Waiting for the Shoe to Drop: Managing Your Fear of Recurrence

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What Is Fear of Cancer Recurrence?

Patient’s Perspective

- "I do feel like I almost live with a time bomb; that this could go off again at any time." – Dana-Farber.org

- “… a metaphorical sword hangs by a single horsehair over the head of cancer survivors and shadows their lives ever after.” – Zebrak & Zelter, 2001
What Is Fear of Cancer Recurrence?

Patient’s Perspective

• “[Cancer worry is] like a whale that moves into your living room... Over time, the whale gets smaller, but it never quite goes away completely. A tenant you can’t get rid of. Maybe it gets down to the size of a magazine rack. Once in a while you bump into it, and sometimes it swells up into your face again, like when you have a mammogram and they call you back for extra views.” – Weiss & Weiss, 2010
What Fear of Cancer Recurrence Is

Definition

• The fear or worry that cancer will return or progress in the same organ or in another part of the body – Vickberg, 2003

• Fear? Worry? Anxiety?
  - Type of Health Anxiety
  - Can range from normal concerns to clinically significant anxiety

• When Can it Start?
  - Potentially emerges at any point after a person is first diagnosed with cancer
How Common Are Fears of Recurrence?

Depends on the Type of Patient

• Reported by 22-74% of people with a history of cancer
  - Depends how you ask the question

• More common in:
  - Women vs Men
    • More common in breast cancer versus prostate cancer
    • Just as common in both if same type of cancer – Simard et al., 2008
  - Younger patients
  - Less educated patients
How Long Do These Fears Last After Treatment?

Timeline

• Longer than most people think
  - 1/3 of patients still report fear of recurrence 10 years after diagnosis

• First year after diagnosis:
  • Overall distress goes down
  • Fear of recurrence remains
    • Reduces once a treatment is successfully completed – Rabin et al., 2004
When Does Fear of Recurrence Happen?

**Common Triggers**

- Upcoming medical appointments
  - Oncology visits
  - Cancer screening
- Anniversary of cancer diagnosis or treatment
- Hearing about another person’s cancer or a person who died from cancer
- Any mention of cancer
- Side effects from past cancer treatment
- Unexplained physical symptoms
Fear of Recurrence during Cancer Screening

Patterns of Anxiety and Worry

• Surveyed 160 women previously treated for early-stage breast cancer
  - Month before the surveillance mammogram
    • Intensity of anxiety and worry about cancer did not change
    • How often women worried about cancer increased
  - Month after receiving results that showed no signs of cancer
    • Dramatic decrease in anxiety and worry as soon as results discussed
    • Anxiety and worry crept back up within a week of the good results
Fear of Recurrence during Cancer Screening
Patterns of Anxiety and Worry

• Not all patients had the same experience
  - 75% had moderate anxiety and worry
  - 25% had very low anxiety and worry

• What set them apart?
What May Increase Fear of Cancer Recurrence?

Associated Factors

• Other mental health problems
  - Anxiety
  - Depression

• Poorer overall well-being and quality of life
  - More symptoms is related to more worry

• Pessimism
  - More worry/dread about everything
What May Increase Fear of Cancer Recurrence?

Associated Factors

• Your habits:
  - Seeking reassurance *too often*
    • Performing too many self-exams
    • Requesting more medical exams than what is recommended

• Your perceptions of:
  - Risk for cancer recurrence
    • Commonly misunderstood
  - Ability to cope if the cancer should return
    • What about your past experience can make a second cancer easier to manage?
• How intense are your fears and worries?
  - Overwhelming distress is not common for most patients
  - Avoiding the subject?
    • Inability to even talk about cancer may be a sign of being overwhelmed

• How often do these worries interfere with your everyday life?
  - Do they stop you from:
    • Getting things done
    • Enjoying relationships with others
    • Planning for your future
    • Attending or scheduling medical appointments
Signs Your Fears Are Problematic

Beyond Normal Concerns

• How much effort do you spend trying to cope with the worry and fear?

  - High effort & low distress
    • Your efforts to cope appear to work for you!
    • Keep up your efforts

  - High effort & high distress
    • Sign that your strategies are less effective or even counter-productive
    • Consider seeking help to learn more effective ways to manage the worry
How To Cope

Strategies for Keeping Fear of Recurrence Manageable

• Learn Your Triggers
  - Note what makes worries more common or more stressful
  - Being more aware reduces the chances you’ll be off guard when worries are most likely to hit

• Wouldn’t that make me worry more?
  - Learning the patterns helps clarify your problem
    • Clear problems have clearer solutions
  - Identify triggers when you aren’t as worried
    • Easier to think about and be objective when you aren’t already distressed
How To Cope

Strategies for Keeping Fear of Recurrence Manageable

• Have a Plan in Place
  - When you know stress will be high, have a coping strategy in place
    • Medical appointment = pleasurable/relaxing distracting activities
    • Concerning symptom = problem-solve, seek appropriate medical advice
    • Hearing about cancer/death = express your feelings with somebody supportive
    • Special event that reminds you of cancer/death = practice gratitude/thankfulness

• If coping on your own is difficult
  - Seek support
  - Consider counseling
How To Cope

Strategies for Keeping Fear of Recurrence Manageable

• **Talk with Your Doctor**
  - Find out **your risk** of recurrence or **possible options** if cancer should recur
    • Explain what you understand to your doctor to confirm the information is accurate
    • Learn what a recurrence could mean in terms of your health
    • Educate yourself about signs of recurrence to know which symptoms matter most
  - Identify behaviors that **you can do now** to reduce risk of recurrence
    • Quit smoking
    • Adopt healthy habits
    • Maintain regular physician visits and medical exams
How To Cope

Strategies for Keeping Fear of Recurrence Manageable

• Manage Everyday Stress
  - When stressed in general, other worries can be magnified
  - Helpful strategies include:
    • Deep breathing exercises
    • Mindfulness meditation
    • Exercise
    • Yoga
    • Problem-solving
    • Pleasurable events/activities
    • Social support
    • Faith

“I can’t worry about that now.
I’m worrying about something else.”
Tools You Can Use

Become Aware

• Track your own common triggers
  - Which can you plan ahead for?

• List your common ways of coping with stress
  - What works?
  - What does not work?

• Explore your thoughts about your risk of recurrence
  - How likely do you think it is?
  - What would it mean to you if you had a cancer recurrence?
Tools You Can Use

Challenge Your Perceptions

• Get the facts about your risk
  - Each patient is different
  - Learn what the statistics mean for you

• Challenge your thoughts about managing cancer recurrence
  - What did you learn about your ability to cope with cancer before?
  - What resources could you rely on?
  - What helped you before?
Tools You Can Use

Change Your Habits

• Notice and **cope** with fear of cancer recurrence
  - Be proactive and **plan a coping strategy** when you are most likely to worry
  - Match the coping strategy to the trigger

• Engage in health habits to **reduce your cancer risk**
  - Increase healthy behaviors
  - Reduce risky behaviors like smoking

• **Follow doctor’s advice** about cancer screening
  - Be cautious about checking more often than necessary
How Can I Seek Help?

Resources Available

• **Supportive Oncology Program**
  - Support Groups for patients and caregivers
  - Individual Services:
    • Psychiatry
    • Psychology
      • Available even if insurance is not covered
    • Social Work

• **Gilda’s Club of Chicago**
  - Supportive network
  - Activities and programs designed to improve coping

"If you don’t stop with the worry warts, you’re gonna croak."
THANK YOU

Questions?