

Informational Needs of Cancer Survivors: HINTS and Survivorship Research

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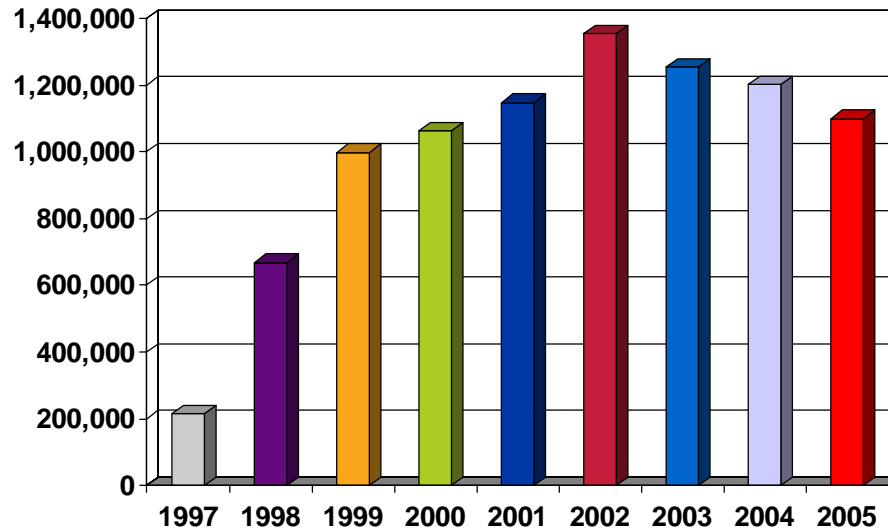
ACS Organization

The American Cancer Society, Inc. consists of a National Home Office with 13 chartered Divisions throughout the United States and a presence in most communities (>3,400 local offices).

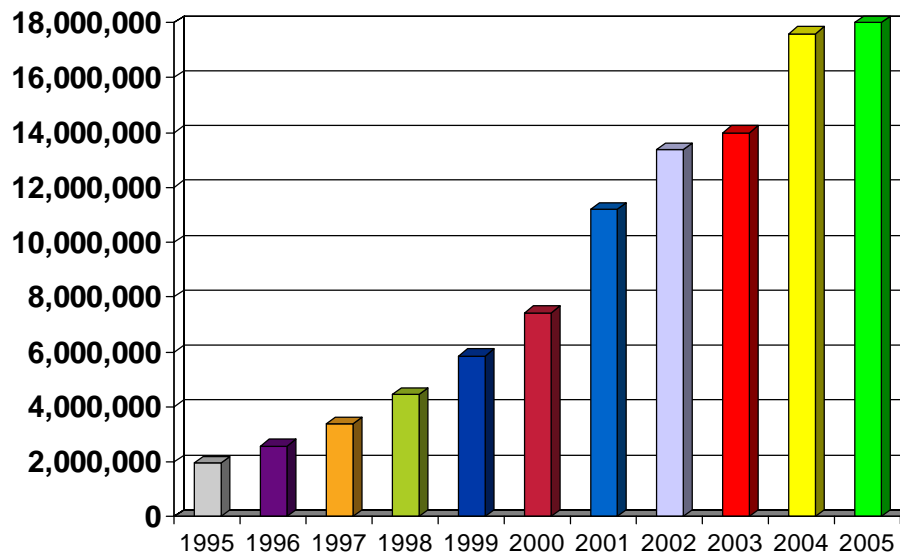
- National Home Office = 1,259 Employees
- Divisions & Local Offices = 5,818 Employees
- Volunteers = > 3 Million



Information Provision



**1.2 million calls to
1-800-ACS-2345**



**20 million
visits to
Cancer.org
Each year**

Cancer Survivorship

Defining Survivorship

Traditional: Those cancer-free at 5 years after diagnosis.

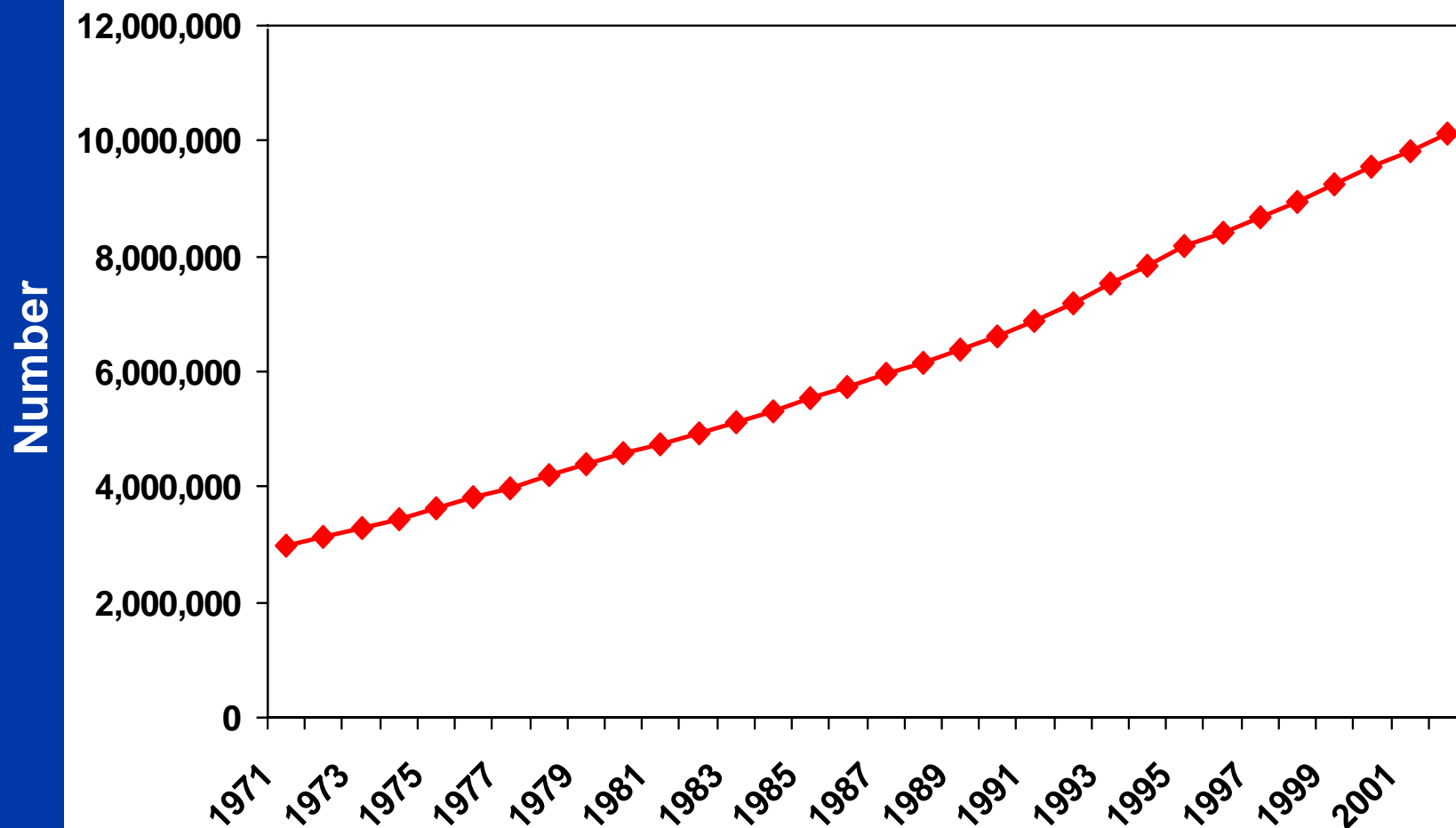
	Diagnosis	Treatment	Disease-Free	End of Life
Survivor				
Caregiver				

Defining Survivorship

Modern: “anyone who has been diagnosed with cancer from the time of diagnosis through the balance of his or her life,”¹

	Diagnosis	Treatment	Disease-Free	End of Life
Survivor				
Caregiver				

Estimate Number of Cancer Survivors in U.S. by Year



Data source: 2004 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2002 were based on the average of the July 2001 and July 2002 population estimates from the U.S. Bureau of Census.

Survivor QOL and Specific Physical Problems

General QOL: for most early-stage cancer survivors returns to “normal” levels soon after treatment is complete.²

Persistent Symptoms: Lymphedema, cognitive deficits, pain, fatigue, urinary or bowel dysfunction, sexual dysfunction, infertility, premature menopause. ²

Late Effects: Second cancers (new primary or recurrence), non-malignant organ or tissue dysfunction (e.g., heart conditions), impaired immune function.²

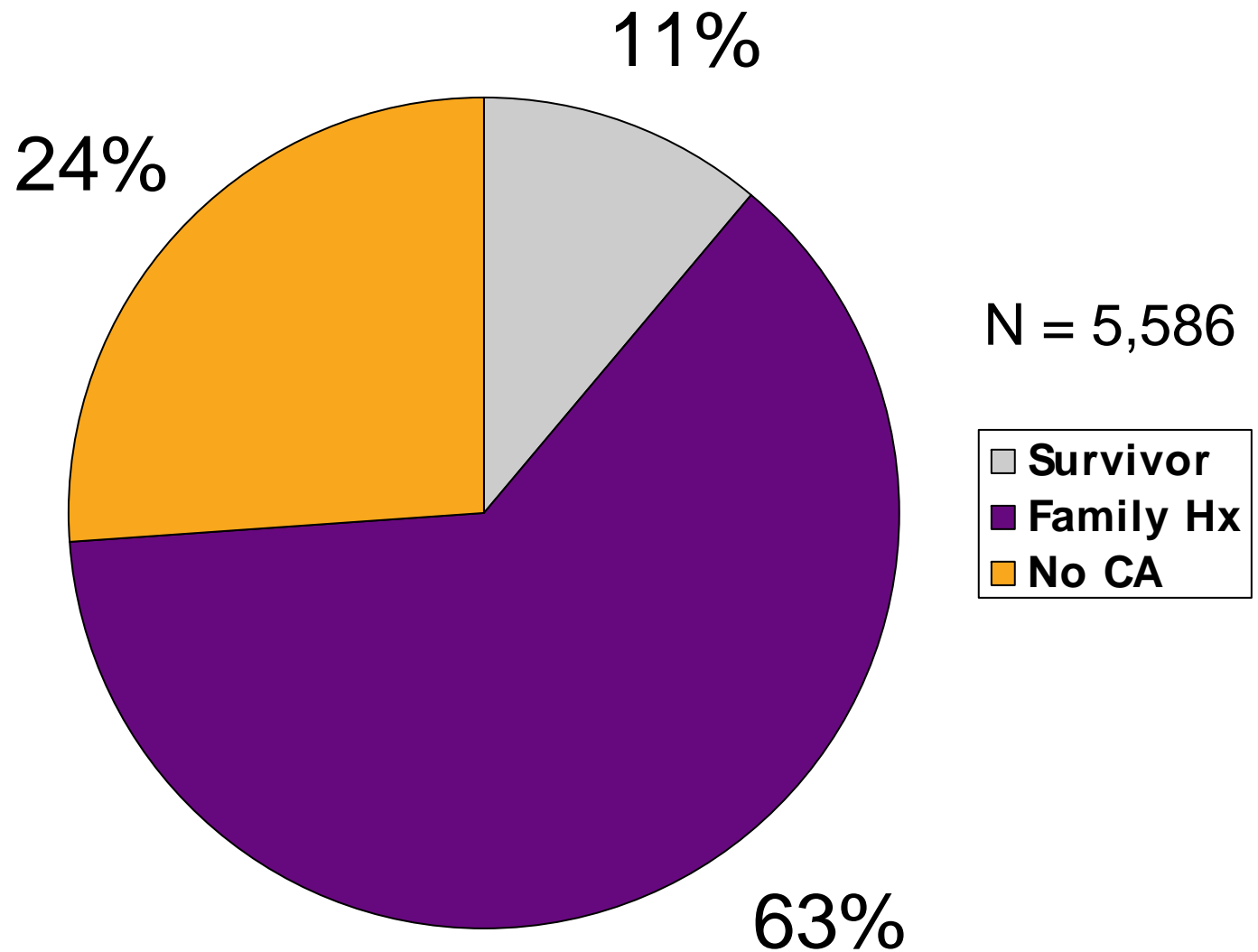
Emotional & Social Concerns

Psychological/Emotional Issues: Anxiety, depression, fears of recurrence, and concerns about passing the disease on to their offspring often surface as persistent emotional and psychological concerns for cancer survivors.³⁻⁶

Social Re-integration: Problems with life and health insurance,^{3,7,8} employment,⁹⁻¹³ finances (Himmelstein et al, 2005), and social re-integration.¹⁴⁻¹⁵

Coordination of Care: Between oncologists and PCPs, lack of standards of care for survivors, lack of awareness of and interventions for side-effects. ¹⁶

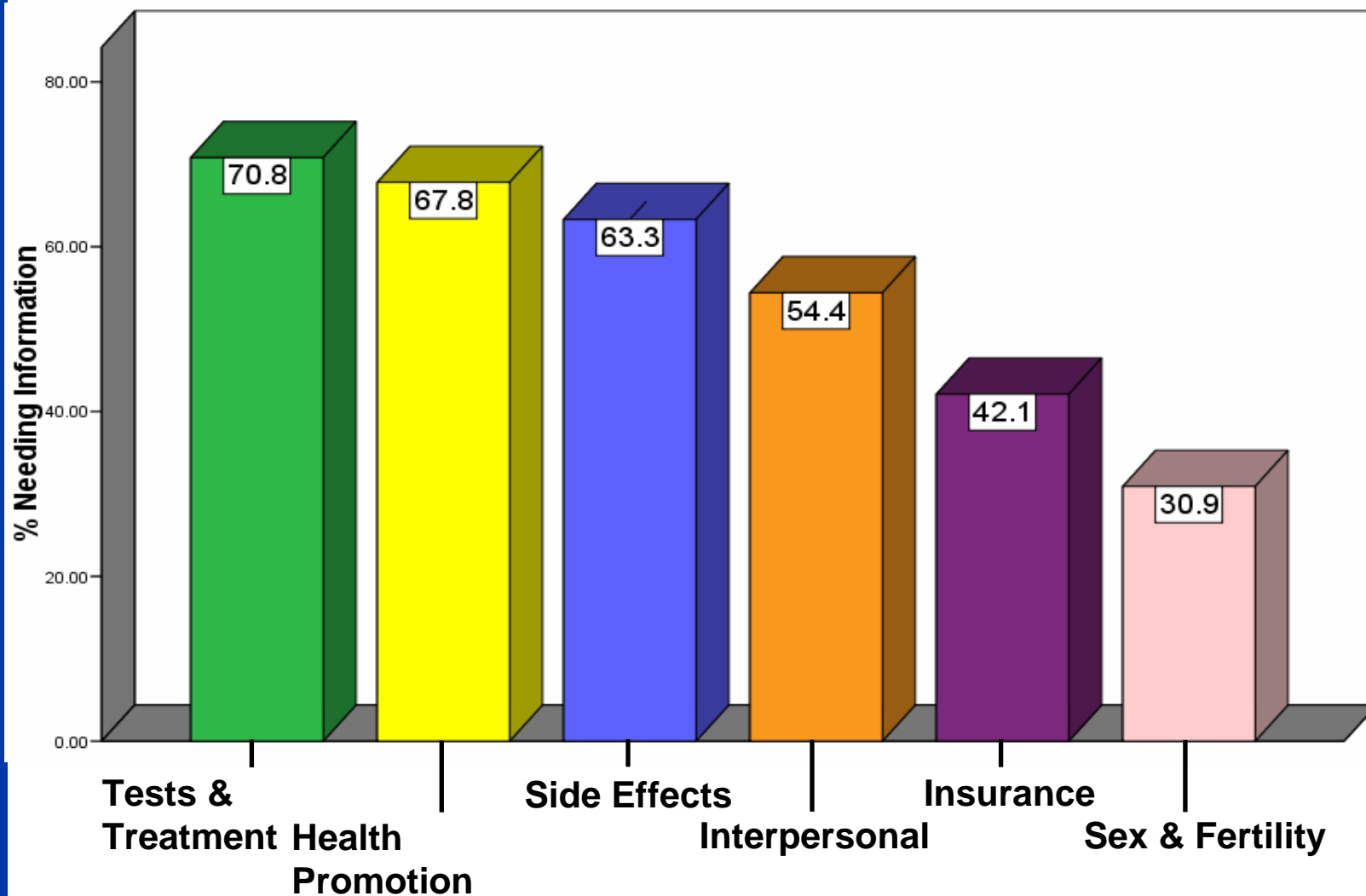
HINTS & Relationship to Cancer



Weighted estimates from HINTS 2005

Survivors' Cancer Info Scanning and Seeking Behavior (SSB)

Survivor Info Needs



2-5 year survivors of NHL, colorectal, bladder, or leukemia

Beckjord E, Arora NK, Hesse BW, Mclaughlin W, Oakley-Girvan I, & Hamilton A (2007). A Population-Based Assessment of Cancer Survivors' Information Needs: Implications for Cancer Care. SBM Annual Meeting.

Cancer History and SSB

Select multivariate odds

ratios

Odds of Seeking info on cancer

- Survivor (1.80)
- Family history of cancer (1.81)
- Female (1.79)
- College educated (1.60)

Odds of being a “High Scanner”

- Survivor (n.s.)
- Family history of cancer (1.20)
- Female (1.97)
- African American (1.98)

Shim M, Kelly B, & Hornik R (2006). Cancer information scanning and seeking behavior is associated with knowledge, lifestyle choices, and screening. J Health Communication

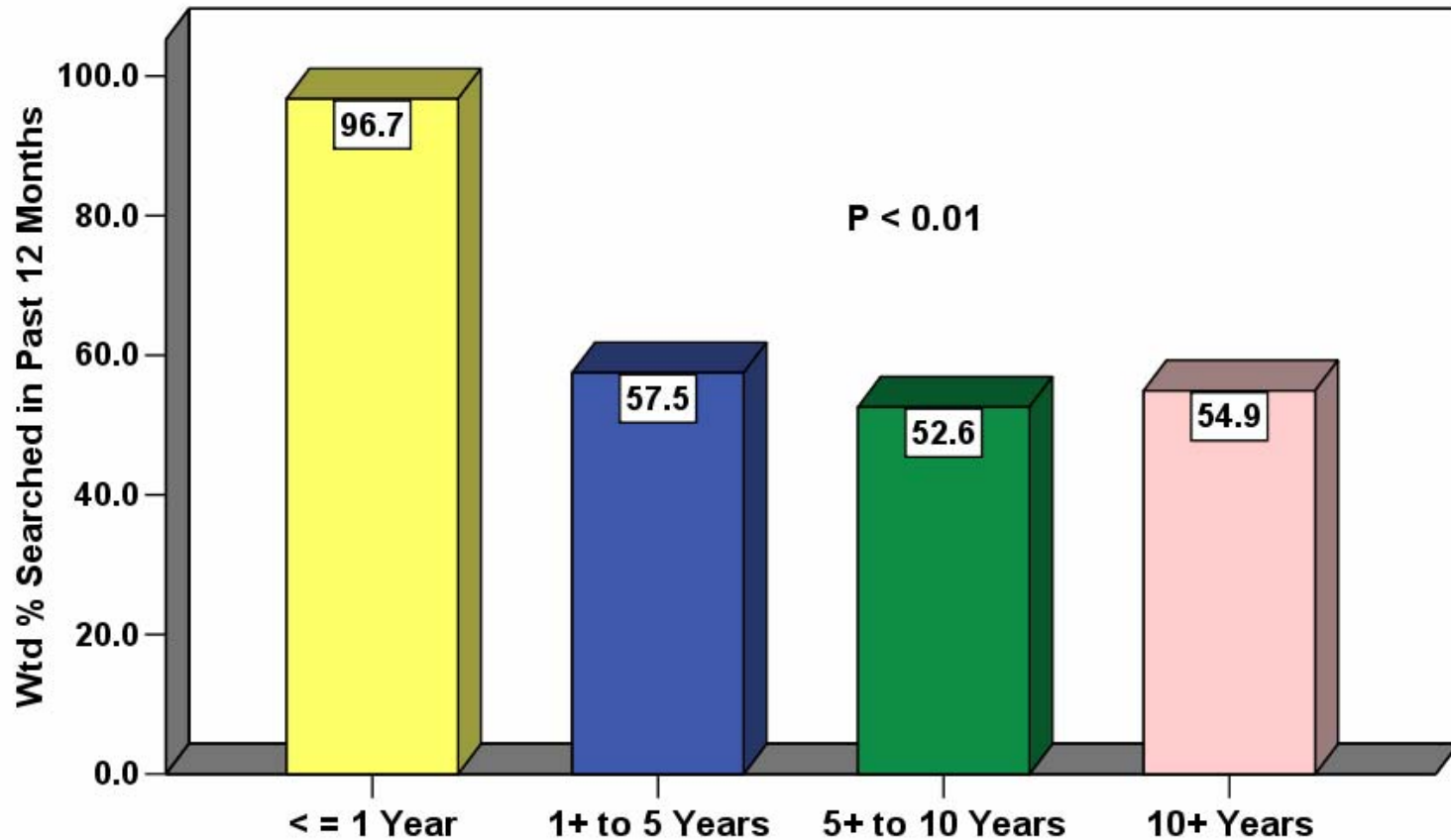
Survivors' info seeking

- 67.5% of survivors sought cancer info
- Predictors of info seeking: Age, gender, income, and regular health care provider

Mayer KM, Terrin NC, Kreps, GL, Menon U, McCance, K, Parsons SK, Mooney KH (2007). Cancer survivors information seeking behaviors: A comparison of survivors who do and do not seek information about cancer.

HINTS

Information Seeking by Time Since Dx



Arora NK, Beckjord E, & Hesse BW (2007). Facilitating Information Seeking among Cancer Survivors: Insights from the 2005 HINTS. SBM.

The Teachable Moment

The Teachable Moment

A naturally occurring transition or health event that “has the potential to motivate individuals to spontaneously adopt risk-reducing or health-protective behaviors.”

Ganz P (2005). A Teachable Moment for Oncologists: Cancer Survivors, 10 Million Strong and Growing! JCO

Survivors' Health Behavior

HINTS (Survivors N = 619)

- Survivors more likely to meet guidelines for colorectal, but not for breast or prostate screening.

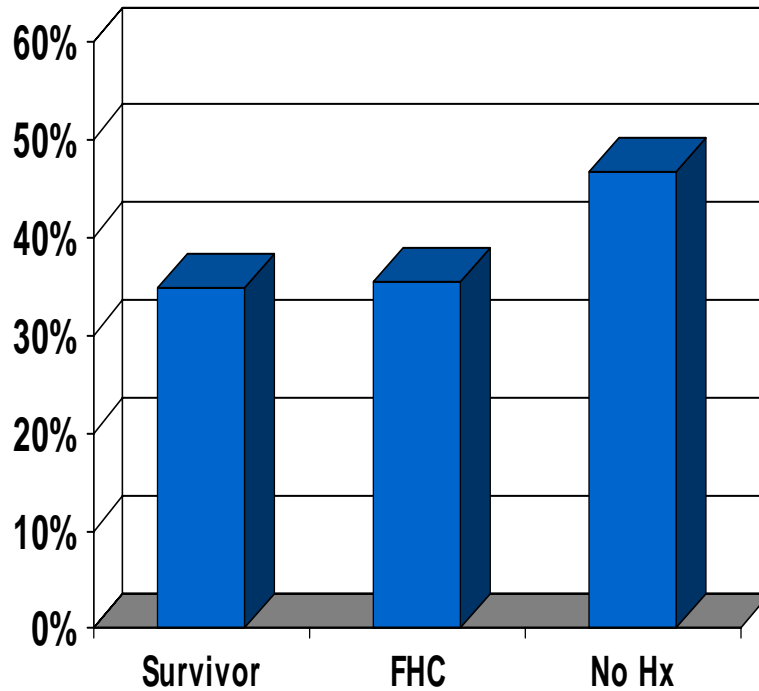
NHIS (Survivors N = 7,384)

- Survivors more likely to meet guidelines for breast and prostate guidelines
- Survivors more likely to meet physical activity guidelines

Mayer KM, Terrin NC, Menon U, Kreps, GL, McCance, K, Parsons SK, Mooney KH (2007). Screening practices in cancer survivors. *J Cancer Surviv*

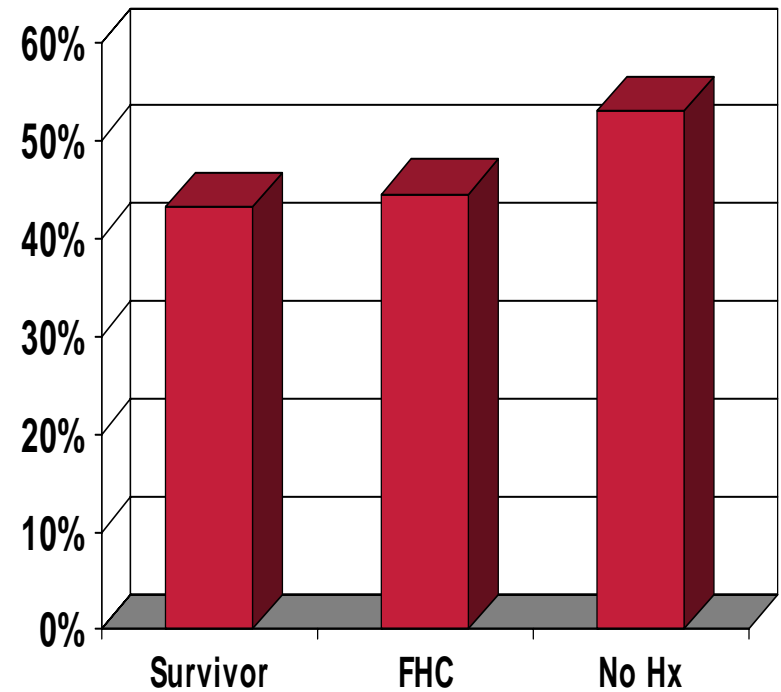
Bellizzi KM, Rowland JH, Jeffery DD, & McNeel T (2005). Health Behaviors of Cancer Survivors: Examining Opportunities for Cancer Control Intervention. *JCO*

Perceived Risk of Colorectal Cancer by Cancer History



■ Absolute Risk "very low"

*Chi-square (2df) = 13.05; p=0.003



■ Comparative Risk "less likely than others"

**Chi-square (4df) = 11.31; p=0.03

Data Source: HINTS 2005

Colorectal Cancer Worry by Cancer History

- Worry-history relationship non-significant
 - Cancer worry assessed for specific cancers
 - Not asked of survivors of colorectal cancer
- HINTS 2007:
 - Cancer worry assessed for cancer in general
 - Asked of all survivors
- Future Directions: Expand beyond frequency to assess bother or impact?

Predictors of Health Behavior in General Population Studies

Perceived Cancer Risk & Worry

- Associated with breast and colorectal screening
- Not with prostate screening (PSA more routine)

Cancer Info Scanning & Seeking Behavior (SSB)

- Associated with prostate, colorectal, and breast screening
- Associated with smoking, exercise, and diet

Moser RP, McCaul K, Peters E, Nelson W, & Marcus SE (2007). Associations of perceived risk and worry with cancer health-protective actions. *J Health Psychology*

Shim M, Kelly B, & Hornik R (2006). Cancer information scanning and seeking behavior is associated with knowledge, lifestyle choices, and screening. *J Health Communication*

Cancer History, Health Behaviors, and Mediation

1. Cancer history (survivor/FHC) related to...
 - Scanning and Seeking Behavior (SSB)
 - Perceived cancer risk
 - Cancer worry?
2. SSB, perceived cancer risk, & cancer worry related to...
 - Cancer screening
 - Preventive behavior
3. Cancer History related to...
 - Cancer screening
 - Preventive behavior

Concluding Remarks

HINTS & Survivorship Research

Strengths

- Nationally representative sample
- Identical recruitment of survivors and comparison group
- Contains important variables:
 - Cancer Info Scanning & Seeking
 - Perceived cancer risk
 - Cancer worry
 - Family history of cancer

Limitations

- Limited space for survivor-specific questions
- No clinical data (stage, treatment)

Family History of Cancer

- Cancer is a problem that affects the entire family via increased risk and burden of caregiving
- Current HINTS: Have any of your family members ever had cancer?
- Which family members ever had cancer? Spouse, 1st degree bio relative (parent, sibling, child), other bio relative.

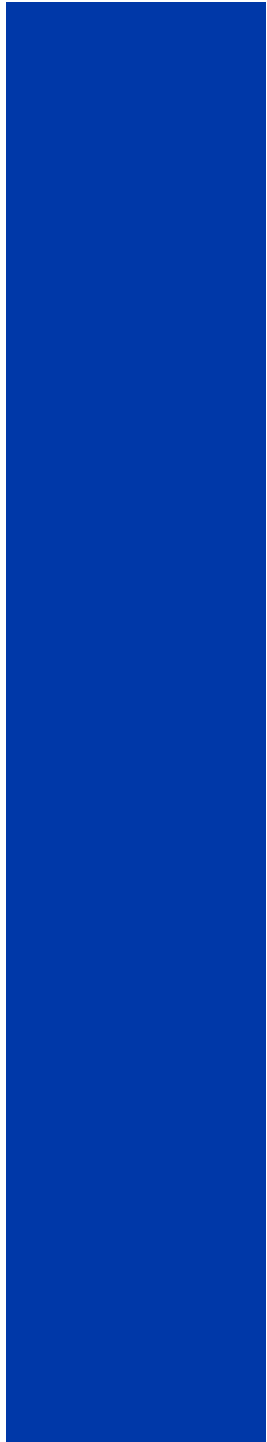
Cancer History & Information Seeking

Survivors

- 67% seek cancer info
- Info seeking persists in 10+ year survivors (around 5 million survivors)
- Male, elderly, and survivors with less education less likely to seek info

Benchmarking

- Provides items and data for benchmarking more specialized survivorship research



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