Evaluation of a Computer-Based Toolkit for Hematological Cancer Patients, Caregivers, and Family/Friends

Presented by

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Disclosure

No relationships to disclose.
Project Overview

Phase I: Needs Assessment and Inventory
- Assess audience information needs and barriers
- Inventory existing materials / resources

Phase II: Toolkit Development
- Develop new materials, interactive toolkit
- Pretest messages, materials, and interface

Phase III: Evaluation
Challenges

Differing Information Needs
- Needs differ by role and cancer phase

Limited Topics
- Most materials focus on cancer type (37%) or treatment (75%)
- Fewer resources for caregivers, family / friends (< 2%)

Saturation
- Overwhelmed by clinical details
- Desired basics, then more detail
Challenges

Readability and Clinical Language

- Most materials (90%) at 10th grade reading level
- Difficulty with clinical vocabulary / statistics

Format / Accessibility

- Format preferences vary—print, audio, Web, etc.
Toolkit Development

Role / Phase Segmentation
- Customized and segmented materials by role and phase

Format and Accessibility
- Self-navigated CD-ROM
- Used simple HTML software
- Materials in PDF format — Print or save to computer
Toolkit Development

Low-Literacy Structure

- Basic overview of topics / issues
- Average 8th grade reading level (Flesch-Kincaid)
- Low density – Few medical terms, basic reasoning, no statistics

Resource Links

- Links to glossary and other materials within toolkit
- Links to external resources for more detailed information

American Cancer Society: [www.cancer.org](http://www.cancer.org) or call toll-free
1-800-ACS-2345 24 hours a day
Blood Cancer Information
for Patients, Caregivers, Family and Friends

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GLOSSARY
RELATED LINKS
USING THE TOOLKIT
PROVIDE FEEDBACK

PATIENTS
- Acute Lymphocytic Leukemia
- Acute Myeloid Leukemia
- Chronic Lymphocytic Leukemia
- Chronic Myeloid Leukemia
- Hodgkin’s Lymphoma (Hodgkin’s disease)
- Non-Hodgkin's Lymphoma
- Multiple Myeloma
- Coping with Side-effects
- Life After Cancer Treatment

CAREGIVERS
- Talking with Your Family and Friends About Cancer
- Cancer Support Groups
- Treatment Options for Blood Cancers
- Coping with Cancer Treatment
- Help with Money and Health Insurance
- Life After Cancer Treatment
- Long-term Side Effects of Cancer Treatment
- Dealing with Advanced Cancer

FAMILY and FRIENDS
- How You Can Help Cancer Caregivers
- Dealing with Strong Feelings
- Cancer Support Groups
- Finding a Hospital or Clinic for Treatment
- Treatment Options for Blood Cancers
- New Ways to Fight Cancers
- Coping with Cancer Treatment
- Help with Money and Health Insurance
- Long-term Side Effects of Cancer Treatment
- Dealing with Advanced Cancer
Toolkit Evaluation

- Distribution of 2,500+ toolkits via ACS, TWC, and RTI
- Evaluation invitation enclosed in toolkit
- Online / telephone survey of real-world users
  - Toolkit source
  - User characteristics
  - Materials read / preferences
  - Navigation ease
  - Readability
  - External resource usage
Evaluation Findings

1) Who used the toolkit?

2) How did individuals use the toolkit? How did the toolkit influence their behavior?

3) How effective were the toolkit features in addressing the challenges?
RQ1: Toolkit Users – Participant Role

- Family / friends most likely to pick up toolkit

![Bar chart showing percentages of Toolkit Users by Participant Role.](chart.png)

- Patient: 31%
- Caregiver: 18%
- Family / Friend: 49%
- Other: 1%
RQ1: Toolkit Users – Cancer Type

- Mix of all cancer types

- Leukemia: 30%
- Lymphoma: 37%
- Multiple Myeloma: 27%
- Other: 2%

0% 10% 20% 30% 40%
Leukemia Lymphoma Multiple Myeloma Other
RQ1: Toolkit Users – Cancer Phase

- Continuing treatment / Post-treatment most likely to use toolkit
RQ1: Toolkit Users – Source of Toolkit

- Family / friends surprisingly common source
- ACS, TWC less common source

- 34% Active Recruitment
- 19% Other
- 26% Family / Friend
- 16% Cancer Org.
RQ2: Toolkit Activities – Access Location

- Almost three-fourths of users accessed toolkit at home

![Chart showing access location]

- 73% at home
- 8% at work computer
- 4% at library, school, pub
- 9% at F/F computer
- 0% at Pat Nav
- 1% Other
RQ2: Toolkit Activities – Patient Materials Read

- Core materials popular among all segments
- Targeted materials appropriate for patients

![Bar chart showing the percentage of materials read by all users and patients across different sections: Overview, Treatment Options, Side Effects, Life After Treatment. The chart indicates a higher percentage of materials read by patients compared to all users in each category.]
RQ2: Toolkit Activities – Caregiver Materials Read

- Targeted materials appropriate for caregivers

Bar chart showing the percentage of users and caregivers who read different materials:
- Talking with F/F
- Support Groups
- Treatment Options
- Coping with Treatment
- Money / Insurance
- Life After Treatment
- Long-Term Side Effects
- Advanced Cancer

Legend:
- All Users
- Caregivers
RQ2: Toolkit Activities – Family / Friend Materials Read

- Targeted materials appropriate for family / friends

![Bar chart showing the percentage of users who read different materials related to cancer. The x-axis lists various topics such as Helping Caregivers, Dealing with Emotions, Support Groups, Finding a Clinic, Treatment Options, New Treatments, Coping with Treatment, Money / Insurance, Long-Term Side Effects, and Advanced Cancer. The y-axis represents the percentage ranging from 0% to 60%. The chart compares the percentage of All Users and Family / Friends for each topic.]
RQ2: Toolkit Activities – Behaviors

- Learning more about cancer, treatment options most common.
RQ3: Toolkit Strategy – Satisfaction

- High satisfaction with topics available and info in materials
- No differences by role

![Bar Chart](image-url)

- Topics: 66% Very, 26% Somewhat
- Material Content: 67% Very, 23% Somewhat
RQ3: Toolkit Strategy – Navigation / Readability

- Main menu of materials very easy to navigate
- Materials highly readable

![Graph showing menu navigation and material readability percentages.](image)
RQ3: Toolkit Strategy – External Links

- American Cancer Society
- Leukemia & Lymphoma Society
- Multiple Myeloma Research Foundation

- The Wellness Community
- Lymphoma Research Foundation
- National Cancer Institute

Bar chart showing:
- Yes: 31%
- No: 61%
RQ3: Toolkit Strategy – External Links

- Reasons for not accessing links:
  - Familiar with resource / visited previously (20%)
  - Toolkit provided sufficient information (19%)
  - Plan to visit resource at later date (16%)
  - No interest in learning any more (16%)
  - Time constraints (8%)
  - Computer or Internet problems (5%)
RQ3: Toolkit Strategy – Resource Contacts

- Modest increase in contacting resources / organizations

<table>
<thead>
<tr>
<th></th>
<th>Prior Contact</th>
<th>Post Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACS</td>
<td>43%</td>
<td>11%</td>
</tr>
<tr>
<td>TWC</td>
<td>4%</td>
<td>5%</td>
</tr>
<tr>
<td>LLS</td>
<td>34%</td>
<td>10%</td>
</tr>
<tr>
<td>NCI</td>
<td>6%</td>
<td>17%</td>
</tr>
</tbody>
</table>

Legend: Prior Contact, Post Contact
Conclusions

- **Targeted Materials.** Customizing and targeting materials based on needs assessment is effective. Guide, rather than restrict.

- **Low-Literacy Structure.** Effective in addressing saturation, readability issues.

- **Non-Clinical Topics.** High interest in other topics—life after treatment, money / insurance, discussing cancer.

- **Accessibility.** Electronic format not a barrier. Most have access.

- **Reaching Early Phases.** Challenging to reach those recently diagnosed or in early treatment. Explore clinic outreach.
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