Development of a Self-Navigated Educational Toolkit for Hematological Cancer Patients, Caregivers, and Family/Friends

Presented by

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Presentation Overview

Background / Previous Work

Challenges

Toolkit Development

Materials Testing and Findings

Conclusions and Next Steps

Background

- Hematological cancers start in the blood and immune system (leukemia, lymphoma, multiple myeloma)
- Previously...
  - Inventoried existing educational materials
  - Interviewed patients, caregivers, and family/friends to identify information needs
  - Identified challenges to meeting these needs
- Goal — Develop an interactive toolkit to address information needs and overcome challenges

Challenges

Differing Information Needs

- Needs differ by role and phase
- Few resources for caregivers, family, friends (< 2%)

Limited Topics

- Most materials focus on cancer type (37%) or treatment (75%)
- Less focus on side effects, support, survivorship

Oversaturation

- Individuals felt overwhelmed with same kinds of information
- Desired basics, then more detailed materials

Challenges

Readability

- More than 90% of materials written at 10th grade reading level
- Majority (53%) written at 12th grade level or higher
- Health literacy consistently raised as issue

Clinical Tone

- Difficulty understanding clinical vocabulary and statistics
- Overly medical, “no hope”

Format / Accessibility

- Format preference varies — print, audio, Web, etc.

Toolkit Development

Addressing Information Needs

- Segmented materials into three roles: patient, caregiver, and family/friend
- Customized materials by role and phase
- Created materials to address unmet needs:
    - Coping with side effects
    - Help with money and health insurance
    - Cancer support groups
    - Life after cancer treatment, etc.

Toolkit Development

Avoiding Information Overload

- Basic overview of topics / issues
- Provided links to other materials within toolkit
- Provided links to external resources for more detailed information

American Cancer Society: www.cancer.org or call toll-free
1-800-ACS-2345 24 hours a day

- Created resource guide listing cancer and support organizations

Toolkit Development

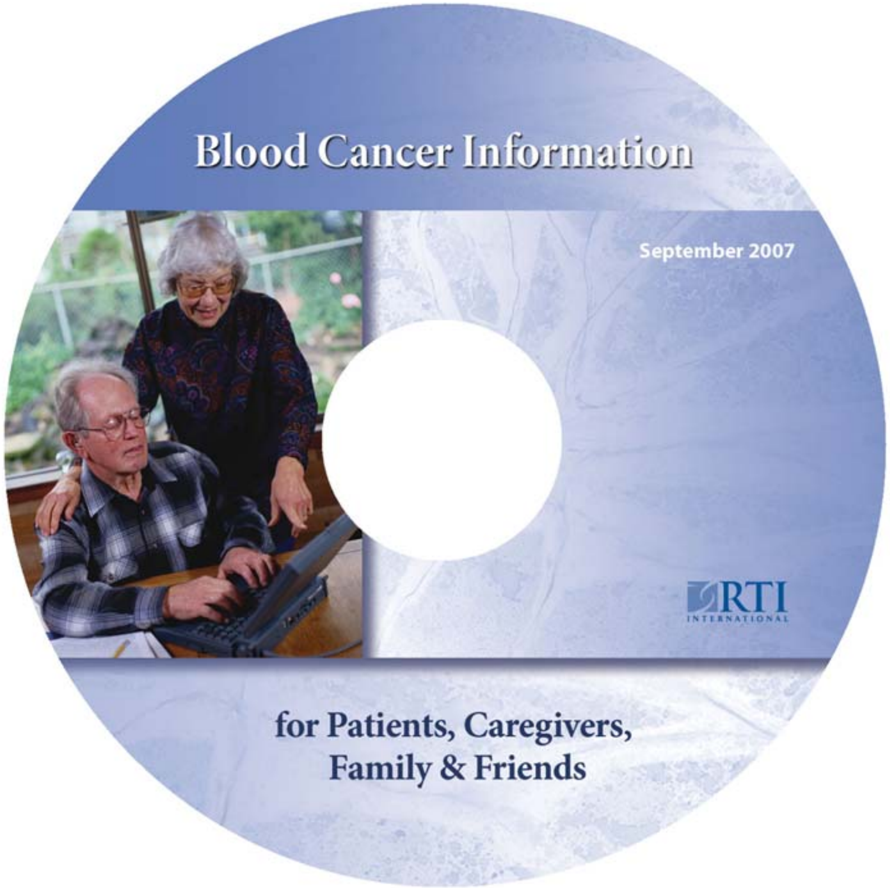
Readability and Tone

- Average 8th grade reading level (Flesch-Kincaid)
- Low literacy structure — Few medical terms, low density, basic reasoning, no statistics
- Segmented materials into sections
- Created glossary to enhance readability
- Positive tone ("Loved one" vs. "Cancer patient") without dodging tough issues

Toolkit Development

Format and Accessibility

- Self-navigated, CD-ROM toolkit
- Used simple HTML software
- Materials in PDF format — can be printed or saved to computer



Toolkit Development

Blood Cancer Information
for Patients, Caregivers, Family and Friends

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RELATED LINKS

GLOSSARY

PATIENTS

- Acute Lymphocytic Leukemia
- Acute Myeloid Leukemia
- Chronic Lymphocytic Leukemia
- Chronic Myeloid Leukemia
- Hodgkin Lymphoma (Hodgkin disease)
- Non-Hodgkin Lymphoma
- Multiple Myeloma
- Coping with Side-effects
- Life Post-Treatment (including Recurrence Tests

CAREGIVERS

- Treatment Options for Blood Cancers: Facts for Caregivers
- Coping with Cancer Treatment: Facts for Caregivers
- Help with Money and Health Insurance for Cancer Caregivers
- Life After Cancer Treatment: Everyday Activities, Long-term Side Effects, and Follow-up Doctor Visits
- Long-term Side Effects of Cancer Treatment: Facts for Caregivers

FAMILY and FRIENDS

- How You Can Help Cancer Caregivers
- Dealing with Strong Feelings that Come with Cancer
- Cancer Support Groups
- Finding a Hospital or Clinic for Blood Cancer Treatment
- Treatment Options for Cancer
- New Ways to Fight Cancer: New Treatments for Blood Cancer
- Coping with Blood Cancer Treatment: Facts for Family and Friends
- Help with Money and Health Insurance

Materials Testing

- One-on-one 60 minute interviews (n=99)
- Tested materials (content, topics, readability) and toolkit interface (navigation, graphics, links)
- Interviewed patients, caregivers, and family/friends in six sites:
  - Indianapolis, IN
  - Los Angeles, CA
  - Miami, FL
  - Peoria, IL
  - Phoenix, AZ
  - Raleigh-Durham, NC

Findings — Content

- Most individuals (81%) very satisfied with materials and topics available
- Suggested additional topics and issues:
  - End-of-life planning
  - Talking to family about cancer
  - Depression
  - Prognosis, remission, and relapse
- Crossover in role and cancer interests

Findings — Readability and Tone

- Found materials highly readable and easy-to-understand (84%)
- Patients more comfortable with clinical terms than caregivers or family/friends
- Some words still difficult (CT scans, kinase inhibitor)
- Most participants happy with tone, but some desired more optimistic approach

"Change the tone to be more positive and healing. Hope is the main thing you need."

Findings — Access and Navigation

- CD-ROM format is accessible (84% own computers, 87% use Internet)
- Little difficulty navigating menu or materials
- Mixed feedback on toolkit menu
  - Liked role distinction and seeing all topics
  - Menu crowded, topic titles too long
- High satisfaction and use of links to additional resources

Next Steps

- Provide toolkits to cancer information and support organizations
- National evaluation of fully-equipped toolkit (online and telephone survey)
  - Feedback on materials and accessibility
  - Toolkit sources and uses
  - Differences by geography, SES, race, etc.

Acknowledgements

- CDC Division of Cancer Prevention and Control (www.cdc.gov/cancer)
- American Cancer Society (www.cancer.org)
- The Wellness Community (www.thewellnesscommunity.org)

Blood Cancer Information Toolkit

http://bloodcancerinfo.rti.org