

# Information Seeking Experiences of Cancer Survivors: Frustrated or Satisfied?

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# Purpose of This Research

- To contribute to our knowledge about the cancer information seeking behavior of cancer survivors
- To give us insight into the breadth of information sources which cancer survivors use
- To determine the quality of cancer survivors' information seeking experience
- To examine variations in the cancer information experience by time since diagnosis

# Survivors' Information Seeking - Sources and Experiences

- In the past, patients primarily relied on their physicians for cancer information. Today, most patients also access information outside of the medical system. (Davison et al. 1997, Degner et al. 1997, Finney-Rutten et al. 2004)
- Patients are often dissatisfied with information seeking and report difficulty with getting needed information (Arora NK et al. 2002).
- Patients are satisfied with treatment information, but less so with information on long-term sequelae (Mallinger JB et al. 2004).

# Data Source and Data Analyses



- All data analysis was done using SAS-Callable SUDDAN to account for the complex survey design
- Chi-squares were used to look at bivariate differences

# Research Questions and Results

# Research Question One

- Who are the cancer survivors in the HINTS population? How do they compare to the general population sample?

# Cancer Survivors in HINTS

- The HINTS survey contains data from 6369 people from the general population; this sample consists of the 720 cancer survivors in the data
- 70% of cancer survivors reported looking for information vs. 45% of the general population subjects

# Types of Cancer and Time since Diagnosis (Weighted Percents)

## ■ Type of Cancer

- Gynecologic – 21%
- Other skin - 17 %
- Breast – 14%
- Genitourinary – 14%
- Melanoma – 9%
- Gastrointestinal – 8%
- Head and Neck – 3%
- Hematologic – 4%
- Thyroid – 2%
- Lung – 2%
- Musculoskeletal – 1%
- Two or More – 5%

## ■ Time since Diagnosis

- One year or less – 16%
- Two to five years– 21%
- 6-10 years – 23%
- 11 or more years – 40%

# Differences between Cancer Survivors and the General Population

- Cancer Survivors were older – 41.1% of cancer survivors were 65 and older vs. 13.3% of the general population
- They were more female - 64.6% (cancer) vs. 50.4% (general pop.)
- They were more likely to be Caucasian in the cancer survivors than in the general population
- There were no significant educational differences between the two groups

# Research Question Two

- Do survivors look for cancer information?
  - Do they look for themselves or do others look for them?
  - When did they last look?
  - Where do they look?
  - Does it vary by time since diagnosis?

# Assessing Information Seeking

- Survey asked:
  - “Have you ever looked for information about cancer from any source?”
  - “Excluding your doctor or other health care provider, has someone else ever looked for information about cancer for you?”

# Do survivors look for cancer information?

	Weighted % (cancer)
Looked for themselves and proxy looked	33.6%
Only looked for themselves	33.2%
Only proxy looked	4.1%
Did not look/None	29.1%

# Last Information Experience

- “Think about the most recent time you looked for cancer-related information from any source (either on your own or by someone else looking for you).”
  - “About how long ago was that?”
  - “The most recent time you looked for information on cancer, where did you look?”

# Information Seekers – When did they last look?

- Last time looked?
  - In the last month – 34.6%
  - 1+ month to 6 months ago – 23.9%
  - 6+ months to 1 year ago – 15.5%
  - 1+ to 5 years ago – 16.7%
  - More than 5 years ago – 9.3%
- No significant differences by time since diagnosis

# Where They Looked First

- Internet – 36%
- Health Care Providers – 20%
- Books/Brochures and Pamphlets – 18%
- Magazines and Newspapers – 12%
- Library – 7%
- Family/Friends and Co-workers – 3%
- Cancer Organizations and 1-800 Numbers – 1.9%
- TV and Radio – 1.7%
  
- Significant differences in source type were seen when looking by time since diagnosis.

# Research Question Three

- How do survivors rate their information seeking experience?
  - Does this vary by time since diagnosis?
  - Is their experience different from the non-cancer information seekers?

# Information Experience

- “Based on the results of your overall search for information on cancer, tell me how much you agree or disagree with the following statements.”

# What Was Their Experience?

- “You wanted more information, but did not know where to find it. Would you say you strongly agree, somewhat agree, somewhat disagree, or strongly disagree?”
  - strongly agree (18%)
  - somewhat agree (36%)
  - somewhat disagree (26%)
  - strongly disagree (20%)
- “It took a lot of effort to get the information you needed?”
  - strongly agree (15%)
  - somewhat agree (36%)
  - somewhat disagree (27%)
  - strongly disagree (22%)

# Satisfaction (continued)

- “You did not have the time to get all the information you needed.”
  - strongly agree (16%)
  - somewhat agree (30%)
  - somewhat disagree (23%)
  - strongly disagree (31%)
  
- “You felt frustrated during your search for the information.”
  - strongly agree (18%)
  - somewhat agree (26%)
  - somewhat disagree (18%)
  - strongly disagree (38%)

# Satisfaction (continued)

- “You were concerned about the quality of the information.”
  - strongly agree (26%)
  - somewhat agree (32%)
  - somewhat disagree (22%)
  - strongly disagree (20%)
  
- “The information you found was too hard to understand.”
  - strongly agree (14%)
  - somewhat agree (24%)
  - somewhat disagree (27%)
  - strongly disagree (35%)

# Differences in Information seeking experience

- There were no significant difference by time since diagnosis.
- When compared to the cancer information seekers that did not have cancer – cancer survivors information seekers were more frustrated and had more difficulty understanding.

# Conclusions

# Cancer Information Experiences

- Cancer Survivors seek information more often than the general population
- Cancer survivors express a high degree of dissatisfaction with their information seeking experience
- There are few differences in information seeking and experience by time since diagnosis

# Limitations

- Cross-Sectional Data so we cannot examine how seeking and experiences change over time.
- We only asked about their most recent cancer information search.
- But then we asked them questions about their overall cancer information seeking experience.
- We have a limited population of cancer survivors with very little medical data about their type of cancer and seriousness of diagnosis.

# Demographics of the Cancer and General Population Samples

		Weighted % Cancer Survivors	Weighted % General Pop.
Age*	18-34	8.8%	33.9%
	35-49	19.7%	32.4%
	50-64	30.4%	20.4%
	65 or older	41.1%	13.3%
Sex*	Female	64.6%	50.4%

\*  $p < 0.05$

		Weighted % (cancer)	Weighted % (general pop.)
Race/ Ethnicity *	Caucasian	83.3%	71.3%
	Hispanic	4.7%	12.5%
	African-Amer.	4.0%	5.2%
	Other	8.0%	11.0%
Education	Less than High School	17.1%	16.9%
	High School Grad	37.0%	31.4%
	Some College/Tech School	22.8%	27.3%
	College Graduate or More	23.1%	24.4%

\* p<0.05

## Differences by Type of Info Seeking

	Self and Proxy	Self Only	Proxy Only	Neither
<b>Gender</b>				
Female	33.5	27.9	6	32.6
Male	34	36.7	2.8	26.5
<b>Age*</b>				
18-34	51.2	29.7	1.8	17.3
35-49	45.7	41.6	1	11.6
50-64	39.6	38.4	4	18
65-95	20.2	27.2	5.6	47

## Differences by Type of Info Seeking

	Self and Proxy	Self Only	Proxy Only	Neither
<b>Race/ethnicity</b>				
Hispanic	35.1	23.2	13.6	28.1
Other	36.1	17.7	8.3	37.9
Black	38.6	21.4	0	40
White	33.3	35.9	3.6	27.1
<b>Education*</b>				
Less than HS	24	19.6	6.1	50.3
HS grad	28.4	35.9	4.5	31.2
Some College	38	35.3	4.3	22.4
College or More	46	37.1	1.2	15.7