

Christoph Hanssmann, MPH, CHES and  
Megan Woltring, MS

**“It Was Pretty Easy to Understand”:**  
Family and Caregiver Involvement in  
Hospital-Based Health Education  
Materials Development

October 7, 2009 Health Care Education Association Conference



Welcome

Family and Caregiver Involvement in Health Education Review

Session Overview

1. Barriers and opportunities
2. Family Review Form development
3. Working with families
4. Breakout and group discussion



---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

### Family and Caregiver Involvement in Health Education Review

At the end of this presentation, you will be able to:

1. Identify ways to involve families in health education materials development
2. Begin to incorporate family and caregiver involvement in development of education materials
3. Discuss and share strategies for effective involvement of families and caregivers



### Barriers and Opportunities

Roles of Health Education and "Families as Consultants" Program

- Family Resource Center (FRC) houses:
  - Patient and Family Education
  - Family-Centered Care Initiatives
- Roles
  - Patient and Family Education supports clinicians to develop materials through health education review
  - Family-Centered Care Initiatives: provide liaison between hospital and families/caregivers
  - Family-Centered Care coordinators maintain Families as Consultants database

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

---

## Barriers and Opportunities

### Evolution of a Process

- Former process
  - Part of our standard work
  - Several barriers to meeting expectations
- Problem assessment
  - Standard not consistently met
  - Recognized need for consistent, ongoing involvement of families
- Trying something new
  - Did not replace prior standard-- built in a safe-guard
  - Internal family review when clinician review is not possible

---

---

---

---

---

---

---

---

---

---

## Barriers and Opportunities

### Opportunities in Creating a New Process

- Chance to revisit goals of family and caregiver review
  - Validate our assumptions about what works
  - Support clinicians to maximize effectiveness of materials
  - Locate areas we may be overlooking
- Examine the ways we gather information
- How we use and communicate data to clinicians
- Utilize existing resources and support systems to build team for ongoing review
- Clinician "buy-in" as a secondary objective

---

---

---

---

---

---

---

---

---

---

## Barriers and Opportunities

### New Family Review Process

- Created a new data-gathering instrument
- Developed a policy for forming and sustaining a committee for ongoing review
- Told clinician contacts that 1 of every 10 pieces would be reviewed by family members as ongoing audit

---

---

---

---

---

---

---

---

---

---



---

---

---

---

---

---

---


---

---

---

**Family Review Form**

**Choosing a Type of Evaluation**



- Formative evaluation
  - Feedback during the planning stage to improve materials
  - Could serve as tool to improve materials (end in itself) or baseline for future process or outcome evaluation
  - Easy to accommodate qualitative data, easier to accomplish without broadly validated instrument

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---

---

---

**Family Review Form**

**Advantages and Disadvantages of Using Formative Evaluation**

- Advantages
  - Fit with limited resources of department
  - Limited expertise and experience in evaluation
  - Ability to utilize multiple types of data
- Disadvantages
  - Inability to link to outcomes
  - Not scientifically rigorous

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---

---

---

**Family Review Form**

Family Feedback Form → Family Review Form

**Former state**  
"Family Feedback Form"

**Broad purpose:**  
Marketing, education, campaigns, etc.

- Goals consistent with broad purpose
- Covers clarity, ease of reading, general visual elements, etc.

→

**Current state**  
"Family Review Form"

**Specific, focused purpose:**  
Patient and family education

- Goals consistent with health education principles
- Covers plain language, learning objectives, specific visual elements, etc.

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---

---

---

**Family Review Form**

Finding the Right Questions

- Searched literature for valid, reliable assessment instruments
- Consulted literature
- Conducted audit of resources used by other institutions
- Used formal and informal networks to solicit guidance

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---

---

---

**Family Review Form**

Finding the Right Questions



"The most important part of any evaluation is asking the right questions."

What do you want to know?  
What difference does it make?

Patient education outcomes that provide a framework for what to ask:

- Knowledge
- Behaviors
- Attitude/Beliefs
- Health status

*From Health Education: A Practical Approach by Kate Lorig*

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---

---

---

## Family Review Form

### Defining our Scope

- Focused primarily on domain of knowledge, also on attitudes/beliefs
- Developed questions that best matched components of health education review
  - Plain language
  - Length
  - Flow
  - Well-matched, instructive visual elements
  - Clarity of learning objectives
  - Family-centered care as guiding principle



Patient and Family Education

---

---

---

---

---

---

---

---

---

---

## Family Review Form

### Pretesting Review Form

- Pretesting phase– Usability survey and form pilot
  - Tested functionality “on the ground”
  - What measures worked, what did not
  - What data gathering methods worked best:
    - Paper
    - Electronic attachments
    - Web – Survey Monkey



Patient and Family Education

---

---

---

---

---

---

---

---

---

---

## Family Review Form

### Pretesting Review Form

- Questions asked in pretesting phase
    - How was your experience of completing this review?
    - Were there parts of the form that were hard to understand?
    - How long did it take you?
    - Was there anything we forgot to ask you about?
- Combined with assessment of responses to initial surveys
- Completion rate of items
  - Other factors indicating problems on survey design or question phrasing



Patient and Family Education

---

---

---

---

---

---

---

---

---

---

## Family Review Form

### Pretesting Review Form - Findings

- No major problems came up in evaluation of form
  - Received limited number back (~8)
  - Most issues focused on clarity of instructions prior to completion of form
- Issues noted by health educators
  - Qualitative portion of Family Review Form not often completed
  - Not much critical feedback included on most Family Review Forms
- Actions taken
  - Amended instructions, streamlined process of sending form
  - Will continue to look at ways to gather qualitative data

---

---

---

---

---

---

---

---

---

---

## Family Review Form

### Outcomes

- In your role in health education, what outcomes are you most interested in?
  - How do you work to achieve these outcomes?
  - What constitutes an "effective" educational piece, if your opinion?
  - What are some strategies you use to make sure that the pieces you develop, review or circulate are effective?
  - Do you think this set of strategies could be strengthened? If so, how?

---

---

---

---

---

---

---

---

---

---



---

---

---

---

---

---

---

---

---

---

## Working With Families

### Partnership: In and Out of the Hospital

- Working with existing infrastructure in the hospital
  - Family-Centered Care Initiatives—Families as Consultants
  - Helped to have set of families to draw from
- Partnering with families—Developing a policy
  - Outlines how communication with families takes place
  - Families with specific experience sometimes targeted for particular types of review
  - Health educator contact serves as main contact person
  - Hospital provides compensation for review at regular rate (\$15/hr for at-home review, \$20/hr for in-person review)

---

---

---

---

---

---

---

---

---

---

## Working With Families

### Partnership: In and Out of the Hospital

- Partnering with families, continued
  - Other forms of review and feedback possible outside of using form—focus groups, interviews, etc.
    - Instrument is intended for smaller, stand-alone pieces
    - Larger pieces require focus groups and interviews—same concept, different method

---

---

---

---

---

---

---

---

---

---

## Working With Families

### Your Institution's Approach

- If your workplace involves families or patients at any stage of educational materials development or review, where are they involved?
  - If they are not involved, what are the reasons for this? Are these made explicit?
  - What about their level of involvement makes sense to you? What doesn't make sense? Why?
  - If families' expertise could be used more effectively, what would that look like?

---

---

---

---

---

---

---

---

---

---



---

---

---

---

---

---

---

---

**Group Discussion**

**Breakout Groups**

1. What are some of the major challenges or barriers to involving families in the development or review of health education materials in your workplace?

- What is one thing that could be done to reduce or eliminate one of these barriers?

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---

**Group Discussion**

**Breakout Groups**

1. What are some of the major opportunities for involving families in the development or review of health education materials?

- How are families already involved in various processes, events or decisions in your workplace?
- What are some of the other departments, collaborating organizations, or other partners that do a lot of work with families?
- In what ways do people in your workplace already value the input, opinions and experience of families?

Seattle Children's Patient and Family Education

---

---

---

---

---

---

---

---



---

---

---

---

---

---

---

---

### Moving Forward

#### How Can we Share Resources?

- Focus on sharing knowledge and strategy
  - Recognition of multiple levels of experience and expertise in evaluation
  - Desire to generate professional networks and peer mentorship
- Putting shared knowledge into practice
  - What kind of infrastructures are available for people to tap into?
  - What kind of support can we contribute to today?
  - Do people have an interest in staying in touch, via an e-mail listserv or occasional virtual meeting?
  - What else would be helpful?

---

---

---

---

---

---

---

---



---

---

---

---

---

---

---

---

## Resources

- Doak, CC, Doak, LG, & Root, JH. (1996). *Teaching Patients With Low Literacy Skills (2<sup>nd</sup> ed)*. Philadelphia: Lippencott.
- Glanz, K., Rimer, B., National Cancer Institute. (2005) *Theory at a Glance: A Guide for Health Promotion Practice*. Washington, DC: U.S. Department of Health and Human Services
- Lorig, K. (1996) *Patient Education: A Practical Approach*. Thousand Oaks: Sage.
- National Cancer Institute. (2004) *Making Health Communication Programs Work: A Planner's Guide*. Washington, DC: U.S. Department of Health and Human Services.
- Wurzbach, ME. (2003) *Community health education and promotion: A Guide to Program Design and Evaluation (2<sup>nd</sup> ed)*. Gaithersburg, MD: Aspen Publishers.



Patient and Family Education

---

---

---

---

---

---

---

---

---

---