

The Impact of Quality-of-Life Issues and Self-Empowerment on the Information Seeking Needs and Behaviors of Young Breast Cancer Survivors

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Agenda

- ❑ Young breast cancer (BC) survivors as an underserved population
- ❑ 'Survivorship' Issues
- ❑ Information-seeking research



Breast Cancer (BC) Facts

- ❑ Chronic disease
 - Shifting definitions of 'cure'
- ❑ 1 in 7 women will have breast cancer
 - 200,000 + new diagnoses yearly
- ❑ Increasing incidence among young women
 - **Young** = < 50 or < 45 years at diagnosis



Breast Cancer (BC) Facts

- ❑ 45 of 100,000 young women diagnosed each year
- ❑ Lifetime mortality risk = 2.3%
- ❑ Increasing numbers of young women survivors
- ❑ Largest group of cancer survivors nationwide
 - 'Survivorship' begins at diagnosis



Survivorship Issues

- ❑ Growing, but underserved population
- ❑ Limited research on long-term survivorship issues in young women
- ❑ BC affects younger women differently
 - More aggressive disease
 - More aggressive treatment



Survivorship Issues

- Higher risk for negative quality-of-life
 - **Physical**
 - Chemotherapy: ‘Chemo brain’ = memory loss, confusion, dizziness, headaches
 - Infertility
 - Heart, kidney, liver, GI, thyroid, skin problems, etc.
 - Radiation: Burns, scarring, pain, numbness, skin contractions, etc.
 - **Emotional** (depression, anxiety, fear of recurrence, PTS, lower satisfaction with providers, information)
 - **Social** (family, marriage, sexual, legal, financial)



Research & Results



Research Goals

Examine the information seeking needs and behaviors of young BC survivors:

- ❑ Ongoing issues or concerns
 - ➡ that trigger information seeking
- ❑ Most heavily used information resources
- ❑ Ease or difficulty in finding information
- ❑ Satisfaction with information found
- ❑ Correlations between info seeking and survivors' psychosocial variables



Research Population

- ❑ **N = 43** young breast cancer survivors
 - < 45 yrs old at diagnosis
 - Any stage of cancer
 - 3 - 8 years post-diagnosis

- ❑ Recently had regular oncology visit
 - Cancer-free
 - No metastasis



Data Collection Process

- ❑ Subjects join study in month before regularly-scheduled oncology visit
- ❑ Go to oncology visit
- ❑ **1 - 2 weeks** after visit:
 - Researcher initiates telephone call to research participants
 - Complete post-visit surveys



Data Collection Process

Complete multiple surveys / scales:

- CESD depression
- STAI anxiety
- HCP social constraints
- HCCQ communication
- BC self-efficacy
- Concerns about health, role, womanhood, death, parenting
- Knowledge of symptoms and signs
- Use of patient-provider communication intervention
- Information seeking needs and behaviors**



What are the issues about which you generally find yourself seeking information?

(e.g., issues triggering info seeking)

Scale:

A (Frequently likely to seek info)

B (Sometimes)

C (Seldom)

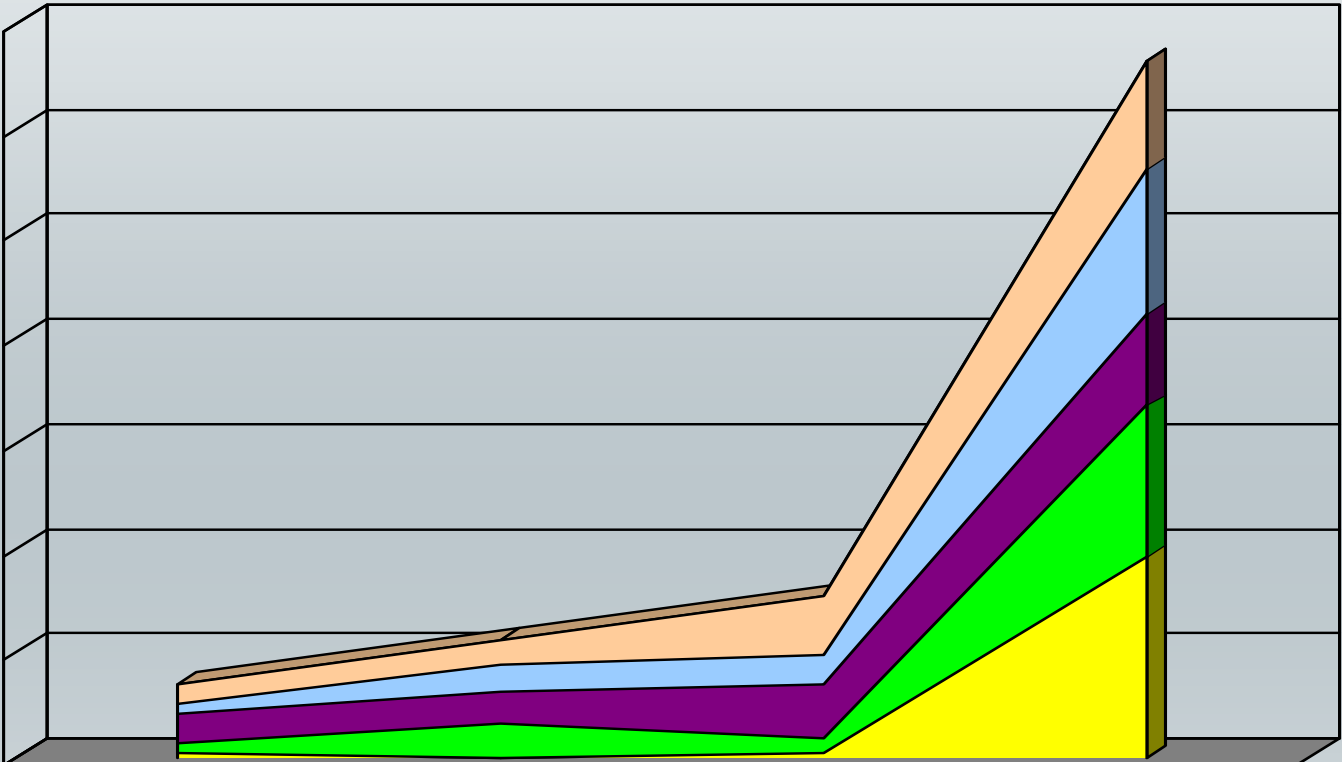
D (Never)

1. Career or work
2. Marriage or dating
3. Family
4. Sexuality or intimacy
5. Fertility or pregnancy
6. Recurrence or metastasis
7. Nutrition or exercise
8. Quality-of-lifestyle issues
 - Mortgage or rent, finances, legal issues, etc
9. Health or life insurance
10. Others...



Issues Triggering Information Seeking

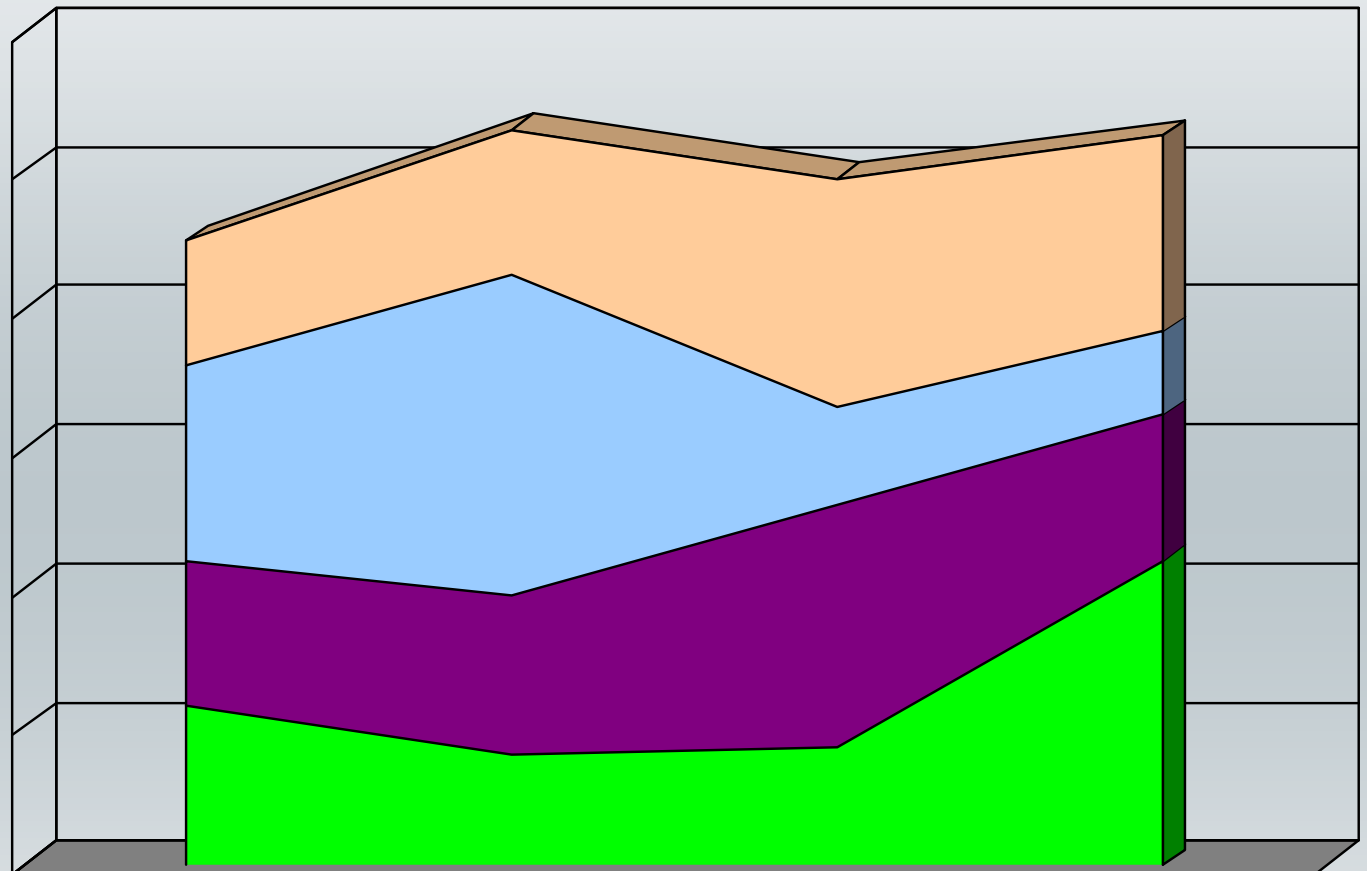
- Career
- Marriage
- Family
- Sexuality
- Fertility



	Frequently %	Sometimes %	Seldom %	Never %
■ Career	9	12	28	51
■ Marriage	5	12	14	69
■ Family	14	16	26	44
■ Sexuality	5	16	7	72
■ Fertility	2	0	2	96

Issues Triggering Information Seeking

- Metastasis
- Nutrition
- Quality of Lifestyle
- Insurance



	Frequently %	Sometimes %	Seldom %	Never %
Metastasis	18	21	33	28
Nutrition	28	46	14	12
Quality of Lifestyle	21	23	35	21
Insurance	23	16	17	44

How often are you likely to use these information resources?

(e.g., information tools usage patterns)

Scale:

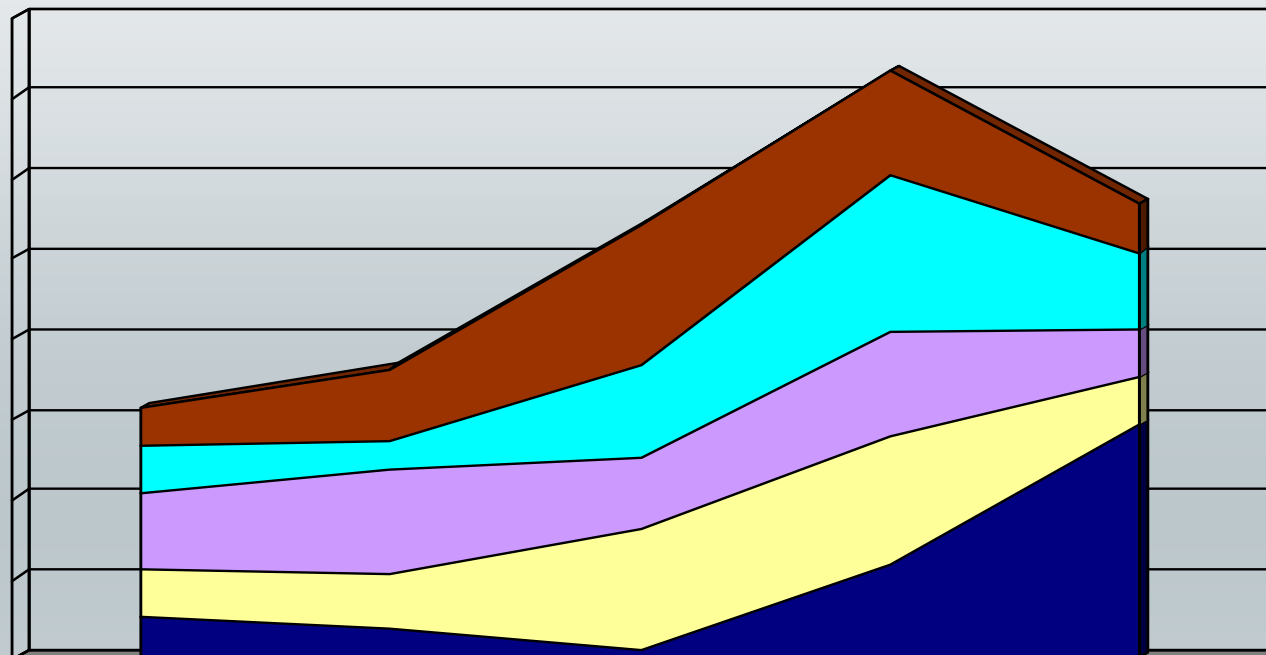
- A (Frequently)
- B (Sometimes)
- C (Seldom)
- D (Never)
- E (Don't know)

1. Books
2. Radio or TV
3. Magazines
4. ACS resources
5. MEDLINEplus
6. Biomedical journals
7. Peer support groups
8. BC survivors
9. Health care providers
10. Libraries
11. Search engines
12. Others...



Information Tools Usage Patterns

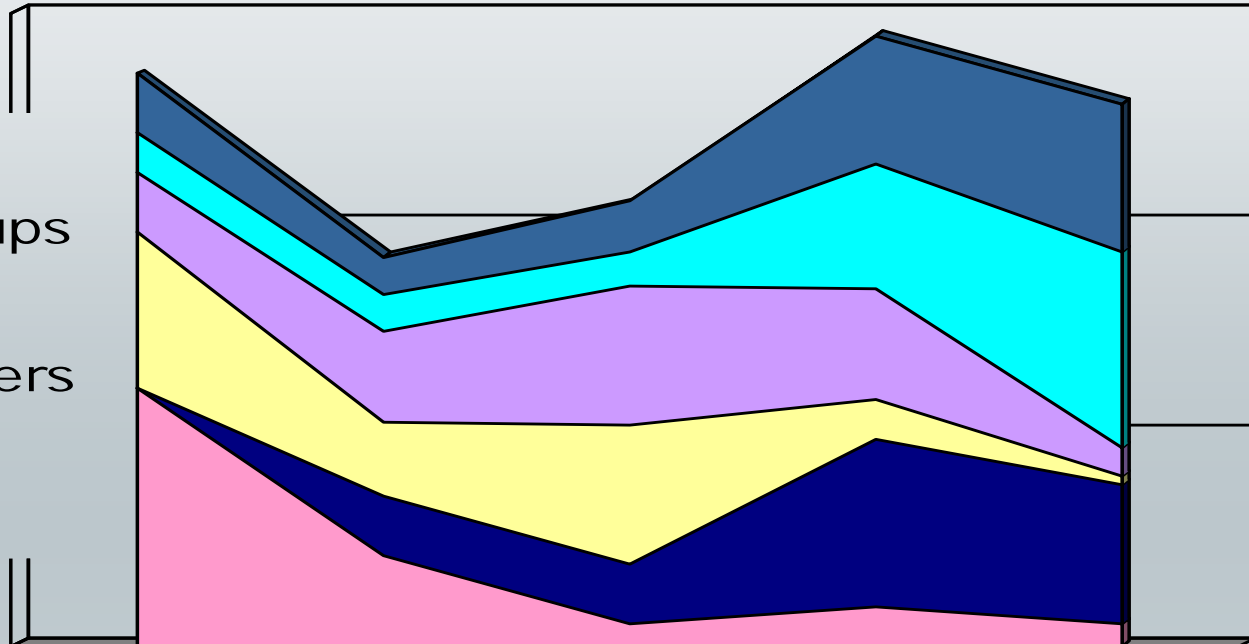
- Books
- Radio, TV
- Magazines
- ACS Sources
- MEDLINEplus



	Freq. %	Some-times %	Seldom %	Never %	Don't Know %
■ Books	9	18	35	26	12
■ Radio, TV	12	7	23	39	19
■ Magazines	19	26	18	26	12
■ ACS Sources	12	14	30	32	12
■ MEDLINEplus	10	7	2	23	58

Information Tools Usage Patterns

- Biomed. Journals
- Peer Support Groups
- Other survivors
- Healthcare Providers
- Libraries
- Search Engines



	Freq. %	Some-times %	Seldom %	Never %	Don't Know %
■ Biomed. Journals	14	9	12	30	35
■ Peer Support Groups	9	9	8	30	46
■ Other survivors	14	21	33	26	7
■ Healthcare Providers	37	18	33	9	2
■ Libraries	0	14	14	40	33
■ Search Engines	61	21	5	9	5

To what extent do you find it easy or difficult to find relevant information?

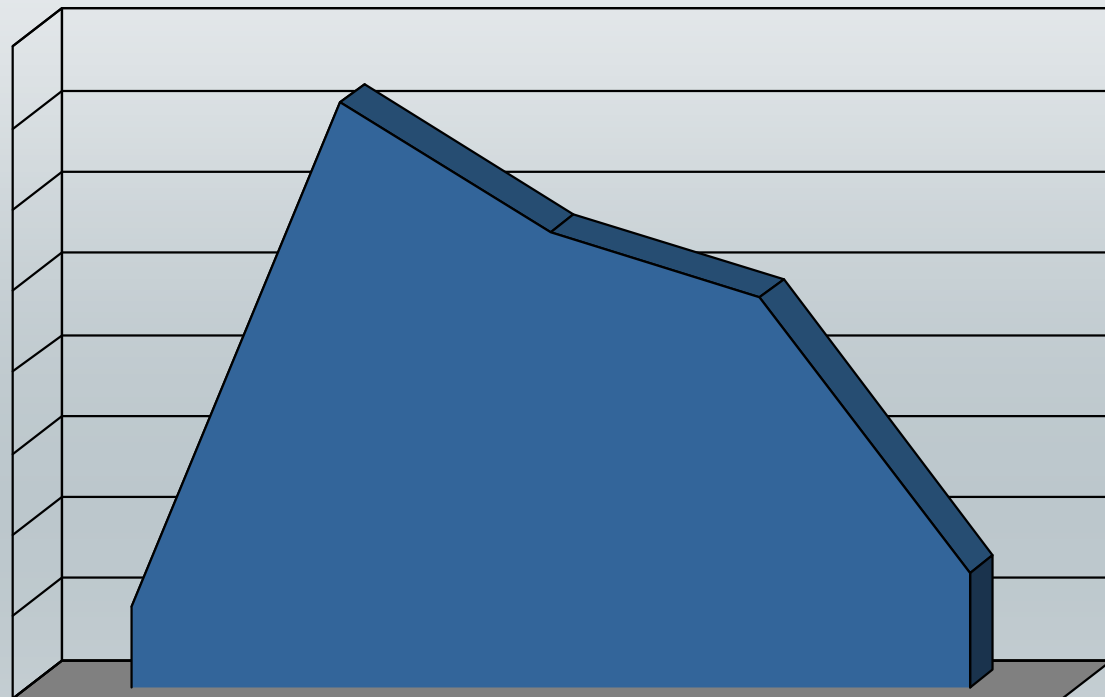
(e.g., retrieving relevant information)

Scale:

- A** (Not at all difficult)
- B** (Somewhat difficult)
- C** (Neutral)
- D** (Difficult)
- E** (Very difficult)



Retrieving Relevant Information



Not at all diff. %	Some-what diff. %	Neutral %	Diff. %	Very diff. %
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■ Ease / difficulty in finding relevant information

5	36	28	24	7
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How satisfied are you with the quality and content of the information resources that you do find?

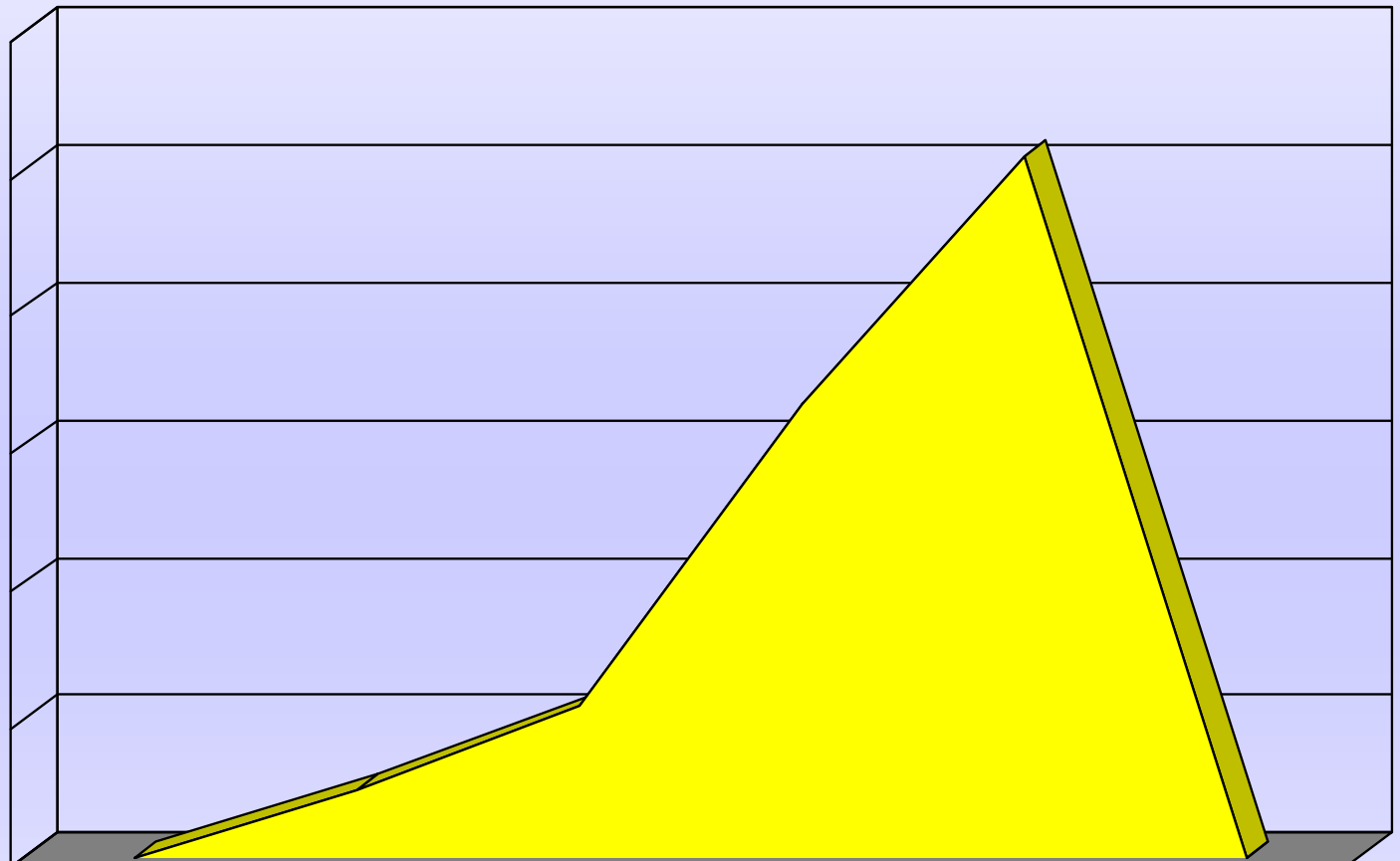
(e.g., satisfaction with sources)

Scale:

- A** (Not at all satisfied)
- B** (Somewhat satisfied)
- C** (Neutral)
- D** (Satisfied)
- E** (Very satisfied)

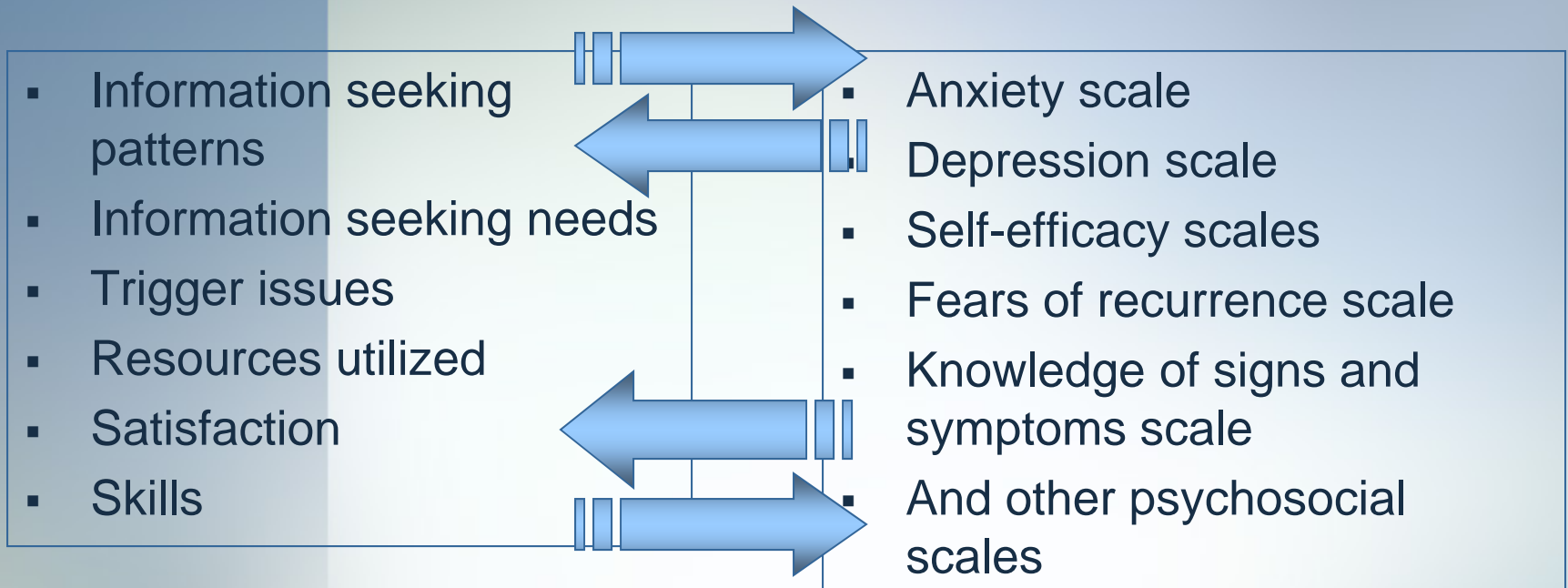


Satisfaction with Sources



	Not at all satisfied %	Somewhat satisfied	Neutral %	Satisfied %	Very Satisfied %
■ Satisfaction	0	5	11	33	51

Psychosocial Correlations



Psychosocial Correlations

Information seeking,
needs, behaviors

- Anxiety
- Depression
- Knowledge of signs and symptoms
- Self-efficacy
- Fears of recurrence



r = not statistically significant

Conclusions & Next Steps

- ❑ Data provide a 'snapshot' of this population
 - 3-8 years post-diagnosis
 - Not in medical crisis
 - Not actively engaged in information seeking and use
- ❑ Too few subjects to make generalizations

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- ❑ Analyze data across time
 - ❑ Analyze 'extreme' cases
 - ❑ Consult with biomedical statistician



Contact me with questions, comments, copies of this presentation, references...!

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