Methods and Applications for Research in Spiritual Care Settings

Elaine Yuen PhD
Association of Professional Chaplains
Annual Meeting
Louisville, Kentucky, June 3, 2015

Where We’re Going Today

- Research and Research Paradigms
- Ethical Considerations
- Research Design
- Why Explore the Literature?
- Methodology
  - Options for Methodology
  - Identifying Your Study Population
  - Surveys and Metrics

Looking for Reality

- Knowledge from Agreement Reality
  - How do we know what is real?
    - A scientific assertion must have both logical and empirical support.
  - Epistemology – the science of knowing; systems of knowledge.
  - Methodology – the science of finding out; procedures for scientific investigation.
  - Agreement Reality – those things we “know” as part of the culture we share with those around us.

Looking for Reality

- Ordinary Human Inquiry
  - Humans want to predict the future. Why?
    - We recognize that the future is caused in part by the present.
    - Cause and effect patterns are probabilistic in nature.
    - Prediction versus Understanding
  - Tradition
  - Authority

Looking for Reality

- Errors in Inquiry, and Some Solutions
  - Inaccurate Observations
    - Measurement devices offer accuracy.
  - Overgeneralizations
    - Large and representative samples are a safeguard against overgeneralization.
    - Replication: repeating a research study to test and either confirm or question the findings of an earlier study.
  - Selective Observations
    - Avoid looking for “deviant” cases.
  - Illogical Reasoning
    - “Gambler’s fallacy”
Looking for Reality

- What’s Really Real?
  - The Premodern View – Things are as they seem.
  - The Modern View – Acknowledgement of human subjectivity.
  - The Postmodern View – There is no objective reality.

What is a Research Paradigm?

- Paradigms – a model or frame of reference through which to observe and understand.
- Paradigms play a fundamental role in science.
- Paradigms are neither true nor false.
- “Patterns happen.”
- Logical explanations are what theories seek to provide.
  1. Theories prevent our being taken in by flukes.
  2. Theories makes sense of observed patterns.
  3. Theories shape and direct research efforts.

Kinds of Paradigms

- Macrotheory – a theory aimed at understanding the “big picture” of institutions, whole societies, and the interactions among societies.
  - Examples: class struggles, international relations, and interrelations between social institutions
- Microtheory – a theory aimed at understanding biocultural-spiritual life at the intimate level of individuals and their interactions.
  - Examples: dating behavior, jury deliberations, student-faculty interactions, clinical care
- Mesotheory – referencing an intermediate level between macro and micro.
  - Examples: studying organizations, communities, and social categories

The ABCs of Comparative Effectiveness Research

- Answer real questions
- Health care decision-making
- Best evidence
  - Internal and external validity
- Comparative
  - Real-world comparisons
- Effectiveness
  - Patient-centered outcomes of interest

Evidence Based Medicine

http://www.cochrane.org/about-us/evidence
Basic Design Clinical Trials

Links between theory and research

- Theory to guide development of sense of questions/problems/concerns
- Theory to guide development of research instruments – surveys, questionnaires
- Theory to guide data analysis
- Theory as the outcome of research – grounded theory in qualitative methods
- Theory to guide development of analysis coding in qualitative methods

Deductive vs Inductive Inquiry/Theory

- **Deductive** – research is used to test theories
  - start with a theory, derive hypotheses, test through observation, analyze using theory as guide
- **Inductive** – theories developed from analysis of data
  - start with observation, search for patterns, theory comes later (perhaps) or theory guides analysis.
- Deductive is associated with quantitative
- Inductive is associated with qualitative

Ethical Issues

- **Autonomy**
  - Voluntary Participation
  - No Harm to Participants (Beneficence / Non-maleficence)
- **Dignity**
  - Anonymity and Confidentiality
- **Honesty**
  - Deception (Truthfulness and Honesty)
- **Justice / Distribution of Resources**
  - Analysis and Reporting

Ethical Issues: Autonomy

- **Voluntary Participation**
  - No one should be forced to participate.
- **Balance of science and ethics?**
  - Possible?
- Community-based participatory research
- International research
### Ethical Issues: Doing No Harm

- **No Harm to the Participants**
  - People being researched should never be injured (physically, mentally, emotionally, socially, psychologically).
  - Examples: Tuskegee Syphilis Study, Stanford Prison Experiment
  - Possible to eliminate 100% of risk?
  - Informed Consent – a norm in which subjects base their voluntary participation in research projects on a full understanding of the possible risk involved.

### Ethical Issues: Confidentiality

- **Anonymity and Confidentiality**
  - Anonymity – guaranteed in a research project when neither the researchers nor the readers of the findings can identify a given response with a given respondent.
  - Confidentiality – guaranteed when the research can identify a given person’s responses but promises not to do so publicly.
  - Good of the individual vs good of the group / community

### Ethical Issues: Impact on Others

- **Analysis and Reporting**
  - Ethical obligation to colleagues in the scientific community.
  - All results must be reported (positive and negative).
  - All limitations must be admitted.
- **Surveillance in public health vs studies**
- **Example: Pandemics H1N1 / SARS**

### Ethical Guideposts

- Do you have a professional ethical perspective that is close to your personal ethical perspective?
- Informed consent as dialogue
- Think beyond methods to broader social principles
- Minimize harm to those involved in study
- Be attentive to relationships with study participants – roles, status, language, and so forth

### Prevention of Material-Child HIV in Africa

- Researchers in Thailand, Uganda and other developing nations
  - Criticized because control groups received a placebo
  - Not acceptable as standard treatment in US
- **Universal standard: anything less is inherently exploitative**
  - only the poor of the world, and usually poor people of color, are placed at risk through their participation in studies.
- **Opponents to universal standard: not realistic where the existing infrastructures for health care delivery cannot support the “best proven therapy”**
  - Control group with placebo was the locally available standard of care
  - Local governments and health professionals were actively involved in reviewing and approving the study design
  - Panel convened by WHO recommended that there was an urgent need to find less costly drug regimens

### Ethics in Chaplaincy

- An ethic of human rights is popular among many in healthcare settings. On the surface it seems to be one of the more intuitive ethics.
- The presentation points out that rights don’t carry much force unless people agree on them.
- Can you identify some human rights related to the health of the public that people agree on? Can you identify others that people do not agree on?
Research Design

Different Purposes of Research

1. Exploration
   - To satisfy the researcher's curiosity and desire for better understanding
   - To test the feasibility of undertaking a more extensive study
   - To develop the methods to be employed in any subsequent study

2. Description
   - Describe situations and events through scientific observation

3. Explanation
   - Descriptive studies answer questions of what, where, when, and how
   - Explanatory studies answer questions of why

Where to Start?

The Most Important Part of Research Is???
Having a valid and useful question!!!!

Research Question

- What are you interested in learning?
- What paradigms or factors impact your question?
- Who cares?
- Start by writing a research title.
- Answer the "so what" question.

Let’s Talk About Causality

Criteria for Nomothetic Causality

1. The variables must be correlated
   - Correlation – an empirical relationship between two variables such that changes in one are associated with changes in the other, or particular attributes in one are associated with particular attributes in the other.

2. The cause takes place before the effect

3. The variables are nonspurious
   - Spurious Relationship – a coincidental statistical correlation between two variables shown to be caused by some third variable
Unit of Analysis

- **Individuals**
  - Students, voters, parents, children, Catholics

- **Groups**
  - Gang members, families, married couples, friendship groups

- **Organizations**
  - Corporations, social organizations, colleges

- **Social Interactions**
  - Telephone calls, dances, online chat rooms, fights

Faulty Reasoning about Units of Analysis

- **The Ecological Fallacy**
  - Erroneously drawing conclusions about individuals solely from the observations of groups.

- **Reductionism**
  - A strict limitation (reduction) of the kinds of concepts to be considered relevant to the phenomenon under study.

  - **Sociobiology**
    - A paradigm based on the view that social behavior can be explained solely in terms of genetic characteristics and behavior.

The Time Dimension

- **Cross-Sectional Study**
  - A study based on observations representing a single point in time, a cross section of a population.

- **Longitudinal Study**
  - A study design involving the collection of data at different points in time.
    - **Trend Study**
      - A study in which a given characteristic of some population is monitored over time.
    - **Cohort Study**
      - A study in which some specific subpopulation, or cohort, is studied over time.
    - **Panel Study**
      - A study in which data are collected from the same set of people at several points in time.

Qualitative vs Quantitative??
Research Design – depends!

- Quantitative Research – Hypotheses – What do you think is going to happen?
  - Null Hypothesis???
  - Baseline Data
  - Theory Driven Research
  - Statistical Significance
  - Statistical Errors

- How will you explain what happened?

Research Design – depends!

- Qualitative Research – Research Question, may have hypothesis
  - Context is essential
  - Lived Experiences
  - Society and Culture
  - Language and Communication
  - Emancipatory

- Qualitative Research
  - Indicate single phenomenon to understand
  - Nothing is being tested (typically)
  - Use action verbs – discover, describe, understand
  - Emergent design – questions may change, methods don’t
  - Define population

Research Design – depends!

- Mixed Methods
  - Indicate types of methods included
  - Give rationale for combining qualitative and quantitative methods
  - QUAL → Quant; QUANT → Qual
  - Have to be good at both genres of research – hence quite difficult!!!!!!

Research Design – depends!

- Quantitative Research:
  - Identify the guiding theory a priori
  - A model or conceptual framework to test
  - Identify the independent and dependent variables
  - Name the research strategy/methods
  - Define the population and the sampling methods

Research Design – depends!

- Qualitative Research
  - Indicate single phenomenon to understand
  - Nothing is being tested (typically)
  - Use action verbs – discover, describe, understand
  - Emergent design – questions may change, methods don’t
  - Define population

Experimental vs Evaluation Research

- Evaluation Research – research undertaken for the purpose of determining the impact of some social intervention, such as a program aimed at solving a social problem.

- Evaluation could use experimental, survey, qualitative methods

- Experimental methods: Well-suited for projects involving limited and well-defined concepts and propositions.
  - Hypothesis testing
  - Better suited for explanatory than descriptive
  - Causal processes
  - Small group interaction
The Classical Experiment

- Independent and Dependent Variables
  - Independent – an intervention / stimulus (present or absent), cause
  - Dependent – effect

- Pre-testing
- Post-testing – after exposure to independent variable / intervention

- Experimental Group – receives intervention
- Control Group – no intervention
  - should resemble the experimental group in all other respects.

Strengths and Weaknesses of the Experimental Method

- Strengths of Experimental Method
  - Isolation of experimental variable’s impact over time.
  - Replication

- Weaknesses of Experimental Method
  - Artificiality of laboratory settings

- Ethical considerations

Topics Appropriate for Evaluation Research

- Appropriate topics are those with practical significance.

- Needs assessment studies

- Outcome evaluations

- Cost-benefit, cost effectiveness

- Program evaluation

The Social Context

- Logistical Problems – getting subjects to do what they are supposed to do.
  - Evaluation research occurs within the context of real life.

- Use of Research Results
  - Why evaluation research results are not always put into practice:
    - Implications may not be presented in a way that is understandable to the non-researcher.
    - Results may contradict deeply held beliefs.
    - Researchers may have a vested interest in the results.

Reviewing the Literature

- How does prior work support your work?
  - Establishes an historical context
  - Grounds your work
  - Shows your questions or study are unique
  - Should be REVIEW not a summary

- Review versus “critical” review

- Where do you start?

- Journals, books, Internet???
What to include

- Only what is GERMANE to your topic
- Establish methods as appropriate –
- Include all most recent literature AND
- Include all older literature that are “really” important to make your case for your study.

Some Resources

- What's out there
  - Theory/Paradigms
  - Methodology
  - Audiences

- Healthcare Chaplaincy Handbook
  https://www.healthcarechaplaincy.org/docs/publications/tem
  pelton_research/hce_research_handbook_final.pdf

- Massey et al: Taxonomy of Chaplaincy Activities
  http://www.biomedcentral.com/1472-684X/14/10

- Professional Chaplains and Health Care Quality Improvement
  http://www.thehastingscenter.org/Research/Archive.aspx?id=
  1212

Methodology:
Characterizing Phenomena

- Conceptions, Concepts, and Reality
  - Practice: Friendship
    - Conceptualization – the mental process whereby fuzzy and imprecise notions (concepts) are made more specific and precise.

Measuring Anything that Exists

- Conceptualization
  - The process through which we specify what we mean when we use particular terms in research.

- We cannot meaningfully answer a question without a working agreement about the meaning of the outcome.

- Conceptualization processes a specific, agreed-upon meaning for a concept for the purposes of research.

Conceptualization

- The process through which we specify what we mean when we use particular terms in research.

- We cannot meaningfully answer a question without a working agreement about the meaning of the outcome.

- Conceptualization processes a specific, agreed-upon meaning for a concept for the purposes of research.
Conceptualization

- Indicators and Dimensions
  - Indicator – an observation that we choose to consider as a reflection of a variable we wish to study.
  - Dimension – a specifiable aspect of a concept.

Developing Concepts

- Physician advocacy?
- Spiritual care?
- Indicators?
- Dimensions?

Conceptualization

- Real, Nominal, and Operational Definitions
  - Specification – the process through which concepts are made more specific.
  - A nominal definition is one that is simply assigned to a term without any claim that the definition represents a “real” entity.
  - An operational definition specifies precisely how a concept will be measured – that is, the operations we will perform.

Developing Concepts: Physician Advocacy?

- Nominal:
  - objective and subjective advocacy knowledge
  - comfort and ability to work in advocacy
  - projected advocacy involvement

- Operational:
  - Online, 39-item, questionnaire
  - Administered before and after a one-month rotation
  - Advocacy components: journal club, small group discussions, and community site visits.
  - Survey Items: sociodemographic characteristics, objective and subjective advocacy knowledge, reported comfort and ability to work in advocacy, and projected advocacy involvement.

Comfort and Ability to Work in Advocacy

Process of Conceptualization

- Creating Conceptual Order
  - Conceptualization
  - Nominal Definition
  - Operational Definition
  - Real World Measurement
Operationalization Choices

- Defining Variables and Attributes
  - An attribute is a characteristic or quality of something (ex: female, old, student).
  - A variable is a logical set of attributes (ex: gender, ethnicity/race, age).
  - Every variable must have two important qualities.
    1. The attributes composing it should be exhaustive.
    2. Attributes must be mutually exclusive.

Index versus Scale Differences

- Index – a type of composite measure that summarizes and rank-orders several specific observations and represents some more general dimensions.
- Scale – a type of composite measure composed of several items that have a logical or empirical structure among them.

Typologies

- Typology – the classification of observations in terms of their attributes on two or more variables.

http://www.annfammed.org/content/5/6/511.full.pdf

3 major barriers: lack of insurance coverage, poor access to services, and unaffordable costs

Things to remember

- Identify the concepts/constructs in your research question
- Define them clearly and provide an operational definition for your study
- Once you have done the above – you can begin to determine the ways available to measure or uncover them in your research.
- From here, you can develop your survey instrument, find one to use, or establish your interview/observation questions.

Your Study Population

THINKING ABOUT YOUR RESEARCH PARTICIPANTS
Sampling versus Census

- Sampling – the process of drawing a sample from a population.
- Generalize – to make statements about a population based on the sample
- Census – a study of the whole population rather than a sample

Types of Sampling Designs

- Simple Random Sampling – a type of probability sampling in which the units composing a population are assigned numbers. A set of random numbers is generated and the units having those numbers are included in the sample.
  - Not necessarily the most accurate sampling method.
- Systematic Sampling – a type of probability sampling in which every kth unit in a list is selected for inclusion in the sample.
  - Slightly more accurate than simple random sampling.
- Stratified Sampling
  - Stratification – the grouping of units composing a population into homogenous groups (strata) before sampling.
  - Slightly more accurate than simple random sampling.
  - Stratification is a modification to simple random and systematic sample methods.

Things to consider in Quantitative Research

- What is the population?
- How many is enough?
- To stratify or not to stratify?
- To match or not to match?
- What is a statistically significant sample size given your research? Confidence level = .05, .01, .001, .0001, etc.
- When is statistical significance not important?

Nonprobability Sampling

- Reliance on Available Subjects
  - Convenience sampling
  - Does not allow for control over representativeness.
  - Only justified if less risky methods are unavailable.
  - Researchers must be very cautious about generalizing when this method is used.

- Purposive or Judgmental Sampling – a type of non-probability sampling in which the units to be observed are selected on the basis of the researcher’s judgment about which ones will be the most useful or representative.
  - Small subsets of a population
  - Two-group comparison
  - Deviant cases
  - Over-samples

- Snowball Sampling – a non-probability sampling method whereby each person interviewed may be asked to suggest additional people for interviewing.
  - Often used in field research, special populations
**Take-aways about sampling**

- Depends on your question, whether quantitative or qualitative
- Quantitative needs to be generalizable, so random sampling important
- Qualitative needs to generate understanding of context, so again random sampling is nice, but purposive is more important

**Survey Design**

**Descriptive, Explanatory and/or Exploratory**

- **Descriptive** – answering what, where, when or how questions
  - Best example is the Census
- **Explanatory** – answer questions of why
  - Best example is voting patterns
- **Exploratory**
  - Conducting a survey before qualitative work to explore concepts ahead

**Guiding Principles for Survey Development**

- Systematic – planned and executed to insure appropriate content and sound data collection
- Representative of the population
- Objective – insuring that data are observable and explicit as possible
- Quantifiable – yielding data that can be expressed in numerical terms

**Possible Limitations**

- Surveys depend on respondents
  - Trust – respondents who are accessible and cooperative
  - Attention may make respondent feel special and bias results
  - Vulnerable to over-rater / under-rater bias
  - Favorable OR unfavorable response bias from interviewer / interviewee interaction
  - Recall bias

**Validity**

- **Content validity**: How well do the survey items test my specific research question? (i.e. achievement tests)
- **Criterion validity**: Do the items compare well with other external variables? (i.e. intelligence scores to predict future performance)
- **Construct validity**: How well does my survey explain my theory and hypotheses? (i.e. tests of personality types to validate typologies)
- **Face validity**: Does the instrument measure what it claims to measure?
Reliability

- Consistency and accuracy
- Test – retest

- Response variation of the subject
- Variation in test content or situation
- Variation in administration

Some general guidelines

- Define your research question in explicit terms

When considering an existing survey:
- Was it designed for a different purpose, population or circumstance?
- Was it validated?
- Are the items clear? Are the questions focused and structured?
- How long will it take?

Practical considerations

- Focus groups
  - What’s important to people in the study population?
  - How do they frame or contextualize these issues? What words / ideas do they use?

- Field testing
  - Are there ambiguous or redundant items?
  - How much time will administering the survey take?
  - Other considerations

Types of surveys: Record review

- Advantages
  - Nonreactive
  - Inexpensive
  - Allow for historical comparison and trend analysis
  - Often provide excellent baseline

- Disadvantages
  - Confidential restrictions
  - May be incomplete, inaccurate, out-of-date
  - Changing rules year to year
  - Often depend on how collected
  - Purpose of records not related to purpose of survey
  - Factual data only (no behaviors / attitudes)

Types of Surveys: Mail / Email Questionnaires

- Advantages
  - Inexpensive
  - Wide-ranging
  - Self-administered
  - Can be anonymous

- Disadvantages
  - Low response rate can occur
  - No assurance questions were understood
  - No assurance was actually answered by respondent

Types of Surveys: Telephone Interviews

- Advantages
  - Less costly than face-to-face
  - Can be conducted in daytime or evening
  - Unlimited callbacks
  - Respondent in own home, more at ease
  - Extended geographic coverage

- Disadvantages
  - Unlisted numbers
  - People without a phone
  - Can be viewed as intrusive to privacy
  - Rules out face-to-face information such as visual cues and home environment
### Types of Surveys: Face-to-Face Interview

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Personalized</td>
<td>- Expensive and time-consuming</td>
</tr>
<tr>
<td>- Permits in-depth, open responses</td>
<td>- May have imbalance in racial, ethnic, SES status</td>
</tr>
<tr>
<td>- Flexible and adaptable</td>
<td>- between interviewer and interviewee</td>
</tr>
<tr>
<td>- Allows for impressions of gestures, tone of voice, etc.</td>
<td>- Open to manipulation or biases of the interviewer</td>
</tr>
<tr>
<td></td>
<td>- Personality conflicts</td>
</tr>
<tr>
<td></td>
<td>- Skilled and trained interviewers</td>
</tr>
</tbody>
</table>

### Existent survey data

- Some are ongoing annual systems while others are conducted periodically
- Two major types
  - Based on populations, containing data collected through personal interviews or examinations
  - Based on records, containing data collected from vital and medical records.
- National Center for Health Statistics
  - [http://www.cdc.gov/nchs/surveys.htm](http://www.cdc.gov/nchs/surveys.htm)
- Community Health Data Base
  - [http://jeffline.jefferson.edu/Collections/PHMC/](http://jeffline.jefferson.edu/Collections/PHMC/)

### Quantitative vs Qualitative language

<table>
<thead>
<tr>
<th>Reliability – accuracy of effort – would I get the same if I went in again?</th>
<th>Dependability – confirmable (audit trail, member checks)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Validity – is this the truth, unbiased in any way?</td>
<td>Trustworthy</td>
</tr>
<tr>
<td>Generalizability – is this a typical sample?</td>
<td>Believability (consistent data, triangulation)</td>
</tr>
<tr>
<td></td>
<td>Authenticity</td>
</tr>
<tr>
<td></td>
<td>Transferability</td>
</tr>
</tbody>
</table>

### Putting it all together

#### Parts of the Research Proposal

1. **Introduction** – sets the stage for the proposal, introducing the problem/concern and why it is important
2. **Review of literature** – establishes this problem/concern in the prior literature
3. **Specifying the problem/concern/question very specifically**
4. **Research design**
   1. Population and sampling
   2. Data collection method(s)
   3. Ethical issues
5. **Data analysis**
6. **Bibliography**

### An Example: The Effect of Conflict Coaching on Caregiver Well-Being
Specific Aims

- Examine the associations between key family relationship dynamics (cohesion, conflict, and communication), CG emotional well-being, CR functioning and CG desire to institutionalize
- Test the effect of conflict coaching on family relationship variables, CG emotional well-being and CG desire to institutionalize, and
- Evaluate the acceptability of conflict coaching
- Study Design: single cohort study, pre-test post-test

Data Collection Methods

- 20 English-speaking, primary family caregivers to an older adult, non-institutionalized care recipient with Alzheimer’s Disease
- Demographic characteristics and pre-measures on all instruments will be collected at first meeting
- Post measures on all instruments and an acceptability questionnaire will be completed at the final meeting.
- All data gathered via care-giver self-report
- Estimated completion time 20 minutes

Table 1: Measures of family cohesion, conflict and caregiver burden

<table>
<thead>
<tr>
<th>Variable</th>
<th>Measure</th>
<th>Items</th>
<th>Scale</th>
<th>Psychometrics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Relationship Dynamics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conflict</td>
<td>Family Environment Conflict subscale</td>
<td>40 in</td>
<td>Likert</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>short form</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>FES</td>
<td>Y/N</td>
<td>Internal reliability for Relationship scales range from 0.61 to 0.78</td>
</tr>
<tr>
<td>Cohesion</td>
<td>FES Cohesion subscale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>FES Expressiveness subscale</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care Recipient Functioning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental</td>
<td>Modified Caregiver Strain Index</td>
<td>3</td>
<td>Likert 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-3</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.80 internal reliability</td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>Modified CSI</td>
<td>8</td>
<td>Likert 4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-4</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.88 internal reliability</td>
<td></td>
</tr>
<tr>
<td>Caregiver Well-Being</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CG burden</td>
<td>Zarit Burden Interview</td>
<td>12</td>
<td>Likert</td>
<td>Meets the criteria and long term stability</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0-4</td>
<td></td>
</tr>
<tr>
<td>CG depression</td>
<td>CES-D</td>
<td>20</td>
<td>Likert</td>
<td>0.85 in community sample</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1-4</td>
<td></td>
</tr>
<tr>
<td>Institutional placement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CG desire to Institutionalize</td>
<td>Desire To Institutionalize Scale</td>
<td>6</td>
<td>Y/N</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Sharma H 2005)</td>
</tr>
</tbody>
</table>

Table 2: Caregiver and Care Recipient Demographic Data

All will be gathered through CG self-report

<table>
<thead>
<tr>
<th>Category (CG)</th>
<th>Care recipient (CR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Relationship to CR</td>
<td></td>
</tr>
<tr>
<td>Comorbidities</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>Number of other family members in the household</td>
<td></td>
</tr>
<tr>
<td>Household income</td>
<td></td>
</tr>
</tbody>
</table>

1. Marital status: married, single (never married), divorced, widowed
2. Census categories for ethnicity/race
3. Daughter, son, spouse, niece, nephew, other (describe)
4. No impairment (Stage 1), Very Mild (Stage 2), Mild (Stage 3), Moderate (Stage 4), Moderately Severe (Stage 5), Severe (Stage 6), Very Severe (Stage 7)
5. Charlson Comorbidity Index
6. High school diploma or less, some college, college degree, graduate/professional work
7. Income categories found in PHMC Community Data Base