ASSOCIATION OF PEDIATRIC ONCOLOGY SOCIAL WORKERS

How to Design your First Research Study

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Objectives

- Describe what value research brings to social workers (why we should engage in practice informed research)
- 8 steps to conduct research - from ideas to publication
- Describe and practice different kinds of research designs
- Review why incorporating research into practice can enhance care and career
- Provide each person the opportunity to create a mock design for their own study.

Why Adding Value

• In order for hospital social workers to **demonstrate their effectiveness** both in terms of patient outcomes and cost-effectiveness, they must begin to engage in intervention or outcome-based research.

• This type of research is the ideal mechanism through which hospital social workers can negotiate their position and value within the hospital setting (Davis, 2004)

Most clinicians are interested in scholarly productivity (particularly publishing), but very few do. Do you agree?

Yes

No

Do research? NO WAY, NO HOW!

- Most clinicians are interested in scholarly productivity (particularly publishing), but very few do.

- Lack of time

- Limited resources (research assistants, data analytic support) and incentives (lack of billable hours)

- Lack of training/expertise and experience

- Sense that the role of clinician and scientist may be incompatible, that for clinicians to be both researchers and practitioners – the role may be incongruous.

- Culture (if program is clinical by design, research may be perceived as intrusive or unnecessary and not encouraged).

What skills do social workers have to conduct research?

- Assessment skills
- Diagnostic judgment
- Clinical wisdom
- Case formulation
- Recognize meaningful patterns and organize information in ways that reflect a deep understanding of what we observe
- Treatment planning/implementation
- Ability to work with the treatment teams

Integrated Clinical Care and Research

- There are many types of research that can potentially support clinical utility including clinical observation, qualitative research, systematic case studies, process-outcome studies, randomized controlled trials (RCT) and even meta-analysis when a patient population is not available.

- This is only a overview!

WHERE DO I START?

HOW DO I START

- This is often the hardest obstacle to get past for many clinicians.

- It requires patience to develop a good question that provides clinical utility and an ability to tolerate some false starts while pursuing the best path to answering the question.

Steps to Remember

1. Identify the research question.
2. Review the literature.
3. Formulate the hypothesis/aims of the study.
4. Select the research method and design the study.
5. Collect the data.
6. Analyze the data.
7. Draw conclusions.
8. Report the findings.

1. Define a research question in an area of personal interest

- Listen carefully to patient/family stories with similar or markedly dissimilar components
- Attend conferences, listen to what others consider "topics of interest"
- Think about what is critical, what is hard/not being addressed, what is interesting
- Read the professional literature

For example, one might have a desire to know whether guided imagery reduces procedural distress, or be interested in learning the prevalence of sleep problems for caregivers during inpatient admissions.

Identify collaborators

• Secure buy-in from key team members.

Take home message! If the medical team has a *sense of ownership* over the design and study outcomes, they will be more likely to encourage patient/subject participation.

• Explore costs (financial and time) that will be associated with your research design and whether the patient/subjects you are interested in studying are available at one's setting.

There are creative ways to get around monetary barriers. For example, student interns from local colleges as healthy volunteers for academic credit, or provide food for focus group participants (instead of cash).

Let's Brainstorm Research Questions

2. Review the literature

• Once a question is developed, search the literature for any studies that might have already tested the theory or question.

• Write a summary of everything that has been done that is relevant to the research question and why the question is an important one to ask. Ask how it might contribute to better diagnosis, prognosis or treatment.

Eg. if one wants to know if parental sleep issues contributes to poor coping, describe what has been published about this topic previously.

• If there a specific conceptual model to guide the research question, describe the theory and how the research question fits into the theoretical design.

• If ever in doubt as to the best ways to proceed, always seek the help of an experienced researcher for guidance.

3. Develop specific study aims

• With a research question established, literature review and theory completed, it is time to describe one's specific aims.

• What would you like or expect to learn from the study?

- List 3-5 central hypotheses/expectations about what one can be expected to find.

• It is important to write aims that are "actionable" so that at the completion of the study, an objective reader can assess how well the aims were met.

For example:

1) To determine if guided imagery reduces procedural distress
2) To develop a psychometrically valid Pediatric cGVHD Symptom Scale (PCSS) and a companion parent proxy measure as a counterpart to the Lee cGVHD Symptom Scale

4. Choose the study design best suited to answer the research question

• A study design includes identifying who the subjects or participants will be, whether the study will be **exploratory** (hypothesis generating) or hypothesis driven, if there will be a comparison group, and what the key independent and dependent variables are.

• The *independent variable* is the variable that is controlled, changed, or manipulated by the research (e.g. guided imagery)
• The *dependent variable* is the variable that is measured or observed (distress, sleep disturbance).

• Sampling strategy, research design, selection of variables and operationalization (defining) of the variables are very important elements of the research as these can affect the validity of results substantially.

• List the strengths and weaknesses of the design and review them with colleagues knowledgeable in research design.

What is qualitative research?…

- Semi-structured or unstructured attempt to learn about inner process, feelings, memories.

- Have goals, but emphasis is on open-ended responses, possibly quite lengthy, about a topic, relationship, process, or decisional experience.

- Personal narrative guides the presentation of findings.

Why do Qualitative Research?

- Novel group studied
- Little data or theory in the area
- Novel or subtle or personal/subjective, complicated emotions involved
- Considerable interest in the “how” and “why”, not just the “what”
- Can be precursor to larger quantitative study (hypothesis building) or study in its own right.

Types of Qualitative Research

- Focus Groups
- Group Process notes
- Semi-structured interviews
- Unstructured interviews
- Written narrative

References for Qualitative Research

Weiss, RS. Learning from Strangers: The Art and Method of Qualitative Interview Studies. Free Press: NY, 1994

Huberman AM and Miles MB. The Qualitative Researcher's Companion. Sage Publications, Thousand Oaks CA, 2002

Denzin NK and Lincoln YS. Collecting and Interpreting Qualitative Materials. Sage Publications, Thousand Oaks CA, 1998

Hsieh HF and Shannon SE. Three approaches to qualitative content analysis. *Qualitative health research* 2005; 15: 1277-1288.

Miles MB, Huberman AM, Huberman MA, et al. *Qualitative data analysis: An expanded sourcebook*. Sage, 1994.

Mixed Methods: Qualitative and Quantitative Research

	Qualitative	Quantitative
Conceptual	Concerned with understanding human behaviour from the informant's perspective	Concerned with discovering facts about social phenomena
	Assumes a dynamic and negotiated reality	Assumes a fixed and measurable reality
Methodological	Data are collected through participant observation and interviews	Data are collected through measuring things
	Data are analysed by themes from descriptions by informants	Data are analysed through numerical comparisons and statistical inferences
	Data are reported in the language of the informant	Data are reported through statistical analyses

Source: Adapted from Minchiello *et al.* (1990, p. 5)

www.simplypsychology.org/qualitative-quantitative.html

Mixing Qualitative and Quantitative Designs

Parent Identified Barriers to Transition from Pediatric to Adult Health Care

- Overall Goal: To further understand the barriers to successfully transitioned care as experienced by parents.

- One could add medical data, outcome measures (anxiety)

- One could add different time points (prior to transition, immediately following transition, and one year post transition) for a longitudinal design.

5. Planning the data collection

- How to get to the subjects?
- Telephone or face-to-face?
- How structured?
- Where to start?
- Risks of distress?

Considerations in conducting the research project

- Confidentiality/Privacy
- Recording
- Training Interviewers
- The quiet subject
- The rambling subject
- Distress in a subject
- Bringing the interview to a close
- Distress assessment - Benefit/Burden

6. Analyzing the qualitative data

Transcription

– Manual, machine or use service

Analyses

– Themes and Categories

What questions does it raise? Iterative Process

- Develop initial code dictionary
- Code minimum of 10% to assess inter-rater reliability
- Codes develop into themes (agreement)
- All interviews coded

Example: What happens to a marriage/relationship after a child is diagnosed with cancer

Emerging Themes:

Fear of disease outcome
Lack of time together
Conversations focused on Child only
Lack of Intimacy

"If we had been able to have time together. Just him and I. That didn't happen that I remember. I mean we had MRI time so every three months we would sit down and look at each other and have a conversation and you know most of the time we would cry and you know just be scared, but that's the only time we had together."

YOUR TURN!

Briefly think of a qualitative study that might enhance your practice

7. Drawing Conclusions (outcomes)

- What is the critical, meaningful outcome(s)?
- Implications

8. Report the findings

- Local feedback (main findings and implications to practice)
    - Report to your social work or pediatric oncology team
- Conferences (present at APOSW!)
- Publication (social work or other journal)
    - Limitations, next steps, next research questions

Program Evaluation. Is this Scientific Research?

- Formal program evaluation is typically conducted with the same tools and procedures used in applied research.

- Collection, analysis, and interpretation of data within the context of current knowledge about a topic (Popham, 1993). They are differentiated by their goals.

- Scientific research – To describe, predict, and understand phenomena and their interrelationships in order to contribute to a body of empirical knowledge.

- Evaluation research – To describe and assess the worth of a service or resource in order to facilitate decisions regarding it.

NEEDS ASSESSMENT

Definition:

• Systematic process to acquire an accurate, thorough picture of the perceived and expressed psychosocial and educational needs that can be used to improve care and programming in an oncology program.

• Process involves collecting and examining information about perceived and expressed needs

- then utilizing that data to determine priority goals, to develop a plan, implement services, allocate funds and resources.

• Measure program success and effectiveness.

* Understand if perceived/expressed needs of the patients and family members are being met, whether certain individuals are "falling through the cracks, whether programs being offered are what patients and family members feel they need, promote accountability.

STEPS IN CONDUCTING A NEEDS ASSESSMENT

Clarify the purpose of the needs assessment

1. What do you know? What do you think you know? What do you want to know?
2. What will you do with the information you collect?
3. How will you report the information?
4. Is it user friendly and easy to understand?
5. Are all interested groups included in planning and conducting the needs assessment?
6. Who will be responsible for the various steps?

STEPS IN CONDUCTING A NEEDS ASSESSMENT

1. Identify the population
   - Who: Parents, patients, clinical staff, volunteers?

2. Determine how you will conduct the needs assessment

3. Design a survey instrument or adopt one that already exists
   - Are the instruments easy to use?
   - Is the format easy to summarize and analyze?

4. Collect Data*
   - Develop a system for collecting and organizing data.
   - Determine baseline data.
   - How do you plan to follow up with those not responding?
   - Organize the data by key categories.
   - Use data summary sheets to help determine patterns and make calculations easier.

EXAMPLES OF NEEDS ASSESSMENTS

- Parental Needs
- Adolescent Needs
- Young Adult Needs
- Pediatric Long-term Survivors Needs
- Physician/Medical Provider Communication Needs
- Other examples?

YOUR TURN

List the first 3 steps needed to conduct a successful needs assessment.

LET'S REVIEW WHAT WE LEARNED

QUIZ!

1. Before beginning a research project, social work researchers should:
   a) Define a research question
   b) Conduct a review of literature
   c) Consider the design the study
   d) All of the above

LET'S REVIEW WHAT WE LEARNED

QUIZ!

2. One wants to study anxiety levels of pediatric patients with cancer during their first day at an inpatient unit. What study design would be more appropriate?
   a) Longitudinal study
   b) Retrospective
   c) Cross-sectional study
   d) All of the above

LET'S REVIEW WHAT WE LEARNED

QUIZ!

2. Which step is in the wrong order here
   a) Identify the research question.
   b) Review the literature.
   c) Formulate the hypothesis/aims of the study.
   d) Draw conclusions.
   e) Select the research method and design the study.
   f) Collect the data.
   g) Analyze the data.
   h) Report the findings.

LET'S REVIEW WHAT WE LEARNED

QUIZ!

3. Which statement is incorrect about qualitative research:
   a) It provides detailed description of the topic
   b) Data is collected through observation and interviews
   c) Data collected relies on measurement tools
   d) Data is reported by themes and categories analyses

LET'S REVIEW WHAT WE LEARNED

QUIZ!

4. Who can conduct excellent research?
   a) Psychologists
   b) Nurses
   c) Social Workers
   d) All of the above

GREAT JOB!!!!!

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