Using the Internet to Translate Evidence-Based Interventions and Self-Management Information for Cancer Patients: Lessons from the Field

Society of Behavioral Medicine
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Learning Objectives

• Describe key components of effective internet interventions to support cancer patients and caregivers

• Discuss best practices for development, evaluation, and testing Web-based support for cancer patient self-management (SMMS)
Cancer Survivor

- Individuals are considered cancer survivors from the time of diagnosis, through the balance of his or her life.
- Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.
- Over 12 million cancer survivors in US today

Office of Cancer Survivorship, National Cancer Institute (2010)
Needs of Cancer Survivors

- Cancer patients, survivors and families have significant needs for:
  - Information about treatment and diagnosis
  - Help with symptom management
  - Communication and coordination of care
  - Prevention and surveillance of further problems

Institute of Medicine (2006) *From Cancer Patient to Cancer Survivor*
Overall Purpose

- Build and maintain a platform for translation and dissemination of evidence-based behavioral interventions to meet the needs of cancer survivors
Overview of Symposium

- Web-based Self-Management Systems
- Usability Considerations
- Web Mining for Understanding Information Needs of Users
- Online Social Networking
- Conclusions and Lessons Learned
Web-Based
Self-Management:
The Applications
Anna McDaniel, DNS, RN, FAAN
Funding Walther Cancer Foundation
Phase 1

Web-Based

SYMPTOM MANAGEMENT SYSTEM
Purpose – Phase 1

- To develop and test Web portal for delivery of an evidence-based symptom monitoring and management system (SMMS)
- Based on the following principles:
  - Increased knowledge enhances cancer patients’ coping
  - Strong positive relationship between Internet use and cancer patients’ self-efficacy for participation in care
  - Electronic communication between cancer patients and providers has potential for significant positive impact
Web-Based
Symptom Management Toolkit

• Translate previously tested SM intervention to Web:
  – Tailored information delivery
  – Ongoing symptom monitoring
  – Automated alert messages to providers

• Content management database

• Secure log-in system

• HIPAA compliant data storage

• Interface for user input and data capture

• Programming logic to support system
Symptom Management Intervention

- Weekly login to system to report symptoms during first 8 weeks of chemotherapy
- Based on symptoms reported, customized “Toolkit” of self-management strategies is displayed
- If any symptom reaches threshold, alert is delivered to oncology provider
Schema of System Interaction

Send e-mail reminder to patient
1. Receive e-mail reminder
2. Log on patient interface
3. Report symptoms

1. Deliver custom toolkit
2. Update symptom history

Send e-mail alert to provider
1. Receive e-mail alert
2. Log on provider interface
3. View patient symptom history
4. Contact patient
5. Log out

(if severe symptoms reported)

1. Read custom toolkit
2. View symptom history
3. Log out*

*May log on to access custom reports at any time
Phase 2

Web-Based

CAREGIVER MANAGEMENT SYSTEM
Purpose – Phase 2

• Extension of Web-based system to assist family caregivers of cancer patients with strategies to:
  – Communicate with patient, family members and providers
  – Manage caregiver stresses
    • Anxiety, burden, finances, insurance, and others
  – Manage time, maintain employment and other roles
  – Assist family members providing care from a distance
Pathways for Caring

• Linked to patient symptom report and Toolkit
• Functionality to address caregiver concerns
  – Taking care of self
  – Working as a family
  – Making things happen
  – Coping with caregiving
  – Caring from a distance
• Allows open-ended communication with research nurse
Caregiver Support Intervention

- Weekly login to system to review patient symptoms during first 8 weeks of chemotherapy
- Indicate need for symptom management information
- Report information needs to address caregiver’s own concerns
- Based on needs assessment, customized “care guide” is displayed
Schema of Enhanced System
Interaction

Send e-mail reminder to patient

1. Receive e-mail reminder
2. Log on patient interface
3. Report symptoms

1. Deliver custom toolkit
2. Update symptom history

Send e-mail alert to provider

1. Receive e-mail alert
2. Log on provider interface
3. View patient symptom history
4. Contact patient
5. Log out

Deliver custom care guide

1. Read care guide
2. Log out*

(if severe symptoms reported)

1. Receive e-mail reminder
2. Log on caregiver interface
3. Review patient symptoms
4. Report concerns

1. Deliver custom toolkit
2. View symptom history
3. Log out*

*May log on to access custom reports at any time
Thank you
Introduction

• Our goal and purpose:
  – Provide guidance to developers of patient-facing medical interfaces
  – Contribute to nursing practice

• Presentation provides:
  – Description of our development methodology
  – Discussion of its results
Considerations in the Design of PATIENT-FACING INTERFACES
Context Is Unforgiving

- Cancer touches people from all walks of life, leaving them distressed and vulnerable.
- Resulting in groups of people who differ widely in their characteristics.
- They all suffer – either personally or for a loved one:
  - Will be tired and stressed
  - Will be very afraid
Users’ Needs Must Be Met

- User needs are diverse:
  - Patient has symptoms to be managed
  - Caregiver(s) has needs to be supported
  - Health provider has need for updates
  - Administrator(s) has tasks to be supported

- Tool must be accessible to all of them:
  - If it is Web-based, many people can get to it
  - It should be easy to read and understand
A Good Experience is Also Essential

- Application must be supportive
- Using it must be non-stressful
- Recommended best practices in human-computer interaction must be followed
  - Requires a *user-centered development methodology*
Designing the Interface

Description of Design-Related Development Methods
Gaining the User’s Perspective

• We began by using focus groups:
  – Group of common citizens who had been touched by cancer in the past
  – Group of nurses

• Performed Card Sorts:
  – To identify all their ‘issues’
  – To see how they mentally organized cards
  – To get their priorities
Card Sort Method
Developing the Tool

- **Iterative development process** used:
  1. Interface conceptualized
  2. Prototype developed
  3. Usability testing performed
  4. Interface revised to correct problems
  5. Additional usability testing performed, and more problems corrected
  6. Pilot field test with real users
  7. Process begins again...

(See Stone, Jarrett, Woodroffe & Minocha, 2005)
Interaction Design

• Special problems required unique solutions:
Interaction Design

• Special problems required unique solutions:
  – For some patients, not having a symptom = a severity of two...
• Special problems required unique solutions:
  – Doctors needed clinical toxicity rating of severe symptoms...
Interaction Design

• Special problems required unique solutions:
  – We couldn’t predict what symptoms the patient might report...
• Special problems required unique solutions:
  – Patients needed to review when finished...
Interaction Design

- Special problems required unique solutions:
  - Patients needed help, not merely to report...
Interaction Design

- Special problems required unique solutions:
  - Advice had to be easy for the patients to find...
• Special problems required unique solutions:
  – Advice had to be easy for patients to understand and use...
Interaction Design

• Special problems required unique solutions:
  – Could not predict what information patient wanted...
• Special problems required unique solutions:
  – Need to conduct ongoing research into the tool’s effect...
Interaction Design

- Special problems required unique solutions:
  - Caregiver needed to know what patient reported...

### Pathways for Caring

<table>
<thead>
<tr>
<th>Report Menu</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient's Symptoms</td>
</tr>
<tr>
<td>Taking Care of Yourself</td>
</tr>
<tr>
<td>Working as a Family</td>
</tr>
<tr>
<td>Making Things Happen</td>
</tr>
<tr>
<td>Coping with Caregiving</td>
</tr>
<tr>
<td>Caring from Afar</td>
</tr>
<tr>
<td>Other Concerns</td>
</tr>
</tbody>
</table>

### Patient's Symptoms

On 02/07/2011 your mother reported the symptoms below. If you would like information about how to help your mother manage any of these symptoms, please check the box next to each of them.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Reported Severity</th>
<th>Want Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep Problems</td>
<td>7 out of 10</td>
<td></td>
</tr>
<tr>
<td>Rash</td>
<td>7 out of 10</td>
<td>✓</td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
<td>6 out of 10</td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>6 out of 10</td>
<td>✓</td>
</tr>
</tbody>
</table>

I don’t need information for any of these symptoms

Save and Continue
• Special problems required unique solutions:
  – Caregiver also had needs to be managed...
Interaction Design

- Special problems required unique solutions:
  - Could not predict everything that might be needed...
Special problems required unique solutions.:

- Provider needed to see patient’s situation in context...
Interaction Design

- Special problems required unique solutions: Administrator needed to link patient to caregiver.
• Special problems required unique solutions:
  – Some still working on, i.e. “What did I enter last time?”
Discussion of Analytic Evaluation

METHODS AND TECHNIQUES
Performing Analysis: Testing Usability

1. Recruited volunteers demographically similar to targeted population
2. Administered pretest survey to confirm demography
3. During usability testing
   • Provided participants with role-playing scenario
   • Asked them to perform a series of tasks while using interface
4. Information gathered through observation, participant think-aloud, and discussion
5. Follow-up survey gathered impressions of interface
6. Final de-briefing interview to make sure we did not miss anything

(See Dumas & Redish, 1999)
Performing Analysis: Testing Usability

• Analysis of Pilot Study Data:
  1. System designed to capture all user choices and time spent on each screen
  2. Data parsed in three ways:
     • One record per measurement showing type and value of data
     • One record per participant showing all possible choices and actions during 8-week study
     • One record per participant, per week showing all choices and actions in each of 8 weeks

     – First yielded general descriptive statistics
     – Second yielded simple correlations
     – Third gave time-series correlations
Thank you
Web Mining as a Technique to Understand and Meet the Information Needs of Cancer Patients

Katherine Schilling, MLS, Ed.D., AHIP
Funding Walther Cancer Foundation
Describe the collection and analysis of SMMS patient data:

- Web (data) mining techniques
- Software options
- Research questions and findings
Web Mining

An Explanation of the Process
About Web Mining

- Uncovers user patterns and behaviors
  - Describing (description)
  - Predicting (prediction)
- Web mining = Data mining techniques applied to Web resources
- Knowledge Discovery in Data (KDD)
  - Data ‘dredging,’ ‘fishing,’ ‘scooping’
The Mining Process

1. Design system
2. Collect raw data
3. Process raw data
4. Ask research questions
5. Generates algorithms
6. Software
7. Leads to results
8. "Dictates mining tasks"
9. & Identify potential relationships
Preparing Raw Data

IMPORTANT!

Data Representation
Bad data in = Bad results out

- **Data representation** dictated by:
  - Which data are captured
  - Forms and formats captured
  - Clinical and research questions asked
  - Relationships sought
  - Algorithms used
  - Software, etc.
Preparing Raw Data

IMPORTANT!

Data Representation
Bad data in = Bad results out

• **Data representation dictates:**
  – Data analyses options, choices, possibilities
  – Clinical and research questions asked
  – Knowledge gleaned
Issues for Consideration

- Are most relevant data generated?
- How are data extracted and manipulated?
- What mining software and techniques are used?
- Who sees data and analysis results?
- Are user privacy and confidentiality protected?
Data Mining Software

- **For Purchase**
  - SPSS
    - Numeric
    - Text mining plug-in
  - WordStat
    - Text Based

- **Open Source**
  - Useful for specific tasks
  - Require programming
    - Knime, JHepWork, Orange, Weka, Others
Software Considerations

- Cost
- Operating system, programming language(s)
- Required programming
- Integration with other software, plug-ins
- Data requirements, import and format options
- Interactivity
- Output displays
- Graphing, visual displays, 2D, 3D
- Overall ease-of-use, etc.
Mining the Data

For

CLINICAL AND RESEARCH QUESTIONS
Available Data

- **Patient symptom data**
  - Reported symptoms
  - Toxicity / impact self-assessment
  - Toolkit usage
  - Interface evaluation

- **Provider alerts**
- **System-level usage**
  - Pages viewed
  - Time in page
  - Time in system overall
  - System-initiated events
  - Etc.

1. Receive e-mail reminder
2. Log on patient interface
3. Report symptoms

1. Deliver custom toolkit
2. Update symptom history

1. Read custom toolkit
2. View symptom history
3. Log out*
Research Aims

- To improve SMMS
  - Simplify, clarify, make more effective:
    - Features, functions
    - Content
    - Ease of use
    - Overall utility
Research Aims

- To promote more effective patient self-management:
  - Symptom-management needs
  - General health concerns
  - Lifestyle, quality-of-life issues
Research Aims

- To understand how patients are using the ToolKit:
  - "My Toolkit"
    - Weekly, customized, symptom-driven Toolkit
  - "Complete Toolkit"
Keeping in mind patients’:

- Reading skills
- Health literacy skills
  - Health information literacy
- Numeracy skills
  (numbers, percentages, graphs, tables, charts, risk, prevention, prognosis, outcomes)
Research Questions

- **Who, what, when, where, why and how system-level data?**
  - Who logs in?
  - When?
  - How long?
  - Pages viewed?
  - How long viewed?

- **Symptoms (reporting)**
  - Severity (toxicity)
  - Lifestyle impact
  - Quality of life impact
Research Questions

- **Case trends**
  - By session
  - By patient

- **Toolkit usage**
  - Time spent
  - Symptoms used
    - By symptom
    - By patient
    - By session
    - Other variables
Discussion of

RESULTS AND FINDINGS
Pilot Population

- **Recruitment**
  14 out of 16 eligible
  12 completed 8 week intervention

- **Pilot sample**
  Colon cancer patients receiving chemo
  7 males, 7 females
  Age ranges 37 - 84
  $M = 59.2$ (10.9)
Basic SMMS Utilization

**Compliance**
- 103 scheduled symptom assessment reports
- 73 weekly logins completed
- = 71% completion rate

**Provider Alerts**
- 39 generated
- 20 provider log-ins
- = 51% response rate (at least)
Basic SMMS Utilization

- **73 weekly logins**
  \[ M = 6 \text{ (out of 8 possible per person)} \]

- **183 total logins**
  \[ 1 - 28 \text{ per participant} \]

- **Average time per session**
  \[ M = 19.9 \text{ minutes} \]
  
  - **7.8 minutes on assessment / reporting screens**
  - **5.2 minutes on symptom management screens**
### Time In System

<table>
<thead>
<tr>
<th>Activity</th>
<th>Numbers of accesses:</th>
<th>Minutes engaged in:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluating</td>
<td>36</td>
<td>Mean 7.8</td>
</tr>
<tr>
<td>Assessing</td>
<td>74</td>
<td>Median 5.25</td>
</tr>
<tr>
<td>Managing Symptoms via Toolkit</td>
<td>43</td>
<td>&lt; 1 min.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50 sec.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean 5.17</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Median 2.4</td>
</tr>
</tbody>
</table>
Time In System: By Activity

Usage Across Weeks 1 - 8

BLUE = Assessing symptom severity and impact
GREEN = Managing symptoms via Toolkit
Time In System: By Case

**BLUE** = Assessing symptom severity and impact  
**GREEN** = Managing symptoms via Toolkit

Mean time in minutes

Patient Cases 1 - 11
Case Analysis

Q: Why was this patient more engaged in Toolkit than average?
  - Worse symptoms than average?
  - Exploring more online?
  - Reading about symptoms online (vs. printing)?

A: Do not have data to know!

A: BUT, patient IS reporting:
  - Higher symptom impact
  - Lower symptom improvement
  - Lower rating on Toolkit ease-of-use
Symptom Frequency

- Self-rated during 8 weekly sessions
- Self-ratings on a 1 - 10 severity scale

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Frequency (n = 315)</th>
<th>Mean Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>60</td>
<td>4.5</td>
</tr>
<tr>
<td>Nausea</td>
<td>51</td>
<td>4.1</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>43</td>
<td>4.5</td>
</tr>
<tr>
<td>Pain</td>
<td>37</td>
<td>4.4</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>33</td>
<td>3.9</td>
</tr>
<tr>
<td>Sleep</td>
<td>28</td>
<td>3.6</td>
</tr>
<tr>
<td>Constipation</td>
<td>22</td>
<td>4.4</td>
</tr>
<tr>
<td>Hand Foot</td>
<td>15</td>
<td>4.3</td>
</tr>
<tr>
<td>Stomatitis</td>
<td>5</td>
<td>1.4</td>
</tr>
</tbody>
</table>
## Symptom Severity, 1

- Rated weekly during 8 weekly sessions
- Self-ratings on a 1 - 10 severity scale

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Mean Severity</th>
<th>Frequency (n = 315)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dyspnea</td>
<td>6.5</td>
<td>2</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6.0</td>
<td>1</td>
</tr>
<tr>
<td>Appetite</td>
<td>5.8</td>
<td>4</td>
</tr>
<tr>
<td>Dry Mouth</td>
<td>5.5</td>
<td>2</td>
</tr>
<tr>
<td>Cognitive fx</td>
<td>5.0</td>
<td>2</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4.7</td>
<td>69</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>4.5</td>
<td>43</td>
</tr>
<tr>
<td>Pain</td>
<td>4.4</td>
<td>37</td>
</tr>
<tr>
<td>Constipation</td>
<td>4.4</td>
<td>22</td>
</tr>
</tbody>
</table>
Symptom Severity, 2

- Rated weekly during 8 weekly sessions
- Self-ratings on a 1 - 10 severity scale

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Mean Severity</th>
<th>Frequency (n = 315)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hand-foot</td>
<td>4.3</td>
<td>15</td>
</tr>
<tr>
<td>Nausea</td>
<td>4.1</td>
<td>51</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>3.9</td>
<td>33</td>
</tr>
<tr>
<td>Sleep problems</td>
<td>3.6</td>
<td>28</td>
</tr>
<tr>
<td>Stomatitis</td>
<td>1.4</td>
<td>5</td>
</tr>
<tr>
<td>Rash</td>
<td>1.0</td>
<td>1</td>
</tr>
</tbody>
</table>

... list continued from previous screen
‘Nagging’ Symptoms

Consistent moderate severity combined with high frequency =

- Look for other relationships
- Tailor Toolkit to specific patient needs

<table>
<thead>
<tr>
<th></th>
<th>Mean Severity</th>
<th>Frequency (n = 315)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>4.7</td>
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<tr>
<td>Constipation</td>
<td>4.4</td>
<td>22</td>
</tr>
</tbody>
</table>
User Satisfaction

• Formative evaluation
  – Weekly online
  – User feedback (10 point scale)
    Helpfulness               6.4
    Ease of use              7.9
User Satisfaction

• Summative evaluation
  – Follow-up telephone interview \((n = 11)\)
  – 20 item modified UTAUT
  – 4 point scale
    \(M = 3.12\)
    Cronbach’s alpha = 0.89
Clinical Outcomes

- Fewer symptoms reported at follow-up than baseline (ns)
- Significantly lower symptom severity at follow-up
  \[ T = 3.4 \]
  \[ p = 0.006 \]
- No differences in SF12 from baseline to follow-up
- CESD scores slightly lower at follow-up
  \[ 17.5 \text{ vs } 15.2 \text{ (ns)} \]
For Effective Evaluation:

SUMMARY

Web Mining
Practical Applications

- Confirms expectations
- Reveals surprises
- Useful for making evidence-based decisions:
  - Interface design, structure and organization
  - Contents
  - Audience behaviors
  - Audience needs
    - System developers and administrators
    - Healthcare providers
    - Patients
    - Caregivers
Practical Applications

Highly personalized greetings, interaction and content

Symptom Management Toolkit

Evaluation Session
Constipation
Is your constipation better, about the same, or worse?
☐ better  ☐ about the same  ☐ worse

Did you see any of the information in the "My Symptom Management Toolkit" to help manage your constipation?
☐ yes  ☐ no

How helpful was the information you received about constipation?
☐ very helpful  ☐ somewhat helpful  ☐ not helpful

Symptom-By-Symptom Listing

Symptom

- Headache
- Dyspnea
- Mouth Sores
- Melanoma
- Neutropenia
- Numbness/Tingling
- Fatigue
- Painful, breakthrough
- Physical monitoring
- Rash
- Remembering Things
- Sexual Dysfunction

Symptom Management Toolkit

My Symptom Management Toolkit
Based on your current symptom report, a personalized resource, "My Symptom Management Toolkit", has been created for this week. Click on a topic below to view information that may be helpful, or use the menu to the left.

My Symptom Management Toolkit

- Headache
- Dyspnea
- Mouth Sores
- Melanoma
- Neutropenia
- Numbness/Tingling
- Fatigue
- Painful, breakthrough
- Physical monitoring
- Rash
- Remembering Things
- Sexual Dysfunction

Symptom History

About Me
Contact Us
Legend

A collaboration between Michigan State University and Indiana University
Practical Applications

Opportunities for journaling, conversation, interaction or social networking
Thank you
Online Social Networking as a Method to Deliver Theory-Based Support for Long-term Breast Cancer Survivors

Kim Wagler Ziner, RN, PhD
Funding Walther Cancer Foundation
Learning Objectives

- Describe key components of Web-based social networking among long-term breast cancer survivors
- Discuss best practices for development, evaluation, and testing of Web-based social networking for long-term breast cancer survivors’ self-efficacy and self-management
Methodology

An Introduction to the Intervention
Key Components of the Program

- Content delivery algorithms based on survivors’ responses to program-based breast cancer survivor self-efficacy survey
- Theory-based Program
- Evidence-based content
- Interface for moderated social networking
- Interface for healthcare provider individual coaching
Significance

- Adult survivorship clinics remain rare
- Many long-term breast cancer survivors lack optimal survivorship information and skills
- According to Bandura (1997):
  - Self-efficacy is important in translating information into skilled and helpful action
- Breast Cancer Survivor Self-efficacy is strongly correlated to other quality of life variables in long-term breast cancer survivors (Ziner, 2011; Champion, 2010)
Purpose

- To develop and test a Web portal-based program for delivery of evidence-based survivorship information, support, and social networking targeting breast cancer survivor self-efficacy
Methods

- Convenience sample long-term breast cancer survivors
- IRB approved recruitment database
- Survivors 3-8 years after diagnosis at the time enrolled in recruitment database
- Breast cancer survivors participated in a larger quality of life study
- Goal was to enroll 15-20 long-term breast cancer survivors
- Manage online sessions in groups of 4-5 survivors
Methods

- Central component is breast cancer survivor self-efficacy
  - Measure (scale) used in prior descriptive research
- Breast cancer survivor self-efficacy seemed a target for intervention
- Breast cancer survivor self-efficacy scale developed for and tested in large ($N = 1128$) study comparing quality of life in younger and older long-term breast cancer survivors (Champion, PI).
Breast Cancer Survivor Self-Efficacy

• 14 items, Likert responses
• Summed scale *
• 4 subscales for this study:
  – Asking for help
  – Doing what is important
  – Managing symptoms, emotions
  – Recurrence signs
• Program scores each subscale and recommends survivor work on lowest scoring subscale

Outcomes

• Feasibility
  – Would long-term survivors be interested in study?
  – Would those who try program find it helpful and useful?

• Change in breast cancer self-efficacy two months post intervention
Walk-Through

A Guided Tour of the WEB-BASED PROGRAM
Welcome Screen

Patient Activation

Welcome to Patient Activation Program
Hi, I am Kim Wagler Ziner, RN, PhD. I am a Certified Breast Care Nurse and researcher. This Patient Activation program was designed to help breast cancer survivors improve their confidence in survivorship after treatment is over. Thank you for joining us. In this program, you will take part in 4 sessions. Each session lasts one week:
- **Session I** you will identify a concern.
- **Session II** you will learn what experts know about your concern and select an action that you are willing to try to manage this concern.
- **Session III** you will make a plan to set your action in motion.
- **Session IV** you will evaluate your action.

You will join a group of 4-5 breast cancer survivors who will be going through the program with you. You will be asked to:
- Read material provided in 4 sessions.
- Perform the activities required in each session.
- Respond to the other participants in your group as often as you choose.
- Respond to the nurse 4 times in a private discussion online or in a discussion/community group.

All participation is voluntary. You can stop the program at any time. Any questions or comments? Please e-mail Kim or call me at (317) 274-4342.

Welcome, kim1!
Your group is testGroup1, and the current session is Session I.
Patient Activation

Breast Cancer Self-Efficacy Survey

Please tell me how much you agree or disagree with each statement. Use the scroll bar on the right to view all the questions. You must answer all of the questions before you can proceed.

1. You are able to ask for help when you have problems related to your breast cancer.
   - Strongly Agree  - Agree  - Neutral  - Disagree  - Strongly Disagree

2. You are able to deal with the fact that you had breast cancer.
   - Strongly Agree  - Agree  - Neutral  - Disagree  - Strongly Disagree

3. You are able to deal with physical symptoms from having breast cancer.
   - Strongly Agree  - Agree  - Neutral  - Disagree  - Strongly Disagree

4. You are able to ask for help for problems related to breast cancer without feeling guilty.
   - Strongly Agree  - Agree  - Neutral  - Disagree  - Strongly Disagree

5. You are able to handle any fears you have about breast cancer returning.
   - Strongly Agree  - Agree  - Neutral  - Disagree  - Strongly Disagree

6. You are able to successfully handle life situations since you had breast cancer.
Breast Cancer Self-Efficacy Survey

Patient Activation

Breast Cancer Self-Efficacy Survey
Please tell me how much you agree or disagree with each statement. Use the scroll bar on the right to view all the questions. You must answer all of the questions before you can proceed.

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   - Neutral
   - Disagree
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4. You are able to ask for help for problems related to breast cancer without feeling guilty.
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   - Neutral
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   - Strongly Disagree

5. You are able to handle any fears you have about breast cancer returning.
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

6. You are able to successfully handle life situations since you had breast cancer.
Program Recommendation

Patient Activation

Select a concern you want to work on

From your responses to our survey it looks like what may help you the most is Doing what is important after breast cancer.

You can also select a topic you prefer to work on from the following:
- Doing what is important after breast cancer
- Handling symptoms, changes, emotions after breast cancer
- Asking for help
- Knowledge of signs and symptoms of recurrence

When managing any problem/concern, it is best to first observe what the problem is like.

For example, I would like to spend more time fund raising for breast cancer research. But I also need to spend time exercising, finding more time with my husband, grandchildren, friends, and parents while I maintain a very demanding professional life. I kept a diary of all of my activities throughout the week (work, personal time and travel time).

After this week of observation, I decided the only way I could manage all my wants and needs was to combine a few because I just could not find more time in the day. I chose to exercise more by training for activities related to funding breast cancer research. I now walk in several 5K breast cancer related events such as the Susan G. Komen Race for the Cure and I also am training for those challenging 3-day- 60 mile breast cancer walks.
An Explanation of the UNDERLYING PREMISE
Theory-Based Program

- Self-efficacy
- Self-regulation

## Theory-Based Process

<table>
<thead>
<tr>
<th>Process</th>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-efficacy</td>
<td>• Vicarious experiences noted by experts</td>
<td>• Vicarious experiences noted by experts</td>
<td>• Vicarious experiences</td>
<td>• Vicarious experiences</td>
</tr>
<tr>
<td></td>
<td>• Normalizing somatic responses</td>
<td>• Normalize somatic responses</td>
<td>• Normalize somatic responses</td>
<td>• Normalize somatic responses</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Verbal persuasion</td>
<td>• Verbal persuasion</td>
<td>• Verbal persuasion</td>
</tr>
<tr>
<td>Self-Regulation</td>
<td>• Self-observation</td>
<td>• Self-judgment</td>
<td>• Self-judgment</td>
<td>• Self-evaluation</td>
</tr>
<tr>
<td></td>
<td>• Social comparison</td>
<td>• Social comparison</td>
<td>• Social comparison</td>
<td>• Social comparison</td>
</tr>
</tbody>
</table>

- **Session 1**: Vicarious experiences noted by experts, Normalize somatic responses, Verbal persuasion.
- **Session 2**: Vicarious experiences noted by experts, Normalize somatic responses, Verbal persuasion.
- **Session 3**: Vicarious experiences, Normalize somatic responses, Verbal persuasion.
- **Session 4**: Vicarious experiences, Normalize somatic responses, Verbal persuasion, Performance.
Knowledge-Base

A Description of the

EVIDENCE-BASED CONTENT
### Content Cont’d

<table>
<thead>
<tr>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Content</strong></td>
<td><strong>Session 2</strong></td>
<td><strong>Session 3</strong></td>
<td><strong>Session 4</strong></td>
</tr>
<tr>
<td>- Identifying a concern</td>
<td>- Evidence-base interventions (actions) for concerns</td>
<td>- Role model plans to take action</td>
<td>- Role model self-evaluation</td>
</tr>
<tr>
<td>- Definitions of concerns according to research/evidence-based practice</td>
<td>- Role model use of evidence-based intervention</td>
<td>- Role model strategies for thinking through actions</td>
<td></td>
</tr>
<tr>
<td>- Remainder of program is customized based on the selected concern.</td>
<td>- Survivors may chooses one action</td>
<td>- Between session 3 &amp; session 4 survivors practice and implement their action plan</td>
<td></td>
</tr>
</tbody>
</table>
• Session I definition of concern
• Within handling emotions
  – What is depression...
  – Most people who have depression describe it as...
  – “Experts” references imbedded within content
• Session II
• Evidence-based self-management actions
  – People who have had depression find this helpful...
Discussion of the INTERFACE FOR MODERATED SOCIAL NETWORKING
1. Survivor log-on
2. Takes survey once
3. Views content
4. Social interaction

1. HCP logs onto moderator interface
2. Discussion message to all
3. Individual coaching private message one-on-one
4. Log out

*May log on to access custom program as much as desired for each session*
Theory-Based Group Discussion

Patient Activation

Group discussion 1

Kim  This week's topic
Tell us a little about yourself and your breast cancer experience.
Let us spend some time discussing areas a breast cancer survivor could select to improve the various concerns identified in the breast cancer self-efficacy scale.

Kim1  wrote on Saturday, May 15 at 2:15 am
   text for message

Kim1  wrote on Saturday, May 15 at 10:23 am
   thread test

Kim1  wrote on Saturday, May 15 at 10:28 am
   thread test 2

< Back
## Theory-Based Social Networking

<table>
<thead>
<tr>
<th>Discussion groups</th>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Survivors tell their story</td>
<td>Consider one of these areas that you have managed successfully</td>
<td>My husband and I rarely talk about my fears.</td>
<td>What did you learn?</td>
</tr>
<tr>
<td></td>
<td>Discuss things breast cancer survivor could select to improve concerns identified in the breast cancer self-efficacy survey.</td>
<td>Discuss with the group what actions you found most helpful in your success.</td>
<td>Tell me what you think of this statement and help me practice.</td>
<td>Tell the group about your reward for your action.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>If you would like help from the group with your own plan you can post it to the group.</td>
<td>Will you change your reward next time?</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>If so what might you select?</td>
</tr>
</tbody>
</table>
# Individual Coaching

<table>
<thead>
<tr>
<th>Individual discussions</th>
<th>Session 1</th>
<th>Session 2</th>
<th>Session 3</th>
<th>Session 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Tell me how you plan on observing your concern this week.</td>
<td>• If concern is Doing what is important: Name what is important to you and what you have tried in the past.</td>
<td>• Tell me about your action, benefits, barriers and reward.</td>
<td>• How did you do with your plan?</td>
<td>• What would you do differently?</td>
</tr>
</tbody>
</table>
A Description of WHAT HAPPENED
Results

- First group = 4 long-term survivors
- 3 participants completed the program and reported the program helpful and useful for current survivorship concerns
- 3 completing program:
  - Selected content within “Doing what is important”
- 1 participant not able to complete program:
  - Selected content within “Handling symptoms and emotions”
Evaluation

• **Usability testing**

• **Testers:**
  – Oncology and family practice nurses
  – Long-term breast cancer survivors
  – Students
  – Caregivers of long-term breast cancer survivors
Thank you
Acknowledgements

• Walther Cancer Foundation, Grant # 0066.01
• Indiana University Simon Cancer Center
  – Paul Helft, MD
  – Patrick Loehrer, MD
  – Michael Schug
• IU School of Informatics
• Amy Hu
• Renée Stratton
• Robert ‘Skip’ Comer


Institute of Medicine (2006) From Cancer Patient to Cancer Survivor


Office of Cancer Survivorship, National Cancer Institute (2010)


Panel Discussion

Conclusions and Lessons Learned
Lesson Learned about

THE CHALLENGES OF PROVIDING
WEB-BASED CANCER SUPPORT
Translation Challenges

• ‘Evolving’ content development
  – Logical structure of content required for managing relational database
  – Flexible enough to allow for change and revision

• Health literacy
  – Reading levels
  – Health information literacy
  – Numeracy
Research Challenges

- Multiple consents (nurse, patient, caregiver)
- Recruitment issues
  - Inclusion criteria (Internet access, treatment trajectory)
  - Tracking potential participants
- Multi-site investigators
  - Enrollment at one institution; baseline and follow-up data collection at another
  - IRB issues
Technology Challenges

• System
  – Significant changes in version of programming software
  – Expanding content management database
  – HIPAA security protocol irregularities
  – Server failure

• Users
  – Browser and software versions
  – Computer literacy
Findings and Conclusions from the

**USER-CENTERED DESIGN METHODOLOGY**
Usability Findings

- Many problems were found and fixed in usability testing
- Usability test participants generally positive about experience and expected tool utility
- Initial pilot demonstrated feasibility of development approach
- However, information-seeking behavior of participants varied
- Future sample size should be adjusted upward to accommodate low density of individual symptoms
What Should You Take Away?

• Methodology finds and corrects both software bugs and poorly designed features
• Many can be found only through testing
• Given broad demographic and emotional frailty of those dealing with cancer, a well-tested interface is an imperative
• Therefore, a methodology such as ours should be used as a general practice in the development of interfaces for cancer care
Katherine Schilling

Implications of the
DATA MINING RESULTS
Implications

• Provides ‘snapshot’ of pilot population use of SMMS
  — Reporting trends emerge
  — Symptom patterns emerge
  — Toolkit usage patterns emerge
  • Content used
  • Satisfaction
Answers Generate More Research Questions:

- Do participants really feel better?
  - OR simply adjusting to pain, discomfort, inconvenience
  - OR being polite in phone survey (vs. when answering privately)
• How do symptoms drive usage patterns?
  – Too sick to go online
  – So sick = more desperate for information
  – More sick = more or less satisfied with information found
Answers Generate Questions

- Printing vs. reading online?
  - Impacts understanding of time in system
  - Generational
  - Preference and habit based

- How Toolkit used for health decision making and behaviors?
• How to increase compliance and consistency
  – Too sick to login?
  – Need different kinds of Toolkit content?
  – Need different kinds of Toolkit feedback?
  – Need other delivery systems (mobile app)?
  – Others?
How to engage meaningfully with users

- Content
- Presentation
- Flexibility
  - Updated how often
  - Individually tailored
  - Voice, text, multimedia
Overall Implications

- Study users’ information-seeking behaviors
- Tailor content to meet users’ information needs
- Impact on health behavior and decision making
  - Findings used to improve SMMS features and functionality
  - Promotes effective cancer symptom self-management support
Kim Wagler-Ziner

Lessons Learned and

BEST PRACTICES
Breast Cancer Self-Efficacy Survey

• Lesson learned:
  – I thought this would be extremely tough, and it ended up being easy
Lesson Learned

• As moderator in the group sessions, I had to emphasize the parts of the program that targeted breast cancer survivor self-efficacy:
  
  – Session 1:
    • Tell you story = easy for all
    • Discuss things breast cancer survivor could select to improve concerns identified in breast cancer self-efficacy survey = difficult
Lesson Learned

– Session 2

• Consider one of these areas that you have managed successfully = easy

• Discuss with the group what actions you found most helpful in your success = slightly difficult
Lessons Learned

- Individual coaching
  - Focused and personal = easy
  - I could read and then think about the best response, unlike a support group
Best Practices

- Developing within a structure
- Developing within a team
- Evaluation
- Testing
Advantages

- Web-portal platform
- Content structure similar to public materials
  - (e.g., people who have depression describe it as...) but links made delivery study unique
- Lesson learned: do not re-invent evidence-based content
- Research within the Web-portal is accessible with study unique username and password
- HIPAA compliance: Social networking user-determined alias for privacy
Development within a Structure

- Disadvantages
  - Portal problems impact all programs
Development within a Team

- Team leader PhD, Nursing and Informatics
- Content experts
- Programming experts
- Usability experts
- Web-user engagement experts

Lesson learned: Survivors like it simple
Q&A Session

Do You Have Any

QUESTIONS?