Strategies and Policies for Health Care Organizations to Address the Needs of Patients and Families with Low Health Literacy

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Some highlights from yesterday

Session 1
Current health literacy demand of cancer communication across the continuum is suboptimal

Session 2
Literacy- appropriate cancer communication approaches exist and training should be widely disseminated

Session 3
• **Sylvia Chou**: Cancer misinformation is prevalent- need to build the evidence base
• **Lisa Fitzpatrick**: Communication chasm between public and scientists re: cancer
• **Ivan Oransky and James Hamblin**: scientists have a role to play in improving science journalism and lay understanding.

Session 4
**April Oh**: NCI Priorities: Reduce communication inequalities, multi-level interventions, participatory methods, dissemination and implementation science including iteration and context sensitivity
**Galen Joseph**: Lessons from health literacy research broadly can be applied to cancer communication
Health Literacy and Healthcare Organizations

A Health Literate Organization:

1) Leadership makes health literacy integral to its mission, structure, and operations
2) Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement
3) Prepares the workforce to be health literate and monitors progress
4) Includes populations served in the design, implementation, and evaluation of health information and services
5) Meets needs of populations with a range of health literacy skills while avoiding stigmatization
6) Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact
7) Provides easy access to health information and services and navigation assistance
8) Designs and distributes print, audiovisual, and social media content that is easy to understand and act on
9) Addresses health literacy in high-risk situations, including care transitions and communications about medicines
10) Communicates clearly what health plans cover and what individuals will have to pay for services
Background in Health Literacy/Language and Cancer

Cancer Care Continuum

Prevention

- HL and cancer related knowledge are significant predictors for preventive behaviors.
- Using plain language, teach-back method, simple typography and design are strategies to address HL barriers.

Detection

- Low HL is associated with poor cancer screening uptake
- Higher HL is associated with more screening knowledge.
- Employing effective communication strategies can facilitate informed decision making.

Diagnosis

- Studies did highlight important considerations in the definition and measurement of health literacy
- Low HL significantly associated with higher levels of fear of progression

Treatment

- Patients with low HL are at a disadvantage in having their information needs met
- Higher HL is associated with higher quality of life

Survivorship

- Survivors want to advance healthcare literacy to share ownership in treatment and management decisions
- the need for information and education on the transition between "active treatment" and "survivorship"

End-of-Life Care

- Online palliative care and oncology patient resources found zero articles written below a seventh grade reading level
EXAMPLES OF END-OF-TREATMENT CONSULTATION NOTES

Example of an End-of-Treatment Consultation Note:
Breast Cancer

Date of note: April 12, 2005
Name: Jane Doe Age: 39
Date of tissue diagnosis of cancer: August 4, 2004

Diagnosis: Breast cancer
Stage of cancer: T1N1M0 Stage II
Pathologic findings: 1.5 cm. infiltrating ductal cancer in the left breast, moderately differentiated,
ER positive, PR negative, Her2Neu negative; 3 of 10 nodes positive for metastatic cancer

Initial treatment plan:
• Surgery: Lumpectomy and axillary dissection
• Radiation therapy: 6 weeks of radiation therapy to the left breast
• Chemotherapy: 4 cycles of AC followed by Taxol; dose-dense regimen

Treatment received (specify dates, location, and providers):
Surgery performed as planned by Dr. David Smith at Happy Valley Hospital on 8/23/04.
Chemotherapy administered by Dr. Mary Scott at Westside Oncology Center from 9/15/04 to
2/1/05. Patient received full dose as specified in published protocol Citron et al., JCO, 2003.
Case Study: Survivorship Care Plans

Problem

- Survivorship care plans (SCPs) communicate critical information needed for cancer survivors’ long-term follow-up care.
- Required for accreditation
- Unclear efficacy in practice
- Unclear usability/tailoring for diverse populations
Methods: Survivorship Care Plans

IOM Concordance

- We analyzed collected SCPs (n=16) from diverse care settings for concordance with Institute of Medicine (IOM) recommendations for SCP content, which include:
  1) a record of all care received (treatment summary)
  2) a follow-up care plan incorporating available evidence-based standards of care

- We adapted standardized methods from a study that created an evaluation tool for breast and colorectal cancer-specific SCPs by operationalizing the 18 sections of the IOM framework of recommended SCP content into a checklist of identifiable items

- We analyzed collected SCPs by coding whether they contained each component on the checklist, and then generating an overall percentage of included elements.
We used the Suitability Assessment of Materials (SAM) instrument to assess whether patients from diverse backgrounds are likely to understand, accept, and use the plans.

Validated with 172 health care providers from diverse cultures, the SAM instrument assesses patient suitability across 22 key factors, including content, literacy demand, graphics, layout and typography, learning stimulation, motivation, and cultural appropriateness.

The SAM framework provides a numerical score that may fall into one of three categories: superior (2), adequate (1), or not suitable (0).

Overall suitability of a document is assessed by adding the ratings of each factor and dividing by the total possible score to generate a percent score, which is then grouped into ratings as follows: superior (70-100%); adequate (40-69%); and not suitable (0-39%).
Example SCPs

Summary of Cancer Treatment and Follow-Up Plan

Diagnosis
Date of Diagnosis
Additional Information

Pathology
Stage

TREATMENT SUMMARY

Surgery
Surgeon
Phone

Date
Procedure

Chemotherapy/Biotherapy
Medical Oncologist
Phone

Regimen
Drug
Drug

Regimen
Drug
Drug

Regimen
Drug
Drug

St. Francis General Hospital and Trauma Center

ZSFG Breast Cancer Survivorship care plan

Primary Care Provider:
doctor de cabeza

Surgery:
Cirujano

Principal Oncologist Provider:
Oncólogo principal

Radiation Oncologist:
ocólogo de radiación

Navigator:
Navegador

Cancer Type/Location/Histology/Subtype:
tipo de cáncer / localización del cáncer

Year of diagnosis:
año de diagnóstico

Treatment Summary/Resumen del Tratamiento:

Surgical procedure/location/findings:
tipo de cirugía/localización/conclusiones

Body area treated:
área del cuerpo

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Case Study: Survivorship Care Plans

Results

- Majority of plans (n=11) incorporated less than 60% of recommended content
- The average reading grade level 14
- 1 plan received a superior rating for cultural appropriateness

<table>
<thead>
<tr>
<th>Hospital type</th>
<th>SCP</th>
<th>Reading grade level</th>
<th>Cultural appropriateness</th>
<th>Overall SAM score* (%)</th>
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<tbody>
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<td>Safety net</td>
<td>Plan 1</td>
<td>13</td>
<td>Superior</td>
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*Overall suitability using SAM: 70-100% superior; 40-69% adequate, 0-39% not suitable
Case Study: Survivorship Care Plans

Conclusions and Implications

- Suboptimal language access
- Suboptimal literacy level
- Co-design of SCPs may promote usability/usefulness
- Intent of communication with primary care and with patient in one static document may not meet survivors’ needs
Recommendations

- Re-examination of the intent of survivorship care plans
  - Consider separate vehicles for patient and primary-care-provider communication following treatment
  - Interoperability of electronic health records
  - Survivorship resources in interactive formats

- Literacy appropriate patient-facing communication in clinical oncology practice
  - Incentives for patient-provider optimal communication practices: asynchronous, literacy-appropriate, team-based

- Peer-to-peer communication across the cancer continuum
Thank you!