Understanding the Patient Experience Through Qualitative Research

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Learning Objectives

• Discuss the types of research questions that are suited to qualitative methods

• Explain the ways in which qualitative methods uniquely contribute to health and healthcare research

• Examine published research studies that have included qualitative methods
Activity
Brainstorm

• In your role, when something new must be done, what is required to make it work?
• What do you feel others don’t understand about the process?
• What aspects of your answers could you quantify? What aspects couldn’t be fully captured with numeric data?
Qualitative 101
Characteristics of Qualitative Research Design

• Is flexible, capable of adjusting to what is learned during data collection

• Often involves triangulating various data collection strategies

• Tends to be holistic, striving for an understanding of the whole
Characteristics of Qualitative Research Design—(cont.)

• Requires researchers to become intensely involved and reflexive and can require a lot of time

• Benefits from ongoing data analysis to guide subsequent strategies

• **Emergent**: evolves as researchers make ongoing decisions about their data needs based on what they have already learned
Conducting Qualitative Studies
Research questions

• Your research question drives every part of the research process.

• Examples:
  • What is the experience of patients living with chronic kidney disease?
  • What practices do patients on dialysis use to manage their health within their day-to-day lives?
  • Across chronic conditions, what are the common drivers of treatment burden for patients living with chronic illness?
Activity
Brainstorm

• If you wanted to study one of the topics we discussed in our first activity, how would you frame this as a qualitative research question?
Sources of Data: Types of Qualitative Designs

- 3 main types of data:
  - Interview
  - Focus group
  - Observations
Sources of Data: Types of Qualitative Designs

- Many traditions of qualitative research, examples:
  - Grounded Theory
  - Phenomenology
  - Ethnography
  - Pragmatism

- Research question, tradition of research, and type of data determines the type of analyses you will do
Ethnography

- Describes and interprets a culture and cultural behavior
- **Culture** is the way a group of people live—the patterns of activity and the symbolic structures (e.g., the values and norms) that give such activity significance.
- Relies on extensive, labor-intensive **fieldwork**
- Culture is inferred from the group’s words, actions, and products of its members.
- Assumption: Cultures guide the way people structure their experiences.
- Macroethnography vs. focused ethnography
Phenomenology

• Focuses on the description and interpretation of people’s lived experience

• Asks: What is the essence of a phenomenon as it is experienced by people, and what does it mean?

• Acknowledges people’s physical ties to their world: “being in the world”
Grounded Theory

• Focuses on the discovery of a basic social psychological problem that a defined group of people experience

• Elucidates social psychological processes and social structures

• Has a number of theoretical roots—e.g., symbolic interaction

• Originally developed by sociologists Glaser and Strauss
Descriptive qualitative studies tend to be eclectic in their designs and methods and are based on the general premises of constructivist inquiry.

Such descriptive studies seek to holistically describe phenomena as they are perceived by the people who experience them.

The researchers may say that they did a content analysis of the narrative data with the intent of understanding important themes and patterns.
The Analysis Plan

• This is written *a priori*

• For each type of data, write the step-by-step procedures for your data coding and synthesis

• Include what type of qualitative software you will use (e.g. Nvivo, ATLAS.ti)

• **The more detail you use in a qualitative analysis plan the better.**
  • T-test vs. matrix function
The Analysis Plan

- Address team structure and methods of calibration
  - Will you use duplicate coding? How will you determine adequate calibration
- Address reflexivity
- Address how you will handle existing theories
- Include what output will look like
We negotiated our implementation strategy with the municipality, which took active ownership by increasing the number of free COPD courses and smoking cessation courses. The region agreed on providing a special reimbursement to GPs for joint home visits together with the community nurse to newly discharged COPD patients [40].

Targeted self-management support for patients to cope with exacerbations of the disease was an integral part of our strategy, and we developed an action card with advice to patients on management of sputum and exacerbations. The action card was based on the research by Robert Stockley [41,42].

To provide family, friends and the patients themselves with more knowledge to improve their ability to cope with their disease, we designed a web site with information about COPD including contact details to the municipality, patient support groups and the involved GPs.

The standard implementation of the disease management programme from the Central Denmark Region went ahead and thus also covered all the groups in our study.
### Matrix Coding Search Criteria

#### Rows:
- Acceptance
- Adjusting to Dialysis
- Biographical Disruption
- Change in Feelings
- Comparison
- Coping Mechanism

#### Columns:
- Activities of Daily Living (ADL)
- Activity Avoidance
- Activity Management
- Caregiver Workload
- Care for Others
- Coping Mechanism

### Node Matrix

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Patients were instructed in HBPM and self-management strategies at the first visit using culturally/linguistically tailored visual handouts in English, Spanish, and Portuguese and motivational

The RNs provided outreach for continued motivation and adherence and providers integrated the information from each patient’s HBPM diary into their treatment strategy and offered ongoing motivation for HBPM
Analysis Plan

• If possible, review reporting guidelines for your study design; address each point in your analysis plan (e.g. COREQ statement)
  • You can find these at https://www.equator-network.org/
The Analysis Itself

• First, read your data multiple times
• Interpret your analyses in an unbiased manner according to your analysis plan
  • If you have cases where reported experience is different than the majority, that should be examined
• Report your analyses fully without bias; typically done as themes
Mixed Methods

• “Research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or program of inquiry.” (Tashakorri & Creswell, 2007 in Creswell & Plano Clark 2018)

• “multiple ways of seeing and hearing, multiple ways of making sense of the social world, and multiple standpoints on what is important and to be valued and cherished.” (Green 2007 in Creswell & Plano Clark 2018)
Mixed Methods to Meet Specific Needs

- Obtain more complete results
- Explain initial results
- Describe and compare different types of cases
- Develop, implement, and evaluate programs

Why?

Creswell & Plano Clark, 2018
Questions/Discussion
RESEARCH ARTICLE

Do patients with high versus low treatment and illness burden have different needs? A mixed-methods study of patients living on dialysis


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Our past research indicated many patients on dialysis reported burden from their illness and treatment at similar levels to other chronic disease populations.

Boehmer et al., JCE 2016
Why?

What could we learn from the many patients doing well to better support those struggling?
Explanatory Sequential

Quantitative ➔ Qualitative ➔ Findings

Boehmer et al., PLOS One 2021
Sample and Data Collection

143 patients approached

78 patients agreed to participate

33 sampled for interviews

High Burden
11

Low Burden
9
Measure

*Illness Intrusiveness Scale*: 13-item scale used to measure the impact of illness and treatment burden on a patient’s life.

*How much does your illness and/or its treatments interfere with:*

*(e.g. Your feeling of being healthy, your relationship with your spouse or domestic partner?)*

Boehmer et al., PLOS One 2021
Quantitative Procedures

- Descriptive Statistics for patient characteristics and Illness Intrusiveness Scale (IIS)
- Creation of quartiles of high vs. low (IIS)
- T-tests to examine differences in demographics between high and low burden groups.

Boehmer et al., PLOS One 2021
Qualitative Procedures

- In-person interviews, audio-recorded and transcribed
- Inductive content analysis
- First, looking at the total sample
- Second, looking at high vs low IIS
- Finally, comparing with existing theories of treatment burden/patient capacity

Boehmer et al., PLOS One 2021
### Patient Characteristics

<table>
<thead>
<tr>
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<th>Total Sample (78)</th>
<th>High IIS (16)</th>
<th>Low IIS (17)</th>
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<tbody>
<tr>
<td><strong>Patient Sex: n Male (%)</strong></td>
<td>50 (64.1%)</td>
<td>8 (50.0%)</td>
<td>12 (70.6%)</td>
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<tr>
<td><strong>Patient Age: Mean (SD)</strong></td>
<td>60.7 (17.27)</td>
<td>48.4 (11.36)</td>
<td>68.6 (16.81)*</td>
</tr>
<tr>
<td><strong>Time on Dialysis in Years</strong></td>
<td>3.7 (3.78)</td>
<td>3.3 (2.79)</td>
<td>2.6 (1.64)</td>
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<tr>
<td><strong>Dialysis Start Planned</strong></td>
<td>38 (52.8%)</td>
<td>8 (50.0%)</td>
<td>11 (64.7%)</td>
</tr>
<tr>
<td><strong>On Transplant List</strong></td>
<td>24 (31.6%)</td>
<td>9 (56.3%)</td>
<td>5 (29.4%)</td>
</tr>
</tbody>
</table>

Boehmer et al., PLOS One 2021
Rhythm

Boehmer et al., PLOS One 2021
Photo credit: https://flic.kr/p/edCyPF
Biographical Disruption

Boehmer et al., PLOS One 2021

Photo credit: www.flickr.com/photos/pictures-of-money
Appraisal-Focused Coping Strategies

Boehmer et al., PLOS One 2021
Photo credit: www.flickr.com/photos/petiabalabanova
Social Network

Boehmer et al., PLOS One 2021

Photo credit: www.flickr.com/photos/debraulrich
Early Dialysis Journey Experiences

Boehmer et al., PLOS One 2021
Photo credit: www.flickr.com/photos/mr_mum1968
Future Work

Photo Credit: https://flic.kr/p/tevWV
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Questions/Discussion
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