communicating openly with loved ones.
• FEAR OF REOCCURRENCE IS NORMAL.
Arm Yourself with Information

- Cancer recurrence is defined as the return of cancer after treatment and after a period of time when the cancer cannot be detected.

- The length of time is not clearly defined.

- The cancer may come back in the same place it started or somewhere else in the body.
Be Prepared

• Keep your health insurance.
• Keep your follow-up visits with your doctor.
• Get the tests your doctor suggests.
• Keep copies of your cancer treatments and tests.
Learning To Live With Uncertainty

• Worrying about recurrence is very normal, especially during the first year after treatment has ended.
• As time passes, many people say their fear of recurrence lessens.
• Some events that may trigger fears of recurrence are:
  • Follow-up visits or certain medical tests.
Events That Trigger Fears

• Anniversary events (date of dx, had surgery or ended treatment).
• Illness of a family member or friend.
• Finding out someone you know has had a recurrence.
• You develop symptoms similar to those when you discovered you had cancer.
How to Deal With Feelings of Fear

- **Patience**-acknowledge that this is a process and with time, these fears should lessen.
- **Self-Acceptance**-your cancer was not a personal failure or something you could have controlled. Don’t judge or blame yourselves.
How To Deal With Feelings of Fear

• **Recognize Your Feelings**-allow yourself to feel fear. It is a normal human reaction.

• **Remain Open**-Family and friends may offer suggestions to make this easier. Think about and discuss the options.
Cognitive Behavioral Therapy

- CBT is based on the idea that our thoughts cause our feelings and behaviors, not external things like people, situations or events.
- The benefit of this fact is that we can change the way we think in order to feel/act better, even if the situation does not change.
The Situation

You’ve had a bad day, you are feeling frustrated and you decide to go shopping. As you walking in the mall, someone you know walks by, and apparently, ignores you. This starts a cascade of:

<table>
<thead>
<tr>
<th></th>
<th>Unhelpful</th>
<th>Helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Thoughts</strong></td>
<td>He/ She ignored me</td>
<td>He/ She looks a bit wrapped up in themselves- I wonder if there’s something wrong?</td>
</tr>
<tr>
<td><strong>Emotional Feelings</strong></td>
<td>Low, sad and rejected</td>
<td>Concerned for the other person, positive</td>
</tr>
<tr>
<td><strong>Physical Feelings</strong></td>
<td>Stomach cramps, low energy, feel sick</td>
<td>None- Feel comfortable</td>
</tr>
<tr>
<td><strong>Action</strong></td>
<td>Go home and avoid them</td>
<td>Get in touch to make sure they’re okay</td>
</tr>
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Tools To Cope

• Remind yourself that you are doing the best that you can.
• Spend time alone to think about your feelings.
• Ask friends and family for help.
• See a therapist if needed.
• Make time for yourself and do the things you enjoy.
• Take Care of Your Self-health, eat well, sleep well, rest and exercise.
Tools To Cope

• FORGIVE YOURSELF

• LOVE YOURSELF

• DON’T JUDGE YOURSELF
Vulnerability and Belonging (Brene Brown)

• People who have a sense of worthiness had 4 things in common:

  1. Courage to tell the story of who you are
  2. Compassion: Kind to self and others
  3. Connection: Let go of what they should be as a result of authenticity
  4. Fully Embrace Vulnerability: What made them vulnerable made them beautiful. Vulnerability was necessary for life. Its not comfortable but not excruciating
• Vulnerability is the core of shame and fear but is also the birthplace of joy, creativity and love

• To experience life to the fullest, four things need to be practiced:
  • 1. To let ourselves be seen
  • 2. Love with whole hearts
  • 3. Practice gratitude and joy
  • 4. To believe we are enough
True Belonging

• The spiritual practice of believing and belonging to yourself so deeply that you can share your most authentic self with the world and find sacredness in both being a part of something and standing alone in the wilderness. True belonging does not require you to change who you are. It requires you to be who you are.
QUESTIONS