

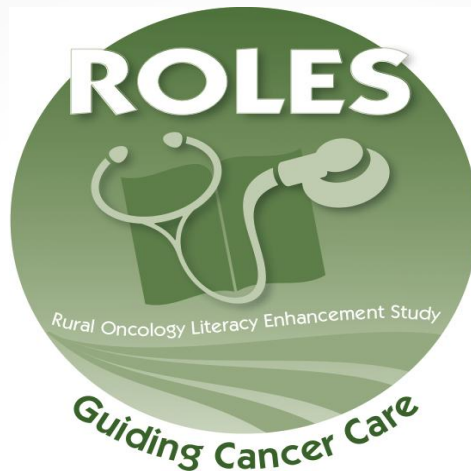
Identifying Health Literacy Barriers, Patient  
Navigation Needs, & Community Resources Among  
Rural Cancer Patients

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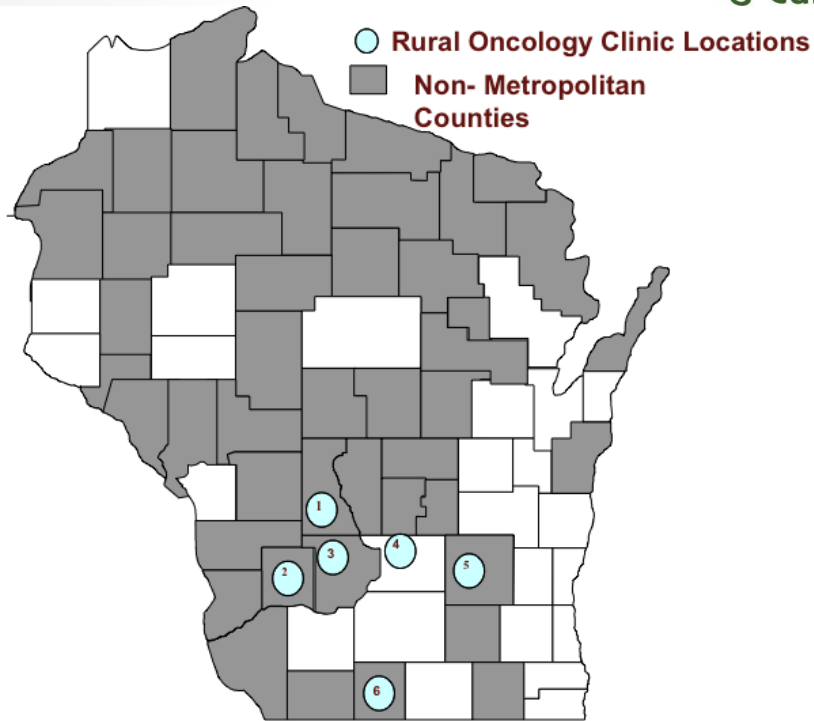
Monday October 29, 2012

APHA Annual Meeting, San Francisco, CA

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## Study Sites



## Study Aims

1. Complete an assessment of the health literacy barriers and patient navigation needs of rural cancer patients in Wisconsin
2. Develop and evaluate a pilot intervention addressing the needs identified by our formative assessment

# Definitions

- Health Literacy
  - “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
  - 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

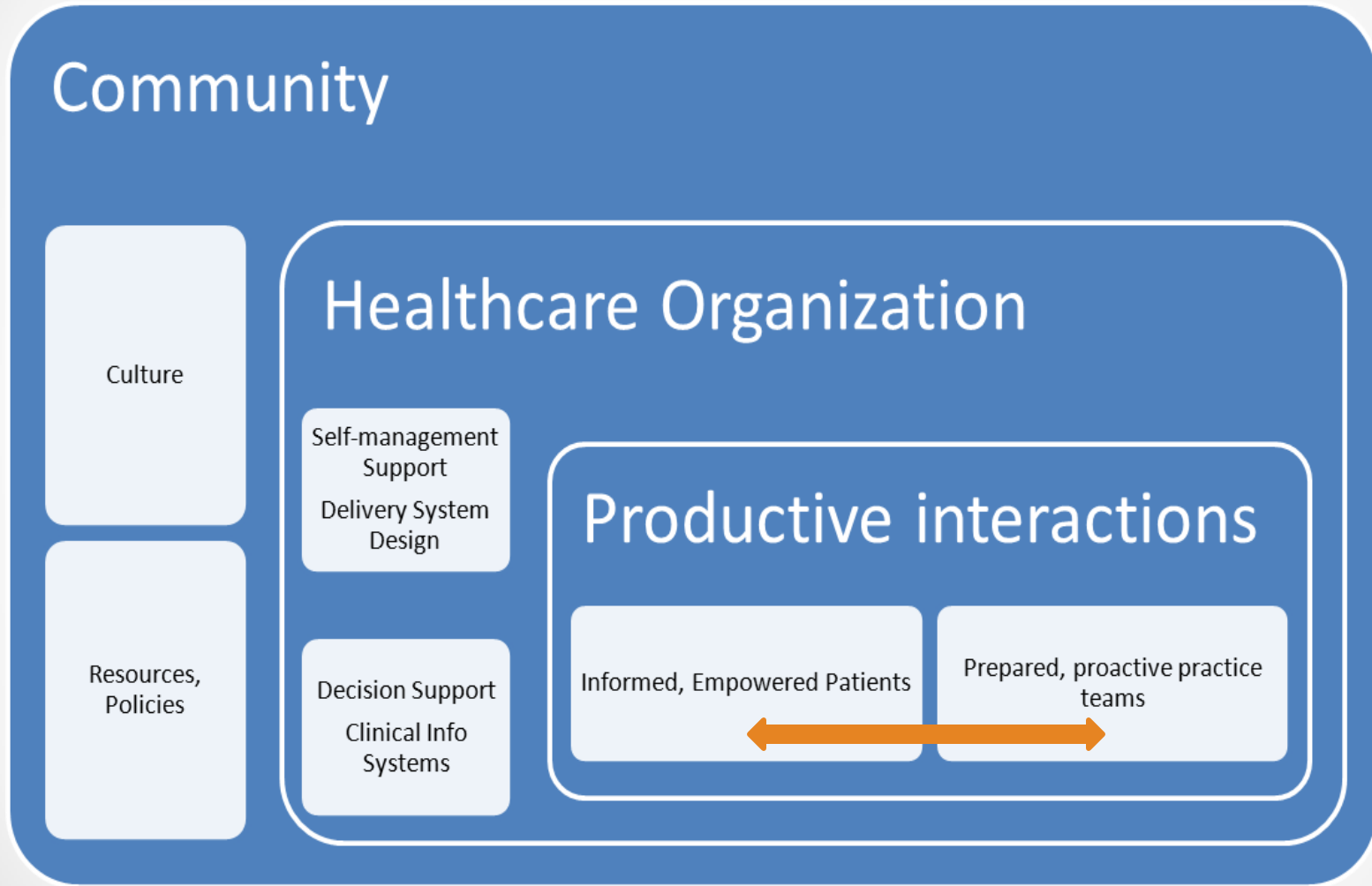
## Patients

- 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:



# 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

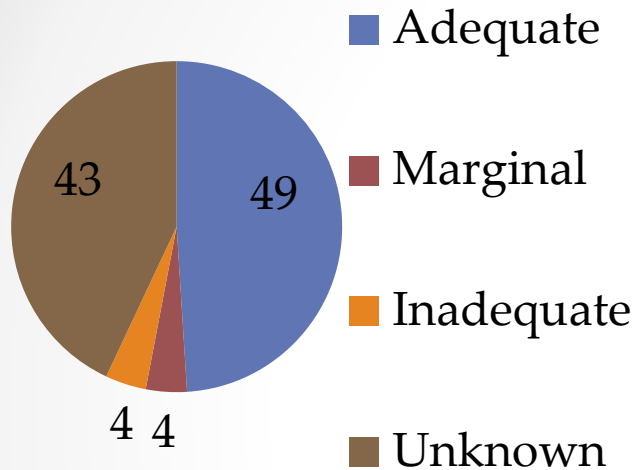


# Self-management support

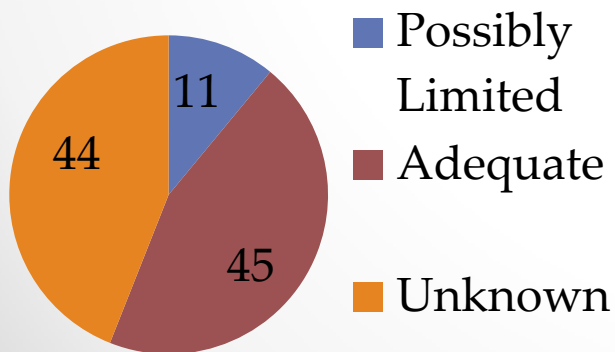
- Shared decision-making & patient-provider communication
  - *“She was rattling off all these things that I needed to do...and my brain just shuts off. It was overload.” (Patient)*
- Caregivers consumers of written materials
- Reluctance to call clinic when experiencing side effects
- Navigating health insurance, financial barriers

# Health Literacy

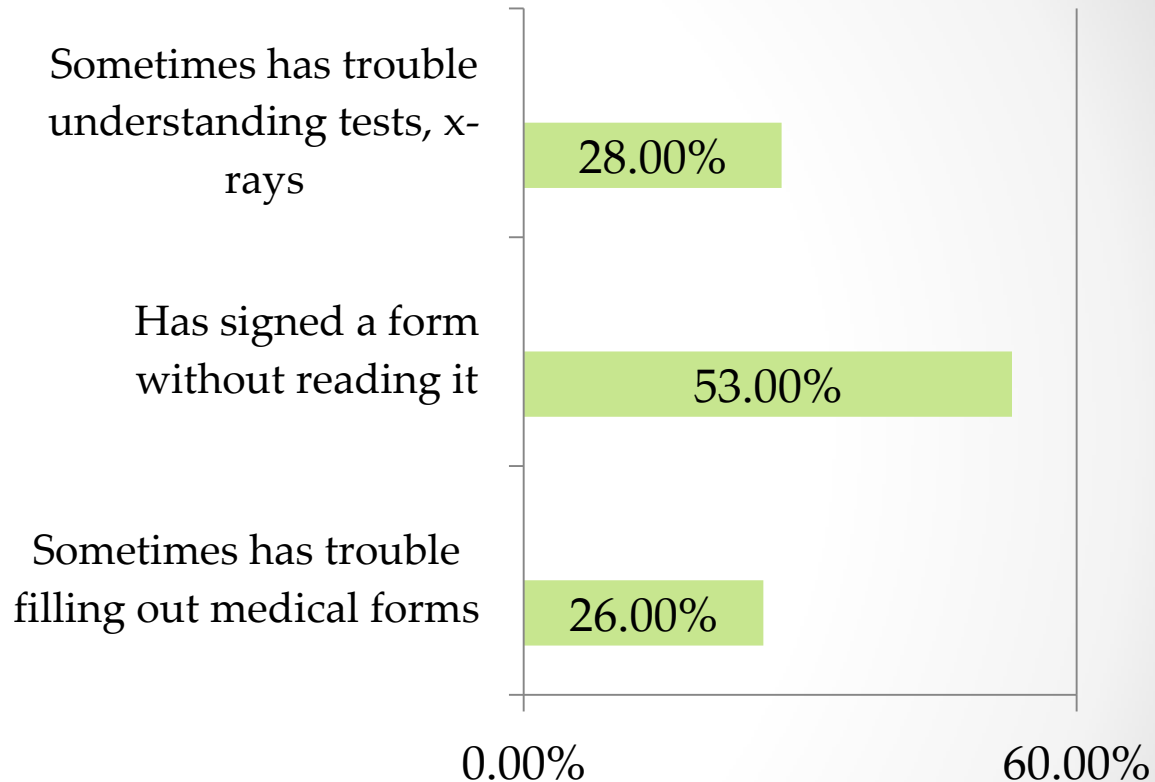
## STOFHLA (%)



## Vital Signs (%)



## Patient Survey (%)



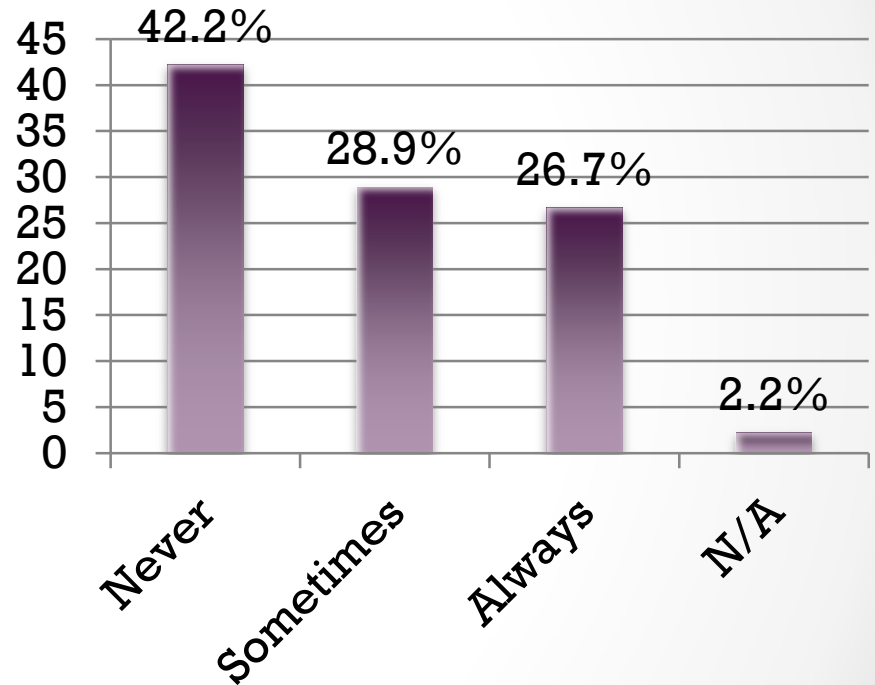
*"I have signed a lot of papers without reading. I figure they're not going to give me nothing to sign if it's bad." (Patient)*

# 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”*

“How Often Does Cancer Staff Ask You To Repeat How You Are Going to Take Your Meds?”



- 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)
  - Build on clinic strengths
- HL practices and PN services as vehicles to empower patients and have proactive practices
  - Cancer is complex
  - 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

# Acknowledgments

- This study was funded by the UW School of Medicine and Public Health, Wisconsin Partnership Fund
- Beaver Dam Community Hospital, The Richland Hospital, Mile Bluff Hospital, Divine Savior Hospital, Monroe Clinic, & Reedsburg Area Medical Center
- ROLES Team: Ana Martinez-Donate, Jeanne Schaaf Strickland, Alyssa Levy, Norma-Jean Simon, Ticiana Leal, William Schelman, Xinyi Wang, Aaliya Bibi, Rebecca Linskens, & Paul D. Smith.

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