Patient Engagement in Primary Care

Presented By:
Manasi A. Tirodkar, Ph.D., M.S.; Laurene Tumiel-Berhalter, Ph.D.;
Rebecca Malouin, Ph.D., M.P.H., M.S.

Moderated By:
Rebecca Roper, MS, MPH, Director, Practice-Based Research Network Initiative,
Agency for Healthcare Research and Quality

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June 4, 2014
Polling Question:
Learning Group Topics
Agenda

• Welcome and introductions
• Presentations
  ► Brief Q&A session following each presentation
• Q&A session with all presenters
• Instructions for obtaining CME credits

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Today’s Presenters

Patient Engagement in Medical Homes

Manasi Tirodkar, PhD, MS
Research Scientist
National Committee for Quality Assurance
The Patient Voices Network:
Engaging Patients in Primary Care

Laurene Tumiel-Berhalter,
Ph.D., Director of
Community Translational Research, Department of
Family Medicine, SUNY University at Buffalo
Today’s Presenters

Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnerships in the Medical Home

Rebecca Malouin, Ph.D., M.P.H., M.S., Associate Chair for Research and Assistant Professor, Department of Family Medicine and Department of Pediatrics and Human Development, Michigan State University

Co-Director, Great Lakes Research Into Practice Network (GRIN PBRN)
Patient Engagement in Primary Care

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Patient Engagement in Medical Homes

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Research Scientist
National Committee for Quality Assurance
Patient Engagement in Medical Homes

Manasi A Tirodkar, PhD MS
Research Scientist
Objectives

• Overview of patient engagement
• Shared Decision-making in Oncology
Framework for Patient/Family Engagement in the Patient-Centered Medical Home  
(Scholle et al, 2010)

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<td>• Partnering with health care team</td>
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<td>• Coordinating care</td>
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<td>Engage patients and families in practice</td>
<td>• Formal participation in teams/councils</td>
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<td>• Formal feedback through surveys</td>
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<td>• Informal feedback</td>
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<td>Engage patients and families in policy</td>
<td>• Engagement in design and implementation</td>
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Logic Model for Conceptualizing the Impact of Patient Engagement
(Adapted From Epstein and Street, 2008)

- **Patient/Family Engagement Strategies**
  - Individual’s care
  - Practice improvement
  - Policy

- Informed, actively involved, participating patient and family
- Accessible, well-organized, responsive health care system
- Patient- and family-centered, communicative team

- Costs of care
- Health outcomes
- Patient experiences
Shared Decision-making in Oncology

- **Case Studies**
  - 3 academic centers, 1 private practice, 2 large medical groups
  - 3 prostate, 2 breast, 1 both

- **Focus groups with patients**
  - 4 groups with prostate cancer patients at 1 site
  - 5 groups with breast cancer across 2 sites
Shared Decision-Making Process

- Identify patients to receive support
- Provide information
- Patient and provider have a conversation about the decision
- Follow-up and support from team including documentation of patient preferences in the medical record

Roles shared among clinicians/staff
Three key themes from patients

- Information
- Emotional support
- Logistical support
Information

• Multi-disciplinary approach is sometimes helpful
  - helpful to understand all the options
  - “Every specialty tries to sell what they do”

• Not sure what information to trust
  - Some view internet as very useful, others don’t
  - Scientific information is sometimes helpful and sometimes felt like cold, hard numbers

• “I didn’t feel like I had a choice”
  - Lack of clarity on what the options are
Emotional/psychosocial support

- **Empathy is important**
  - being “shot through a cannon” in a frenzied rush from diagnosis to surgery

- **Stress management**
  - Shock at diagnosis
  - “there is cancer in me, get it out”

- **Confidence in decision**
  - “I’m not always comfortable with being responsible for my decision, sometimes I want a recommendation”
Logistical

• **Help preparing for consultation**
  - To explain information and answer questions
  - To help develop questions for the provider

• **Care team matters**
  - An abrupt nurse or a tech who did not “connect” was very upsetting, even days and months later.

• **Second opinions**
  - “see the best” - high volume of patients treated is important to men
  - can be double-edged, especially if they did not match the first
Facilitators and Barriers

- Culture change is an essential element
- Focusing on one condition
- Physician support of SDM model

- Lack of sustainable funding
- Resistance from providers
- Lack of standard metrics to measure outcomes and patient satisfaction
Measurement opportunities

• Was the patient given a decision aid or information?
• Did the patient review the information?
• Reasons and factors that influence the patient’s decision (values, preferences)
• The patient’s final decision on type or course of treatment
Conclusions

• In specialty settings with sustained SDM, the focus is the conversation not the information

• Patients want to develop a relationship with the provider which includes emotional support and information

• Sustainability challenges remain

• Measurement is still in its infancy
Implications for Medical Homes

- SDM process works well for a specific decision that needs to be made.
- However, the principles of developing a relationship, giving good information, and providing a supportive team can be applied across the care spectrum.
- Documentation and measurement are important to gain external support.
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The Patient Voices Network: Engaging Patients in Primary Care

Laurene Tumiel-Berhalter, Ph.D., Director of Community Translational Research, Department of Family Medicine, SUNY University at Buffalo
The Patient Voices Network:
Engaging Patients in Primary Care

Laurene Tumiel-Berhalter, PhD
Megan Wilson, Sarah Reilly, MPH
The Patient Voices Network

Office of Community Translational Research
Department of Family Medicine
University at Buffalo
Patient Voices Network

• A partnership between providers, patients, and the University at Buffalo’s Department of Family Medicine

• Participating practices have **Patient Action Teams** that meet on a regular basis

• **Patient Action Team**: a group of patients who provide feedback to the practices and partner with UB in practice based research projects

“A community of educated and involved patients working hand in hand with physicians in making decisions about their own health care”
Patient Voices Network

**The Practices**
- Current PAT sites belong to UNYNET
- Safety net sites in low-income, urban communities in Buffalo, NY
- 3 sites established in 2010
- 1 new site added in 2014

**The Patients**
- Mostly African American, low-income, female, 40 and above
- Most have multiple chronic diseases
- Steering Committee of 4 patients vets activities, establishes Network policies
Examples from Patient Voices: Practice Improvement

Increasing Mammography in Primary Care

- Patient Ambassadors have many roles
  - Making phone calls
  - Scheduling
  - Day of Screening: Providing support, checking patients in
  - Compiling information packets
Examples from Patient Voices: Research

• Developed colorectal cancer intervention
• Helped write grants
• Develop materials (Patient Action Plan)
• Practice feedback survey
• Developing chronic disease self management survey
• Prostate cancer focus groups
Examples from Patient Voices: Residency Training

• “I will be more respectful and patient during encounters. As stated by the patients themselves, respect is very important to them.”

• “I learned to always stop and get to know your patients as a person rather than just a “disease.”

• “The importance in taking the time to listen to the patient’s concerns and to ask what the patient thinks about their options”
Community

- Concerned about you: Breast Cancer Awareness Walk
- Tabling events
- Community Outreach
- Community Education
Helping hands

- Prepare educational materials for diabetes education program
- Prepare educational materials for mammography project
- Prepare materials for Mammography walk
Summary: Key Elements of Patient Engagement

• Time
• Commitment
• Relationship building
• Recognizing patients’ contributions
• One size does not fit all
• Meeting them where they are
• Recognize patients want to help
Acknowledgements

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  - NYSTAR
  - NIMHD R24MD004936
  - WNY Affiliate of Susan G. Komen
Questions
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Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnerships in the Medical Home

Rebecca Malouin, Ph.D., M.P.H., M.S.,
Associate Chair for Research and Assistant Professor, Department of Family Medicine and Department of Pediatrics and Human Development, Michigan State University

Co-Director, Great Lakes Research Into Practice Network (GRIN PBRN)
Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnerships in the Pediatric Medical Home

Rebecca A. Malouin, PhD, MPH, MS
Defining Family-Centered Care (FCC)

- Assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high-quality service.
Rationale for Monograph

- National and state initiatives promote family centered-care as a key component of primary care within the medical home.

- Yet, large proportions of families, particularly families of children with special healthcare needs, continue to report an absence of family-centered care.

- What are best practices, such as structures and processes within practices, that promote patient- and family-centered care?
Funding

- Supported and published by the American Academy of Pediatrics and the National Center for Medical Home Implementation (NCMHI)

- Possible through a cooperative agreement (U43MC09134) with the US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau
The Team

- Consultant and Lead Author
  - Rebecca Malouin, PhD, MPH, (Michigan State University)

- Advisory Committee
  - Michelle Esquivel (AAP, National Center for Medical Home Implementation)
  - Barbara Kahl (Institute for Patient and Family Centered Care)
  - Joanna Kaufman (Institute for Patient and Family Centered Care)
  - Marie Mann (Maternal and Child Health Bureau, HRSA)
  - Lee Partridge (National Partnership for Women and Children)
  - Nora Wells (Family Voices, National Center for Parent/Professional Partnerships)
Methods

- Practice nominations solicited through several national AAP and HRSA/MCHB list-serves
- Nominations reviewed using specific selection criteria by advisory committee
- Selected practices invited for a 30-60 minute key informant interview by “most knowledgeable” practice representative
- Practices then invited to propose a family to participate in 30-60 minute interview
Interview Domains

- Patient- and family-centered practice
  - Partnering with families
  - Roles of families
  - Structures and processes to support patient- and family-centered practice
  - Resources to support family-centered practice

- Outcomes of patient- and family-centered care
  - Challenges
  - Benefits
  - Feedback from families

- Dissemination or shared learning with other practices
Results

- Advisory committee reviewed 29 nominations
- Seventeen practices invited for interviews
- Eleven families participated in interviews
- All interviews conducted in fall 2011
Practices

- Practices represented a range of geographic locations (although many in the Midwest), practice types, sizes, and insurance mix.

- The majority reported use of information technology, most commonly electronic health records.

- The majority reported some form of medical home recognition.
Most Common Tools (n=17)

- Patient/family experience periodic survey (16)
- Translation/interpreter service (16)
- Participation in learning collaboratives (15)
- Family advisory board or consultant (15)
- Resource list or library (15)
- Extended on-call hours (15)
- Triage and longer visits for CSHCN (15)
- Mission statement embodies principles of family-centered care (14)
- Regular forum for discussing quality improvement among staff and families (14)
- Care coordination and follow-up (14)
- Extended hours (14)
- Written care plans (14)
- Patient registries (14)
Example of a Structure: Care Plan

- The care plan has given organization and structure to visits.

- By imposing the structure of the care plan document on addressing aspects of the child’s health, it not only facilitates a systematic, disciplined approach to care in the clinical setting, but in the management of care at home, which ultimately reduces and in many cases eliminates the need for emergent care.

- Includes information such as primary language, religion, spiritual or cultural preferences, a detailed medical history, referral contact numbers for medical, community, and school care providers, medications, immunizations, equipment needs, and a section for personal goals, likes and dislikes, etc. reported by the patient and/or parent.
A Family’s Perspective

- [The care plan] is a whole kind of mini reference letter into all her health issues. So when we go to the emergency I make sure I carry the care plan with me…it kind of helps put a physician and nurses at ease.
Example of a Process: Scheduling

- When a parent calls in to schedule an appointment, whether it’s for a well-child visit or a sick visit, practice staff make a deliberate effort to inquire as to what issues the parent would like to discuss with the doctor during that appointment.

- The scheduler will allot an adequate appointment length to address all of the parent’s concerns, and maintain balance in an individual provider’s schedule by alternating the appointments of patients with fewer concerns with those of more complex, potentially time-consuming cases.

- Through this simple process change, the practice can address the needs of the particular child and family, minimizing wait-times, and alerts providers and staff to any coordination efforts that may be necessary before an appointment.
When I call [for an appointment]… they know not to put us in their tiniest exam room because it’s harder when you’ve got three kids, one that’s in a wheelchair.
Key Findings

- Family professional partnerships and family voice are key elements in family-centered practice.

- Learning collaboratives help practices develop shared philosophy and to learn and test new strategies.

- Other common and emphasized processes and tools include a family-centered practice mission statement and continuous quality improvement to implement additional structures and processes important to families (improved access, coordination etc.).
Potential Policy Implications

- Funding must be allocated to increase implementation of FCC
- Learning collaborative opportunities in which family and professional teams work across settings can jump start change
- Family-to-Family Health Information Centers provide key resources for implementing FCC
- Measurement tools should focus on key processes and structures associated with family-centered care
Positioning the Family and Patient at the Center

A Guide to Family and Patient Partnership in the Medical Home

Rebecca Malouf, PhD, MPH
Department of Pediatrics and Human Development
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Michigan State University

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