Identifying Health Literacy Barriers, Patient Navigation Needs, & Community Resources Among Rural Cancer Patients

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

2. Develop and evaluate an **intervention** addressing the needs identified by our formative assessment
Definitions

• Health Literacy
  o “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)

• Cancer patient navigation
  o Intervention addressing barriers to quality care by providing individualized assistance to patients, survivors, and families (NCI, 2009)
Background

- 80 million (36%) Americans have limited health literacy (Kutner et al., 2006)

- Low HL is associated with increased mortality, underutilization of preventive services (e.g. mammography), increased hospitalizations, use of emergency services (Berkman, 2011; Davis, 2002)

- Emotional toll of cancer may hinder recall, understanding of treatment (Davis, 2002)

- Rural cancer patients experience more health literacy barriers than patients in more urbanized areas (Halverson, 2012)
## Methods & Sample

### Patients
- Patient interviews (N=53) & phone surveys (N=51)
- STOFHLA (N=44), Vital Signs (N=30)
- 60% female
- Mean age=62
- 49% at least high school graduate
- 45% breast, 22% lung, 24% CRC, 6% prostate cancers

### Clinic Staff
- Focus groups (6) & interviews with staff (N=45)
- Self-administered communication assessments (N=45)
- Shadowing of appointments (N=34)
- 91% female
- 52% nurses
Findings via the Chronic Care Model:

Community
- Culture
- Resources, Policies

Healthcare Organization
- Self-management Support
- Delivery System Design
- Decision Support
- Clinical Info Systems

Productive interactions
- Informed, Empowered Patients
- Prepared, proactive practice teams
Culture, Community Resources, & Support

- Rural culture & values
  - Stoic, pragmatic, independent, self-reliant
  - Ability to work
  - Neighborliness
  - “Suffering in silence”

I try to approach the topic right away so that [...] I'm not going to find out three treatments down the road that they really couldn't buy their own food.” (Staff)

- High patient satisfaction with care
- Ad hoc referral to community resources
Healthcare Organization

- 6 clinics do not have oncologists as permanent staff, University of WI-Madison provides outreach
- Do have ONC nurses, infusion, chemotherapy
- Do not have radiation services
- Reactive rather than proactive
- Human resource allocation
Self-management support

• Shared decision-making & patient-provider communication
  o “She was rattling off all these things that I needed to do…and my brain just shuts off. It was overload.” (Patient)

• Caregivers consumers of written materials

• Reluctance to call clinic when experiencing side effects

• Navigating health insurance, financial barriers
Health Literacy

**STOFHLA (%)**

- **Adequate**: 43%
- **Marginal**: 49%
- **Inadequate**: 4%
- **Unknown**: 4%

**Vital Signs (%)**

- **Possibly Limited**: 11%
- **Adequate**: 45%
- **Unknown**: 44%

**Patient Survey (%)**

- **Sometimes has trouble understanding tests, x-rays**: 28.00%
- **Has signed a form without reading it**: 53.00%
- **Sometimes has trouble filling out medical forms**: 26.00%

“I have signed a lot of papers without reading. I figure they’re not going to give me nothing to sign if it’s bad.” (Patient)
Medications

• Fear of overmedication, particularly pain meds

“I have 20 bottles of pills and only 3 of them tell what it is for and then the rest I have to sit there and...try to remember”

• According to staff, mistakes or confusion with medications are patients’ greatest clinical health literacy problem
Delivery System Design

• Fragmented care coordination
  - Burden of recounting labs, medications, making & tracking appointments on patient

• Patient support
  - Staff (nurses) go above and beyond their duties to care for patients
    - Addressing non-medical needs
    - Non-medical needs disrupt treatment plans
Decision Support & Clinical Information Systems

- Patients burdened with keeping track of medical records, results of tests, labs

- Patients unsure of their treatment progress, lack of written treatment plan

- Receiving care in multiple sites (surgery, radiation), lack of coordinated record sharing
In Conclusion

• Identified multiple areas for PN intervention(s)
  o Build on clinic strengths

• HL practices and PN services as vehicles to empower patients and have proactive practices
  o Cancer is complex
  o Beneficial for all patients regardless of SES level

• Interventions *must* be tailored to cultural values, beliefs

• Routine, systematic assessment of non-medical needs

• Improve quality of life and management of health during cancer treatment
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References


