Qualitative, quantitative and mixed methods in PCOR

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Fitting mixed methods into your research
Expert (etic) vs. Lay (emic) knowledge
Hypothetico-deductive research

- Expert driven
- Test relationships among known variables
- Test relationships among variables that experts believe to be important
- Standardized, normed, validated instruments
Hypothetico-deductive research

- Precise
- Replicable
- Generalizable
- In CER, A is/is not better than B
Hypothetico-deductive research

- Surveys
- Chart reviews
- Administrative databases
- EMR, Penn Data Store
- PROMIS
PROMIS Mission, Vision & Goals

PROMIS Mission

PROMIS® uses measurement science to create a state-of-the-art assessment system for self-reported health.

Vision

The Patient-Reported Outcome Measurement Information System (PROMIS®), funded by the National Institutes of Health, aims to provide clinicians and researchers access to efficient, precise, valid, and responsive adult- and child-reported measures of health and well-being.

PROMIS Strategic Goals

- Create and promulgate a set of qualitative and quantitative methodological standards for development and validation of PROMIS instruments.
- Launch a PROMIS sustainable entity that is able to continue and grow the research, development, and dissemination activities for the network.
- Identify and prioritize a set of research and development opportunities for PROMIS that include, but are not limited to, clinical applications.
- Disseminate information on PROMIS to forge strategic alliances with key individuals and organizations that that will help PROMIS fulfill its vision and enhance its adoption in research, clinical practice, and policy.
HOWEVER…
Patient experience may be very different from expert perspective

- **Patienthood is culturally shaped**
  - Meaning of illness
  - Beliefs about etiology
  - Beliefs about treatment
  - Beliefs about suffering
  - Beliefs about fate
  - Beliefs about accepting help
  - Therapy management group
  - Sick role
  - Context matters

When worlds collide
Illness experience may be very different from expert perspective

- Biomedicine is a culture too
  - Scientific method
  - Beliefs about illness
  - Classification systems
    - ICD
    - DSM
Coming together

Experience
Health behavior models

- Value expectancy theories
- Risk perception, self efficacy, behavioral intention
- Rational choice
- Limited consideration of:
  - Cultural models
  - Social facts
  - Structural factors
  - Meaning
  - Historical trauma
  - Framing
  - Power imbalance
Need for an expanded paradigm

“What if we don’t change at all ... and something magical just happens?”
Inductive research

- Observation
- Patterns
- Tentative hypothesis
- Theory

Inductive

Contextual factors

Emic

Provides depth

Ideal when little is known about a topic
Designing a mixed methods PCOR study

- Clear and concise research question
- Whose question is this?
  - Patient engagement in the design and conduct of PCOR studies
- Design decisions
  - What kind of question are you trying to answer?
  - What kind of data do you need?
- Sampling strategies
  - Purposive sampling
- Data collection
  - Engage with patient ideas
  - Many strategies
    - Ethnography
    - Interviews
    - Focus groups
    - Cultural consensus analysis
    - Narrative analysis; thematic analysis, structure of the story- cultural cues
      - Develop typology
    - Ethnographic Decision Modeling
    - Content analysis
    - Life histories
    - Case studies
- Data management
- Data analysis
Designing a mixed methods PCOR study

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Effectiveness implementation hybrid designs

- **Type 1**
  - Primary aim: clinical effectiveness
  - Secondary aim: context for implementation

- **Type 2**
  - Primary aim: effectiveness
  - Co-primary aim: feasibility etc of implementation strategy

- **Type 3**
  - Primary aim: utility of an implementation strategy
  - Secondary aim: clinical outcomes

- Curran, Bauer, Mittman, Pyne, Stetler, Medical Care, 50(3): 217-226, 2012
Question: What words describe the things that led to the patient’s (your) hospitalization this time?
Fig1: Heart Failure Home Management and Hospital Readmission Conceptual Framework

- Inadequate instructions
- Uncertainty regarding recommendations
- Temporal incongruence between behavior and symptoms
  - Cycle of Limit Testing
  - Minimal
- Adherence vs Adaptation
- Symptoms
- Fear and Distress of Consequences
  - Hospital Readmission
  - Hospital Perception
  - Hopelessness and frustration
- Emotional State (i.e. Desire for old lifestyle)
- Socioeconomic Factors
- Comorbidities

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Cluster 1: older, more likely to be male, retired, self-rated health is better, fewest prior admissions for HF
Cluster 2: younger, more likely to be female, more likely to be disabled, self-rated health is fair
Cluster 3: more likely to be unemployed, have poor self-rated health, most prior admissions for HF
Where to turn?

- **Institute for Biomedical Informatics**
  - [http://upibi.org/](http://upibi.org/)
    - Bioinformatics core provides professional bioinformatics services including data analysis and consultation
    - Clinical Research Informatics core provides computational services to support the use of clinical data for biomedical research
    - IBI Idea Factory is a visual analytics facility designed to facilitate collaboration and promote new ways of communicating and presenting scientific innovation

- **Biostatistics Analysis Center (BAC)**
    - Biostatistics analysis and programming
    - Data management
    - Collaboration on study design and proposal development
Where to turn?

- **Clinical Research Computing Unit (CRCU)**
  - [http://www.cceb.med.upenn.edu/crcu](http://www.cceb.med.upenn.edu/crcu)
    - Clinical data management
    - Research technologies
    - Project operations and compliance
    - Research design, development and quality assurance

- **Mixed Methods Research Lab (MMRL)**
  - [https://www.med.upenn.edu/mmrl/](https://www.med.upenn.edu/mmrl/)
    - Consultation regarding qualitative and mixed methods
    - Proposal development
    - Data collection
    - Data management
    - Data analysis
Punchline

- Need a varied toolkit to answer PCOR questions
- What you know depends on how you know it
- There are resources at Penn that can be helpful
Questions and Discussion