

Patient and Family Engagement: Emerging Evidence and Research Opportunities

HELENE MORIARTY, PHD, RN, FAAN

VILLANOVA UNIVERSITY COLLEGE OF NURSING

UNIVERSITY OF PENNSYLVANIA SCHOOL OF NURSING, NEWCOURTLAND CENTER FOR TRANSITIONS AND HEALTH

CORPORAL MICHAEL J. CRESCENZ VETERANS AFFAIRS MEDICAL CENTER



NEWCOURTLAND CENTER FOR TRANSITIONS AND HEALTH
University of Pennsylvania School of Nursing

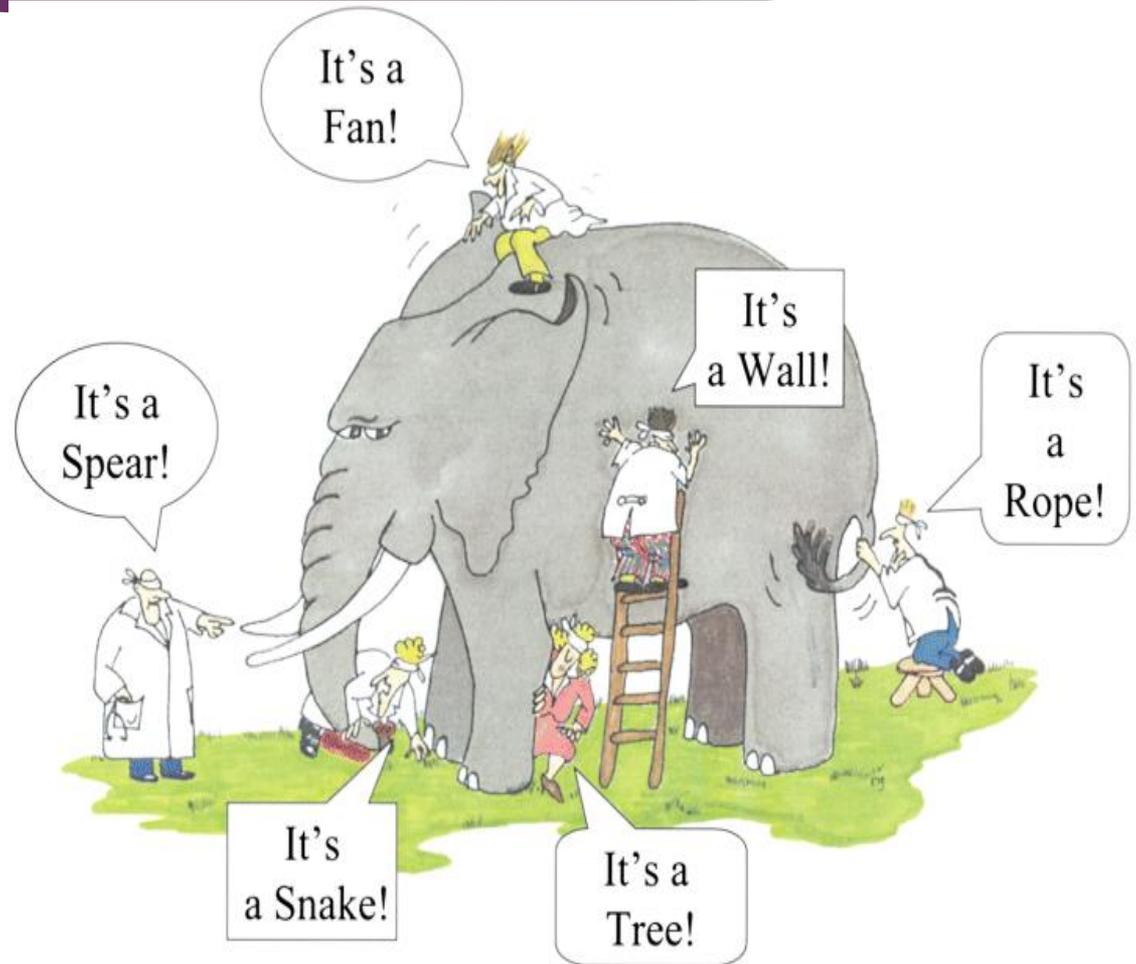


Disclaimer

- ▶ The views expressed in this presentation are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States government.

Complex issues – patient and family engagement

Multiple perspectives essential



Plan

- ▶ Provide broad overview of evidence
- ▶ Highlight evidence for engagement with two populations along life span
- ▶ Describe gaps and research opportunities
- ▶ Listen to patients' & families' voices



Growing evidence

- ▶ Patient engagement contributes to:
 - ▶ Better patient outcomes
 - ▶ Increased patient decision-making
 - ▶ Increased patient satisfaction
 - ▶ Increased patient safety
 - ▶ Lower costs
- ▶ Less evidence with family engagement

Evidence for family engagement: families with adult member with chronic physical illness

- ▶ Interventions including patient and family members
 - ▶ more efficacious than usual medical care
 - ▶ Outcomes--patients and family members with **better physical and mental health and wellbeing**
- ▶ Challenge to extend work

Example: Evaluation of the Veterans' In-home Program (VIP) for Veterans with TBI and Families

- ▶ Background
- ▶ Impact
- ▶ Family engagement is critical to rehab AND family members need support
- ▶ Few intervention studies include person with TBI and family



Moriarty, Winter, et al., Physical Medicine & Rehabilitation, in press. Funded by NIH, NICHD, 1 R21 HD068857-01.

Family engagement--be explicit re family roles and purpose!



Better outcomes for vets

- ▶ use insights & perspectives to identify TBI-related problems
- ▶ enlist support & cooperation in implementing and reinforcing intervention strategies, to maintain use and apply to new situations

Well-being of family members

- ▶ receive education about TBI generally and how TBI is affecting their loved one specifically
- ▶ receive support through provision of coping and problem-solving strategies



Patient- and family-identified target outcomes

- ▶ For person with TBI (at baseline): “What do consider the most important (or #1) problem your TBI is causing for you over the last month?” - --> then #2, #3
- ▶ For family member: similar question
 - ▶ Followed by: How hard is it to deal with or manage this problem? (on scale from 0 (not at all difficult) to 5 (extremely difficult))
 - ▶ Question at follow-up
- ▶ Benefits
 - ▶ Able to measure change in ability to manage target outcome over time
 - ▶ Guided intervention goals, increased engagement
 - ▶ Illuminated differences in pt/family rankings
 - ▶ Clinically, dialogue can → increased communication, empathy

Evidence: Engagement of older adults and their families

- ▶ Why important?
- ▶ Barriers to engagement
 - ▶ Health literacy, language
 - ▶ Cultural differences
 - ▶ Severe illness, cognitive status, behavioral health problems
 - ▶ Patients choose not to be engaged
- ▶ Facilitators of engagement
 - ▶ High patient motivation
 - ▶ Supportive family caregivers
 - ▶ Multiple contacts with HCPs

Nursing Contact and Patient Engagement in a Community Based Care Management Model for Older Adults with Chronic Illness

- ▶ **Retrospective cohort study of 1,524 participants in Health Quality Partners Medicare Care Coordination Program**
- ▶ **Patient engagement (staying in program) linked to**
 - ▶ Greater proportion of in-person (vs telephone) nursing contact
 - ▶ More contacts per year
 - ▶ More contacts in first 6 months of enrollment
 - ▶ More continuity of nurses
- ▶ **Focus groups' theme: *"We Have Somebody In Our Corner"***

"You really count as a person to her, and she's very interested in your wellbeing. She's full of good suggestions, and she doesn't um, uh, what's -- how can I put it? She doesn't put you down at all. She always lifts you up."

Challenges and research opportunities

- ▶ **Build evidence for family engagement**
 - ▶ How to engage families? (family, SOs, long distance caregivers, “hidden” caregivers)
 - ▶ Develop skills for engagement (eg, Gruman’s Engagement Behavior Framework)
 - ▶ Ways to assess and support caregivers (caregiver assessments, eg, Caregivers Count Too! Toolkit)
- ▶ **Creative methods to elicit outcomes most meaningful to pts, families**
 - ▶ Increases engagement, research more relevant, accelerates adoption
- ▶ **How to operationalize and measure patient- and family-centered care?**
- ▶ **Reimbursement models for family support, meetings**
- ▶ **HCPs need skills to engage, culture change**

Challenges and research opportunities

- ▶ **Decision-making around transitional care, home care:** when needed & when to end?
- ▶ **Decision tools** (impact on decisions, satisfaction, care consistent with preferences, costs)
- ▶ **Mobile health apps** (outcomes, factors related to engagement, usability)

JOURNEY





Patients/families
don't care much
about what you
know

until they know how
much you care.

Adapted from T. Roosevelt

Trust is the
foundation.

Thank you

Helene.Moriarty@villanova.edu



NEWCOURTLAND CENTER FOR TRANSITIONS AND HEALTH
University of Pennsylvania School of Nursing

