Qualitative Analysis of Health Literacy Needs of Rural Cancer Patients From Six UW Out-Reach Clinic

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Overview Outline

• Primary Aim
• Methods
• Preliminary Findings
• Preliminary Conclusions
Health Literacy is defined as..

The degree to which individuals have the capacity to obtain, process, and **understand** basic health information and services needed to make appropriate health decisions (Ratzan and Parker, 2000).

“**Understanding is a two-way street**”

*(Eleanor Roosevelt)*
Background

• Approx. 90 million Americans lack the necessary health literacy
• 33% rural cancer pts report low health literacy.
• More common among older, low-income, ethnic minority, and foreign-born populations
• The High Economic Cost of Low Health Literacy - Wisconsin
  – $3.4 to $7.6 billion annually. If unchanged,
  – present value cost of between $51.7 and $116.3 billion (UNC Chapel Hill and the National Bureau of Economic Research (NBER), 2009 Wisconsin Literacy Inc.)
Primary Aims

This study has two primary aims:

1. Complete an assessment of the health literacy barriers and patient navigation needs of rural cancer patients in Wisconsin.

2. Develop, evaluate and test a pilot intervention addressing the needs identified by our formative assessment.
Methods

Study Sites and Target Population

- Six (6) rural UW Carbone Cancer Center Oncology Outreach clinics.
- Breast, lung, colorectal, and prostate cancer patients

Comprehensive formative assessment

- Patient perspective (8-10 /clinic):
  - One-on-one in-depth patient interviews, phone surveys, and health literacy assessment
- Provider perspective:
  - Health Care Providers focus groups (one per clinic)
- Patient-provider communication:
  - Shadowing patient appointments

Secondary analysis of data from ACCESS⁵ (N=1,841)
Methods

Approach

• Grounded Theory
• Qualitative content analysis of the information gathered through the Patient interviews and focus groups with Clinic staff
• Data organized in Nvivo 9
Themes

• Opinion of Clinic and Care
• Communication
• Written Materials
• Symptoms and Side-effects
• Medications
• Barriers - Challenges
• Support Services
Opinion of Clinic and Care Provided

• Close to home, less travel time
• no big city chaos, “Homey” Family oriented, less likely to get lost
• Courteous staff, “We are not just numbers here” Patient quote
• Trust Doctors – “they are doing all they can, so got to live with the illness, the way it is” Pt. quote.

Issues:
• Radiation facility not available
• Lack of privacy and treatment areas, long waits for Chemo.
• Lack of communication b/w PCP & Oncologist
• Lack of coordination with other facilities
• Inadequate dealing of non-oncology staff eg. PORT
Communication

Clinic staff
• Very friendly and remember their names, help in setting appointments etc

Nurses
• Accommodating, explain procedures,
• Available – provide cell no. for contacting after office hrs,
• Call home to check after chemo – need to happen regularly

Doctors
• Fond of Doctors. (explain/encourage questions)
• Some Doctors. rush through info quickly
• Consider empathy and good bedside manners as important factors in selecting treatment site/individuals
• Pts desire to be part of decision making, “talk to you not at you”,

Written Material

Consent Forms
• Most skim thru and rely on explanations by Doctors and Nurses
  “They are pretty easy you know and if you do have trouble you just got to ask on one of
  the nurses you know, I have signed a lot of papers without reading. I just don’t read, I hate
  reading and that’s all I sign anything., I figure they ain’t gonna give me nothing to sign if
  it’s bad”. Patient. quote.
• “sign or no treatment”
• Too sick
• Scared of the legal language
• Caregivers often read and interpret for patients

Health history forms
• Could be simpler with less jargons
• Duplication of efforts (lack of centralized electronic system)
• Feel burdened, recall/memory issues

• Lack written Treatment Plans – verbal, calendars serve as plans
Cancer Related Information

- Varies by Cancer types
- Like the Binder and Folders of information
- Overwhelmed by too much info at the time of diagnosis – Stage specific
- Lack of information on diet, nutrition, clinical trials
- Some read the material (knowledge is power) others more depressed or sick
- Some leave unread info in “piles and corners” or throw it in the garbage.

  “Reading materials are not helpful. It would have to be really interested or something. Its just me as I said I just don’t look at the stuff..yeah and it’s ready to go to the garbage”. Pt. quote.

- Less to do with literacy than their attitude towards the illness (psychology), denial about the cancer, “We will cross that bridge when we reach”, “I am living it now, I don’t need to read about it” Pt. quote.
- Caregivers read materials and explain it to the Pts. , tailor-made.
Symptoms & Side Effects

- Sometimes not informed of some of the side effects and severity
- Many feel long-term impact not discussed enough
- Associated emotional trauma/depression not addressed adequately

Managing Symptoms

- Most cases staff encourage to call to help with acuteness eg. Nausea.
- Sometimes they don’t want to bother staff or family
- Emergency room experiences and waiting in lines.
- Rural attitudes – independence, Self sufficiency, hopelessness, Stoic,

“I am sick I will just deal with it” Pt. quote.
Medication

• “Like my pain medicine. They (clinic staff) just say take one per day for pain, you know. There are a lot of my pills they just say take one per day, for what? So I have to remember which these pills are because I have like four or five of them that I don’t know what But there are some new ones I have to think for a few second, that you know, what is this for? I have like 20 bottles of pills and only three of them (pill bottles) tell what it is for and then the rest I have to sit there and you know try to remember.” Patient quote.

• Medication confusion a huge issue
• Confusions about generic vs. brand name (same meds different names)
• Patients devise innovations, bold letters, color coding, turning the bottle over.
Barriers

Insurance/Financial

• Pre authorizations, lack of details about coverage
• High premiums, and co-pays
• Tons of paper work (insurance and clinic billing)
• Family support required in fulfilling requirements for resources
  “Wife applied for grant, got rejected, reapplied twice and accepted the third time” Patient. quote.
• Some meds are expensive and not covered – samples required

Transportation

• Travel to Madison for radiation is cumbersome,
• Weather, winter travel is an issue
• Pts often are sick and cannot drive need person/transport
Other Challenges

Family
• Are not able to attend to their roles as parents, husbands, wives etc.
• Spouse working hard to handle all responsibilities including household chores
• Caregivers taking time off work, traveling distances
• Care-givers instead of being taken care of

Work related
• Sickness makes them weak and cannot continue
• Some have supportive work environment (flexible, part-time)

Emotional Toll
• Depressed
• Worried about involving their children as this would disrupt their routine lives
• Loosing hair – facing the gaze
• Preparing for death!! Uncertainties about finances and support for their spouses
• Feel devastated in explaining the situation to their grand kids,
Support Services

- Family and friends
- Church groups
- Support groups
- Other resources
  (Breast Health Care, Grace and Friends)
- Social worker
- Religion/spirituality
- Patients supporting other Pts.
Preliminary Conclusion

Clinic Environment
• Promote more Pt. interaction
• More rooms or spaces for Chemo pts

Staff
• More availability esp. Oncologists
• Teach back methods

Written material
• Cancer type and stage specific
• Easy to understand /less jargon and technical language
• Diagrams are good for understanding

Support services
• Buddy/one-to-one approach
• Sharing experiences of other patients
• Patient advocate or social worker (familiar face) required from the beginning of their care
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Demographics

Gender:
Male: 35.8%
Female: 60.4%
Formative Assessment to Intervention

Health Literacy

- Health literacy friendly medical environment
- Self-management and empowerment
- Access to coordinated cancer care
- Links to non-medical community resources

Improve the health literacy environment
Customize health information for low literacy patients
Develop a health literacy curriculum
Train clinic staff to recognize low literacy needs
Coordinate care and create linkages to non-medical care
METHODS: INTERVENTION IMPLEMENTATION AND TESTING

• Quasi-experimental design:
  – Stratified random assignment of clinics to intervention or control condition
  – 150 newly diagnosed cancer patients (breast, lung, colorectal, and prostate):
    • 75 from intervention and 75 from control sites
    • Recruitment quotas by clinic and cancer site to achieve balanced samples
  – Health literacy intervention implemented over a 12-month period
  – Baseline and 6-month follow-up assessment
  – Main outcomes: health literacy barriers, treatments received, symptom management, unexpected side effects, shared-decision making, and patient satisfaction.
Expected Outcomes

• In Wisconsin, 25-50% of cancer patients with low health literacy also report poor physical, functional, and emotional well-being\textsuperscript{5}.

• We expect that our intervention will:
  • Improve patient satisfaction with care
  • Result in fewer unnecessary side effects
  • Facilitate faster time to treatment
  • Enhance the quality of life among rural cancer patients.

• Products of this study include:
  • A working task force on rural health literacy
  • An understanding of the effect of a health literacy-focused intervention on the quality of cancer care
  • Strategies & skills to empower cancer patients with low health literacy