

Fear of Cancer Recurrence among Post-Treatment Cancer Survivors

Defining Cancer Survivorship

- Broad experience on the cancer continuum
- Living with, through, and beyond a cancer diagnosis



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The power of survivorship. The promise of quality care.

Survivorship (Research) Definition

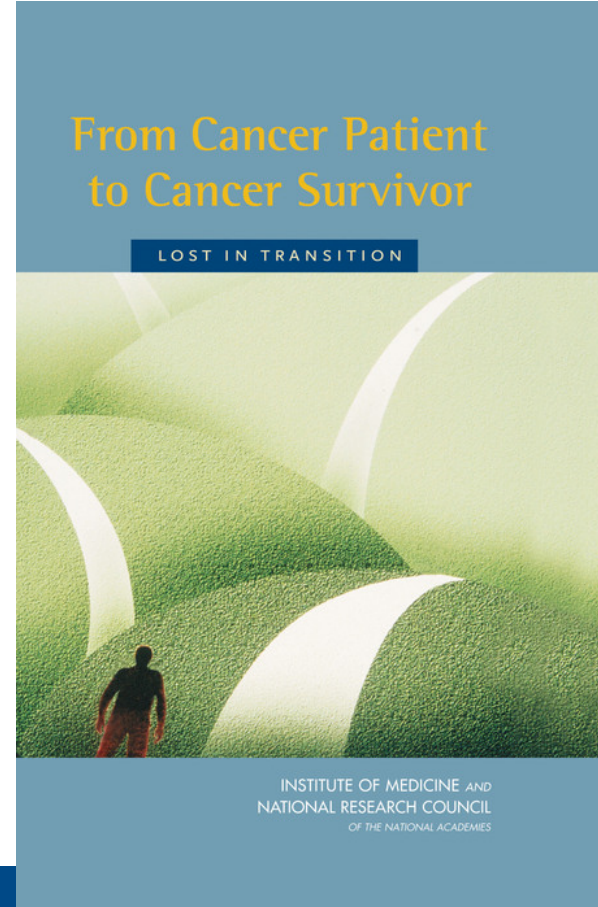
Focused on individuals who have successfully completed curative treatment or those who have transitioned to maintenance or prophylactic therapy (e.g., individuals receiving hormonal therapy after cytotoxic therapy for breast cancer)



Source: <https://www.asco.org/practice-guidelines/cancer-care-initiatives/prevention-survivorship/survivorship/survivorship-compendium>

Survivorship Care

1. Identified many “shortfalls” with care
2. Highlighted consequences of cancer treatment & lack of awareness
3. Prioritized quality of life and psychosocial care

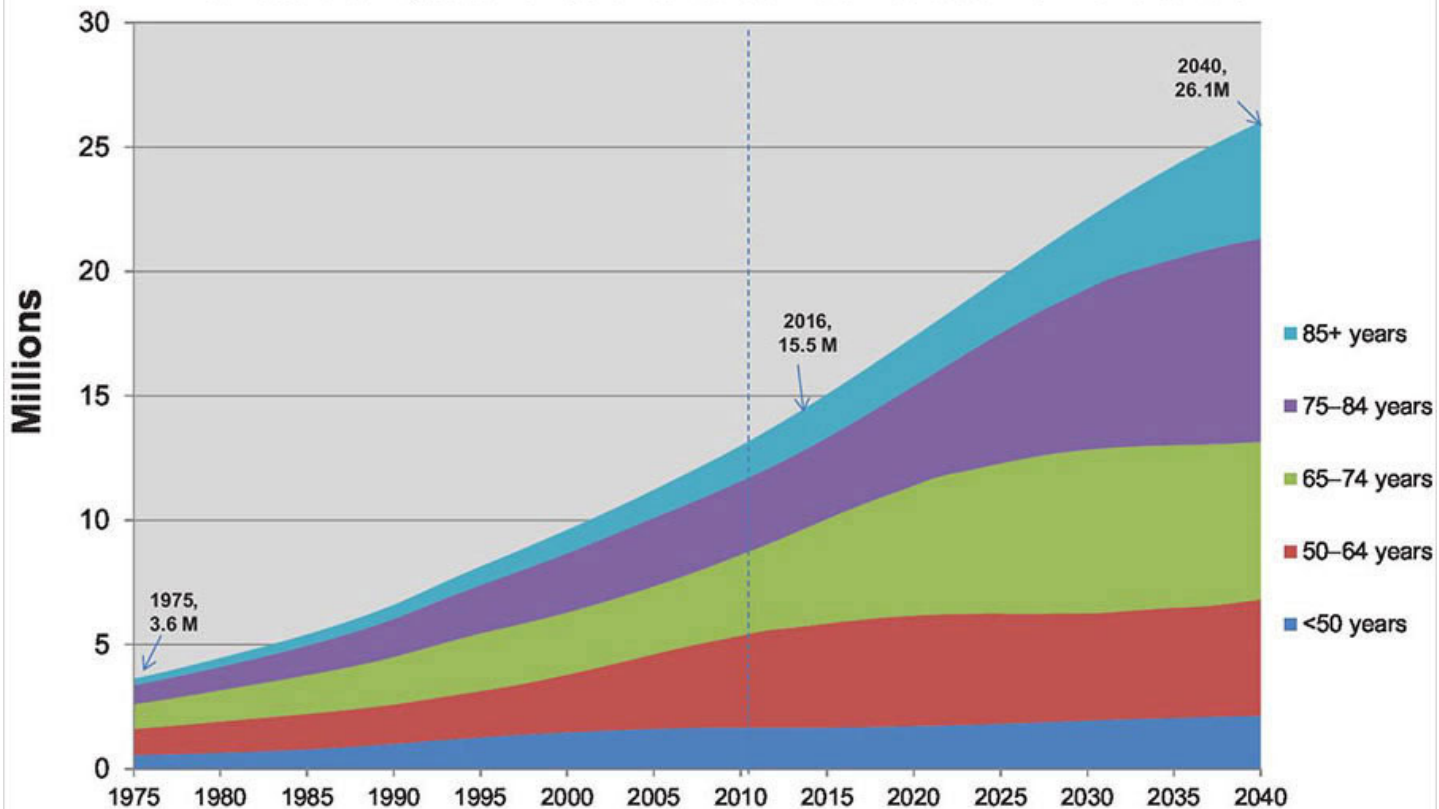


Survivorship Care



- 2012
- Care often not patient-centered
- Care often not high quality
- Changes needed

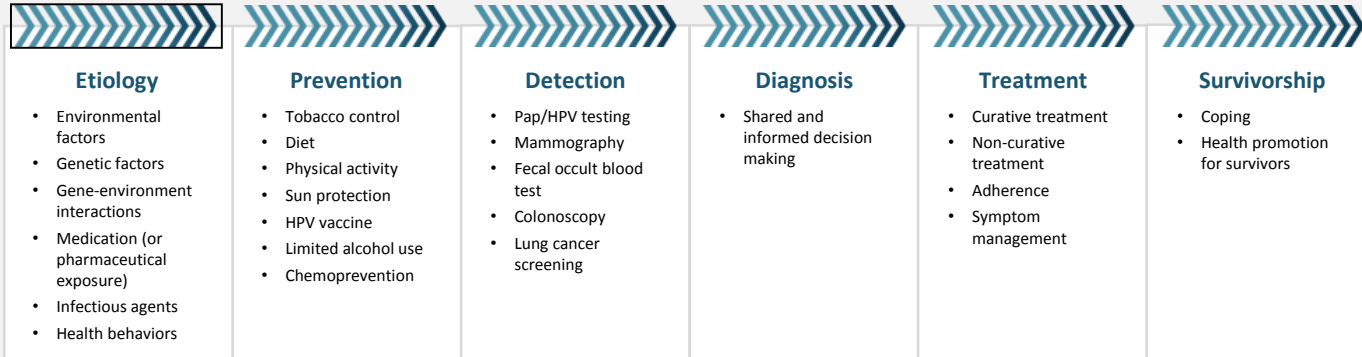
Estimated and Projected Number of Cancer Survivors in the U.S. From 1975 to 2040



----- Signifies the year at which the first baby boomers (those born 1946-1964) turned 65 years old

THE CANCER CONTROL CONTINUUM

FOCUS



CROSCUTTING AREAS

Communications

Surveillance

Health Disparities

Decision Making

Dissemination of Evidence-based Interventions

Health Care Delivery

Epidemiology

Measurement



LET'S PARTY!



Psychosocial Issues in Cancer Survivorship

- Anxiety
- Depression
- Post-traumatic Stress
- Financial Concerns
- Sexual Health Concerns
- Relationship Difficulties
- Work Challenges
- Quality of Life

“No one warned me that once treatment was over everything would change. I was like a rock star while I was having treatment--then poof, I’ve been dropped off of the map and no one seems to care much anymore.”

Prostate survivor

“It’s hard for me to tell my family that I’m so afraid. They are all celebrating that I’m done. I can’t tell them that I get so terrified I can barely breathe. How do I explain that I now live in an ‘in-between’ time?”

Leukemia patient 8 months out of treatment

Fear of Cancer Recurrence (FCR)

- Common problem
- Multiple definitions until recently
- Multiple measurement tools
- Prevalence difficult to determine
 - moderate to high levels
22%-87%



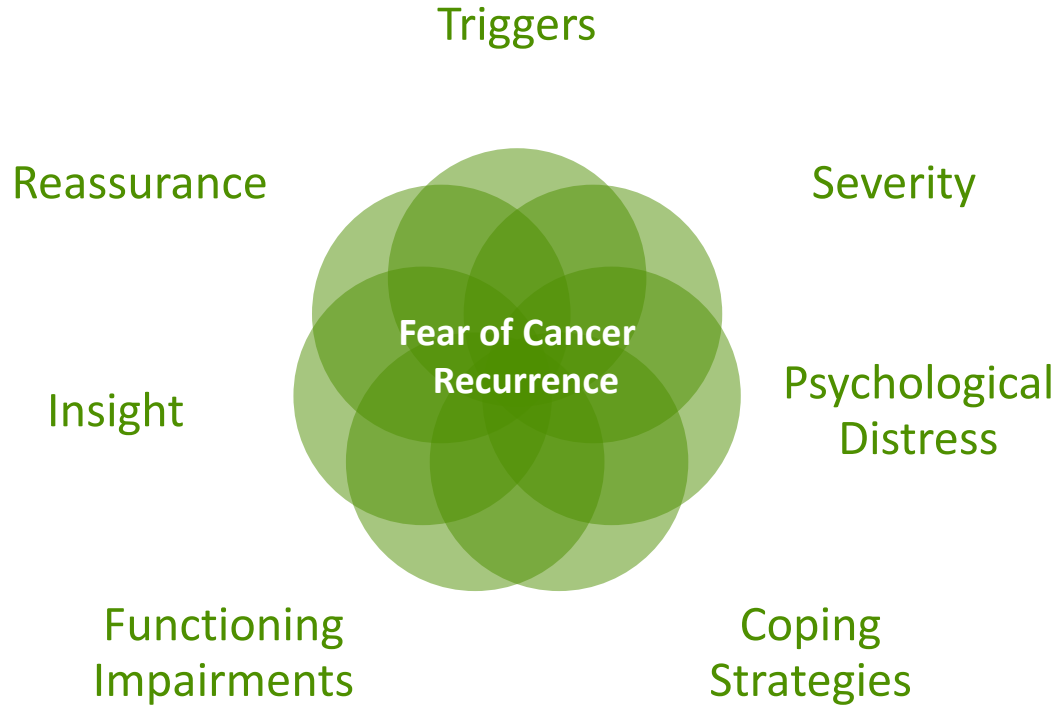
Image: <http://chemosabe-socks.blogspot.com/2012/12/cancer-versary.html>

Current FCR Definition

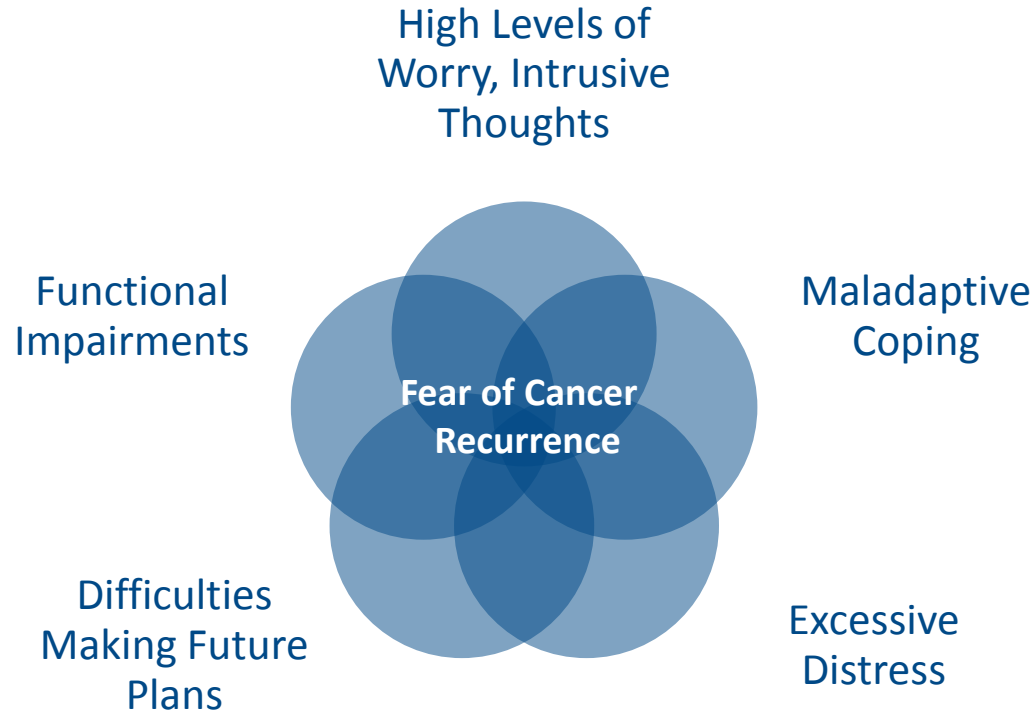
Fear, worry or concern relating to the possibility that cancer will come back or progress.

Lebel S, Ozakinci G, Humphris G, et al. From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Support Care Cancer*. 2016;24(8):3265-3268.

FCR - Multidimensional Construct



FCR – “Clinical” Characteristics



Associations, Determinants, Predictors

Demographic Factors

- Younger age (most cancer diagnoses)
- Lower education level

Medical Factors

- Mostly mixed findings
- Prior recurrence
- Treatment history
- Physical symptoms

Psychosocial Factors

- Communication with more providers
- Family & individual distress
- History of depression & anxiety
- Fewer social supports
- Optimism

Gap

No population-based studies examine FCR and its associations, including the relationship between FCR and distress, depression, and anxiety.

MEPS Experience with Cancer

DATA SOURCE

- Collaborative project
- Nationally representative survey
- Self-administered questionnaire
- Publicly available data

SAMPLE

- N=1592
- Cancer survivors by year post treatment
- Active treatment

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Sample

Adults 18 years or older

Cancer survivors who have completed active treatment

No history of cancer recurrence

All cancers (diagnosis and stage)

FCR Measure

How often do you worry that your cancer may come back or get worse?

- Never
- Rarely
- Sometimes
- Often
- All the time

Validated Measures

- **Depressive Symptoms**
 - PHQ-2
- **Severe Psychological Distress**
 - K6
- **Mental Health Status**
 - SF-12 MCS

Analysis

Population proportions and 95% CIs for sociodemographic and health characteristics

Multivariable multinomial logistic regression

Cancer Survivors Level of FCR (N=1,032)

No (n=358)	Low (n=547)	High (n=127)
34.3% [30.9, 37.9]	54.4% [50.4, 58.4]	11.3% [9.4, 13.6]

Odds Ratios and 95% CIs

Multinomial Logistic Regression Models

	Unadjusted		Fully Adjusted	
	Low FCR	High FCR	Low FCR	High FCR
Depressive Symptoms (PHQ-2)	0.76 [0.45, 1.28]	1.62 [0.85, 3.08]	0.63 [0.32, 1.24]	0.52 [0.19, 1.42]
Psychological Distress (K6)	0.80 [0.40, 1.59]	2.01 [0.89, 4.53]	0.94 [0.41, 2.16]	1.53 [0.42, 5.55]
Mental Health Status (SF-12 MCS)	1.29 [0.90, 1.86]	3.17*** [2.01, 4.99]	1.48 [0.97, 2.26]	2.88** [1.57, 5.29]

p<.01; *p<.001

Full model adjusted for age, race/ethnicity, marital status, years of education, employment status, usual source of health care, health insurance status, MSA, health status, time since diagnosis, cancer type

Characteristics – Increased Risk of FCR

	Low FCR OR [95% CI]	High FCR OR [95% CI]
1-5 Years Since Diagnosis	1.63 [1.02, 2.60]*	1.95 [1.08, 3.64]*
“Good” Health Status	1.49 [1.01, 2.20]*	1.34 [0.76, 2.37]
Late and Long-Term Effects	1.69 [1.08, 2.64]*	4.22 [2.37, 7.52]***

*p<.05; ***p<.001

Full model adjusted for age, race/ethnicity, marital status, years of education, employment status, usual source of health care, health insurance status, MSA, health status, time since diagnosis, cancer type

Implications

- First study to provide needed population-based estimates on predictors of low and high FCR
- Suggests FCR may be distinct from depression and distress
- Future research needed to better understand FCR and to target interventions for cancer survivors most at risk

FCR Interventions & Management Techniques

- Mind-body approaches (MBSR)
- Skills-training for more effective patient-provider communication
- Cognitive behavior techniques
- Acceptance and commitment therapy components

- Examples of interventions currently being tested
 - ConquerFear
 - FoRtitude
 - BREATHE intervention

How to Cope – Get the Facts

You may want to ask your doctor or nurse questions like these if you are worried about recurrence:

- Is it possible the cancer can come back?
- When is it most likely to come back?
- Where would it most likely come back?
- How likely is it to come back? (numbers and statistics)
- Is there anything I can do keep it from coming back?
- How will I know if it's back? What should I look for?

How to Cope – Take Care of Your Body

- Eat a healthy diet.
- Fit exercise into your day. A walk around the block counts!
- Get enough sleep.
- Follow up with your medical appointments (cancer, primary care and other providers).

How to Cope – Pay Attention to Emotions

- Take care of your body. (see previous slide!)
- Acknowledge your fears. Start with yourself.
- Get help with emotional stress. (Do you often feel overwhelmed or find your emotions interfering with your life?)
 - Talk about it.
 - See professional help.
 - Find a support group.
- Manage stress.

How to Cope – Try Self Talk

- It is unlikely that this is cancer.
- I was screened _____ months ago and things were fine.
- If I have this in two weeks I will go to my doctor.
- I can always go to my doctor sooner if I need reassurance.
- There are millions cancer survivors, I am one of them.

Source: When Cancer Exists in the Mind, Anne Coscarelli, Ph.D.

http://www.simmsmanncenter.ucla.edu/information/from_the_director/articles/2009_CancerExistsInMind.asp

How to Cope – Try Self Talk

- I have people that I can rely on.
- I have a doctor that I can count on to help me with this.
- I can call my friend, who always helps me to feel better.
- I'm going to do something that I enjoy.
- I'm going to write this all down in my journal and leave it.

How to Cope – Plan for Distraction

When I am worried, I will try to distract myself with ...

- Exercise
- Meditation/Use of relaxation
- Television or a movie
- Work
- Pleasurable reading
- Social activity with a friend such as a phone call, going to dinner, etc.

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Next Steps

- Advocate
 - Patient- and family-centered care
 - Quality cancer care for all, across the cancer continuum
 - Improve survivor/family-provider communication
 - Prepare patients and families for psychosocial side effects
 - Psychosocial concerns need to be assessed and addressed
- Research
 - Can we (how can we?) prevent “clinical” levels of FCR?
 - How do we identify patients and families most at risk for FCR?
 - What is the best treatment (intervention) to address FCR?

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“It is about change, about grieving for expected futures, finding strength amidst darkness, self-discovery, searching for meaning, re-evaluating who I am and who and what is important to me, looking for hope and finding ways to cope with the unknown.

It is hard, wonderful and always surprising.”

Bone marrow transplant patient, 2 years out from second transplant