What is ACCORDS?

ACCORDS conducts pragmatic research in real-world settings to improve health care and outcomes, by providing:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally
<table>
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<tr>
<th>May 23, 24, &amp; 25</th>
<th>COPRH Con 2022: Disseminating, Scaling and Sustaining Pragmatic Research: Improving Health in Diverse Settings</th>
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</thead>
<tbody>
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<td>10:00 - 3:00 PM MT</td>
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Reporting and Presenting Data from Qualitative and Mixed Methods Studies

Presented by:

Allison Jaure, PhD, MPH
Professor of Public Health
University of Sydney
Reporting and presenting data from qualitative and mixed methods studies

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ACCORDS Seminar, University of Colorado, School of Medicine
May 18, 2022
1. Methods of analyzing qualitative data
2. Reporting qualitative data and demonstrating rigor
3. Presenting qualitative data in a visual manner
1 | Methods of analyzing qualitative data
Analysis

• Capture the breadth and depth of the data
• Comprehensible, insightful, trustworthy, compelling, original
• Answer the research question
• Describe phenomena
• Develop a theory or explanation
Principles

• Aligns with the topic and scope of the research question
• Consider audience
• May be done concurrently with data collection
• Generally inductive
• The researcher is an active participant
<table>
<thead>
<tr>
<th>Quantitative</th>
<th>Qualitative</th>
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</thead>
<tbody>
<tr>
<td>• Descriptive statistical analysis, variance of responses, determine general trends</td>
<td>• Reading of the data, making memos, conceptualizing the data, grouping concepts into themes, identifying patterns and relationships among themes</td>
</tr>
<tr>
<td>• Inferential analysis and refined analysis using the appropriate statistical tests</td>
<td>• <strong>Coding</strong> and identifying concepts, grouping into themes</td>
</tr>
<tr>
<td>• Software used to conduct statistical analysis</td>
<td>• Software used to store, label, retrieve data (facilitates but does not do analysis)</td>
</tr>
<tr>
<td>• Quantified estimates of effect or associations, statistics</td>
<td>• Narrative and rich description</td>
</tr>
<tr>
<td>• Frequency</td>
<td>• Breadth and depth</td>
</tr>
<tr>
<td>• Emphasis on <strong>generalisability</strong> (involves statistical analysis to determine the extent to which the findings can be extrapolated to another population)</td>
<td>• Emphasis on <strong>transferability</strong> of concepts and theories (the reader determines whether the findings “fit” or resonate in their own context or experience)</td>
</tr>
</tbody>
</table>
Coding

• Starting point for most forms of qualitative data analysis
• “Process of defining what the data are about” (Charmaz 2006)
• Coding is highlighting relevant segments of words and involves
  - Classifying relevant words
  - Conceptualising the data
  - Raising questions
  - Seeking explanations
  - Noticing relationships
• What can be coded? (setting and context, definition of the situation, perspectives, events, activities, consequences, relationship and social structure, meaning [define and direct an action])

Codes are tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study. Codes usually are attached to “chunks” of varying size – words, phrases, sentences or whole paragraphs, connected or unconnected to a specific setting” (Miles and Huberman 1994)
Coding exercise

Participant 1: Woman, 20s
My whole life I just thought what’s the point, what’s the point of like entering a relationship with any nice guys. When all you are going to do is disappoint them because your body is a failure. You don’t know how long your transplants are going to last for, every time you come in here it’s just depressing if you don’t know what the result’s going to be like. You’re just living on edge your whole life. It’s hard to explain, but I just… even if you have the post transplant, you kind of still look at your body like it’s a ticking time bomb.

Participant 2: Woman, 30s
And I just remember sitting with my endocrinologist when I was child, because I’d had it at a younger age, and he said, “You’re gonna lose your eyesight. You’re going lose your kidneys. You’re never going to have children… It affected me greatly because you’re going through adolescent so you envision that that’s your fate, and if a doctor’s told you that, you’d believe it. So, I found it difficult to comprehend any other sort of future, to be honest. So, it wasn’t until you start to hear other stories of women having children as a type I diabetic that you realise that there was a lot of – there’s a lot wrong with what he’d said.

Identify concepts (zoom chat)
Perspectives on Pregnancy in Women With CKD: A Semistructured Interview Study

Allison Tong, PhD,1,2 Mark A. Brown, FRACP,3 Wolfgang C. Winkelhauer, MD,4 Jonathan C. Craig, PhD,1,2 and Shipanji Jekudason, PhD

Decisional burden

Devastating loss
- Denied motherhood
- Resolving grief
- Social jealousy
- Barriers to parenthood alternatives

Bodily failure
- Conscious of fragility
- Noxious self
- Suspended in limbo

Intransient guilt
- Disappointing partners

Intransient guilt
- Disappointing partners

Rationalizing consequential risks
- Decisional ownership
- Choosing survival
- Compromising health
- Avoiding fetal harm
- Responding to family protectiveness
- Unjustifiable gamble

Acceptability and justification

Strengthening resolve
- Hope and opportunity
- Medical assurance
- Resolute determination
- Reticent hope

Reorientating focus
- Valuing life
- Gratitude in hindsight
An iterative process

<table>
<thead>
<tr>
<th>Identify concepts (narrow/focussed)</th>
<th>Group similar concepts together</th>
<th>Separate groups of concepts</th>
<th>Bring concepts under a category i.e. theme</th>
<th>Identify relationships, patterns</th>
</tr>
</thead>
</table>

Re-reading and discussion

Descriptive (close to the data) ➞ Analytical/theoretical
Thematic analysis
• Usually inductive – derived from the data
• Constant comparisons within and across sources
• Output ➔ themes (full of meaning)

Content analysis (?)
• Deductive: code data into codes identified and defined apriori
• Used when a meaningful denominator exists for reporting proportions
• Inter-rater reliability

Grounded theory analysis
• Open coding: generating preliminary initial concepts from the data
• Axial coding: reviewing, developing, linking, grouping codes/concepts
• Selective coding: organising and formalising relationships, developing theoretical frameworks
• Memoing
Theory

An organised, coherent, systematic articulation of a set of [ideas or concepts] that are communicated as a meaningful whole. (Reeves 2008)

• Directs your attention
• Provides a framework for thinking about a problem
• Guides study design (e.g. what to focus on)
• Guides data analysis (e.g. tools for interpretation ➔ not to be a restrictive lens)

Developing theory
• Individual insights ➔ understanding the wider relevance (conceptual transferability)
Process – one way to do it

1. Read transcripts (familiarisation) and memo
2. Make initial codes
3. Map/list ideas

- Independent coding?
- Discuss (+ 1 who read the transcripts)
- Revise
- Refine

Focus: attitudes, values, beliefs, goals (not specific action or behavior)
Tips: thesaurus, word maps, google phrases, theories/models

Women's perspectives of pregnancy in CKD

Scope note
- Contraception, genetic testing, family planning, pregnancy, complications, IVF, surrogacy and adoption
- Treatment decision making

BODILY FAILURE
- Despising the noxious self – body is a failure, a ticking time bomb, damaged [link to guilt] “Your body has failed you, and you can’t carry on that legacy,” “like a freak,” “toxic”
- Racing against deteriorating health – imposing pressure and urgency, racing against deteriorating health and age, conscious of time, “It puts a rush on something that should be natural,” Pushing to get the transplant done
- Conscious of fragility – being vigilant and protective of self, isolation in hospital, separation from family in high risk pregnancy clinic, vulnerable
- Suspended in limbo – having to wait to change medications post transplant, waiting for a better kidney

DEVASTATING LOSS – unfair, victim of injustice
- Denied motherhood – being denied motherhood, broken, stolen, and shattered hope, being told they cannot have children, multiple complications, trauma “To my face I was told, ‘so you can’t have children’ then I was just stuck there going, I can’t.” abortion contradicting personal values,
- Disempowered by medical catastrophizing – helplessness, losing control/choice, submitting to medical authority, questioning physician's advice and decisions e.g. unable to understand why she could not be put on dialysis to carry the pregnancy to term. “I don’t think the [warning against pregnancy] should have been so definite, because you trust your doctors and you believe in what they say is gospel. It was very hard for me to make a decision against their advice. Before saying “don't get pregnant, you could die” maybe they should just outline the risks.” Losing right to reproductive freedom or to choose motherhood. Unable to exert control due to unpredictable prognosis.
- Grieving over intangible loss
- Unfulfilled desires
- Social jealousy – seeing other kids is a painful reminder, “I get jealous of pregnant women, because I was ripped off, I’ve been sick”
- Onerous pursuit of alternatives – multiple barriers: surrogacy, adoption due to stigma, legal requirements, cost
4. Code in software

Codes/themes may be revised during this step
4. Generate a report

Report Builder

Report Elements to Include
Header Elements
The following will appear at the start of the report:
- List of all cases
- Case filter criteria
- List of filtered cases
- List of all codes
- Code filter criteria
- List of filtered codes
- Include descriptions
- Include groups
- List of all sources

Code Reference Elements
Reports include only the currently filtered cases and codes. To change the filters, use the Cases > Filter Cases and Codes > Filter Codes menu items before exporting or displaying the report.
- Case name
- Code frequency for this case
- Code
- Code groups for this code
- Source name
- Source type
- Position in the source
- Coded source material
- Exclude time codes
- Annotation
- Make code references hyperlinks

Source Types
- Text
- PDF (text)
- PDF (image)
- Image
- Movie or audio
- Theme

Data Masking
Mask Confidential Data...
No items masked

Sort By
- Case Name
- Code (by name)
- Code (by groups)

Export Report...
- Open Exported Report

Display Options
- Document
- Table

Display Report

Use Settings File...
Save Settings As...
<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
<th>Illustrative quotations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bodily failure</td>
<td>• Being damaged</td>
<td>There is a side of feeling like you’re damaged or there’s nothing else. Your body is a failure. Your body has completely failed you. I thought to have to have a relationship, and it’s made me very nervous about proceeding. I’m hesitant to even think about how I know that this will come up. Even if you have the transplant, you kind of still look at your body like it’s a ticking time bomb. JF You feel like you’re still looking at your body like it’s a ticking time bomb. JF You feel like a freak. JF You feel like your body has failed to you, and you can’t carry on that legacy. The fact that they didn’t know how much nutrients she was receiving from my body at the same time because my body was toxic itself being on dialysis. CB Because the idea of you having so many issues with your body already, I don’t think it’s the right thing to do personally, because I really think you need to be healthy for the baby; if you’re not really healthy it’s very hard to grow a baby well.</td>
</tr>
<tr>
<td></td>
<td>• Insecurities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Toxic Body cannot provide baby with nutrition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Ticking time bomb</td>
<td></td>
</tr>
<tr>
<td>Critical timing</td>
<td>• Racing against deteriorating health, pressure</td>
<td>Even though 30 is still young, you’re body may not be that age. Like with all the medications and everything. So as long before I got too old and too sick. It was pretty terrifying because it puts a time limit on things. It puts a rush on something that should be natural. I’m in a position where I’m like if I wait too long am I going to lose the opportunity to have a baby. Because I don’t know what’s going to happen, like my kidney might last me for 10 years, it might last me for 20 or it might only last me 5. I’d sort of expected my kidney to deteriorate faster than it did, so I thought, “Well, I’ve still got a lot of time”, you know. And then it sort of dwindled on, just slowly rejecting. So it is on my mind now that I’m 36, which is getting old-ish in terms of – by the time I get a transplant. ML I can remember being shocked in the office when he said, “I want you to have all your kids over and done with by the time you’re 30,” ‘cause I thought – Wow – That’s young and I better get cracking – I’ve gotta get cracking on that. And it wasn’t really something I really – I hadn’t put enough thought into planning the family. So we kind of just did it and it was a disaster really because I couldn’t cope.</td>
</tr>
<tr>
<td></td>
<td>• Accelerating transplant</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Missed opportunity</td>
<td></td>
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</table>
7. Write up

**Conscious of physical and medical fragility**: Pregnancy would “put extra strain on the kidney” and potentially jeopardize their health and lives, and that of their baby. Women nervously anticipated complications and early hospitalisation. Symptoms such as bleeding or abdominal tightness were alarming as this could indicate imminent miscarriage or a life-threatening complication. Some women realized that their anxieties caused them to miss the “joy” of pregnancy. Being closely monitored in hospital provided reassurance; however some felt isolated and helpless.” Significant financial strain was incurred for women residing in regional areas.

**Noxious self**: Young women disclosed a deep and silent “heartbreak” from being irreversibly “damaged” by CKD. They were trapped in a “body that has completely failed you,” and unable to “carry on that legacy.” Feeling like a “freak” intensified insecurities in pursuing relationships. Some women on dialysis described their body as “toxic” and thus could not provide their baby with adequate nutrition. Transplant recipients were concerned about the risks of immunosuppressive medications to fetal growth and well-being, and because stable health could never be guaranteed – “you still look at your body like it’s a ticking time bomb.”
2 | Reporting qualitative data and demonstrating rigor
“A concise, coherent, logical, non-repetitive, and interesting account of the story the data tell – within and across themes.”

“Convince the reader of the merit and validity of your analysis.”

(Braun & Clarke 2006)
<table>
<thead>
<tr>
<th>Quantitative</th>
<th>Qualitative</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Objective reality to be observed and discovered</td>
<td>• Reality is socially constructed by an individual, which cannot be measured but it can be interpreted; contextual</td>
</tr>
<tr>
<td>• Reliability: stability of findings</td>
<td>• Reliability: consistency and trustworthiness of findings (Kvale)</td>
</tr>
<tr>
<td>• Validity: truthfulness of findings i.e. measurement</td>
<td>• Validity: whether a method investigates what it purports to investigate (Kvale)</td>
</tr>
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Reporting

EQUATOR www.equator-network.org

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

*International Journal for Quality in Health Care; Volume 19, Number 6: pp. 349–357*

### Domain 3: analysis and findings

#### Data analysis

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<th>Item</th>
<th>Question</th>
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<td>24.</td>
<td>Number of data coders</td>
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<tr>
<td></td>
<td>How many data coders coded the data?</td>
</tr>
<tr>
<td>25.</td>
<td>Description of the coding tree</td>
</tr>
<tr>
<td></td>
<td>Did authors provide a description of the coding tree?</td>
</tr>
<tr>
<td>26.</td>
<td>Derivation of themes</td>
</tr>
<tr>
<td></td>
<td>Were themes identified in advance or derived from the data?</td>
</tr>
<tr>
<td>27.</td>
<td>Software</td>
</tr>
<tr>
<td></td>
<td>What software, if applicable, was used to manage the data?</td>
</tr>
<tr>
<td>28.</td>
<td>Participant checking</td>
</tr>
<tr>
<td></td>
<td>Did participants provide feedback on the findings?</td>
</tr>
</tbody>
</table>

#### Reporting

<table>
<thead>
<tr>
<th>Item</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>29.</td>
<td>Quotations presented</td>
</tr>
<tr>
<td></td>
<td>Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? E.g. <em>participant number</em></td>
</tr>
</tbody>
</table>
General tips when presenting findings (themes)

**Convey meaning:** Develop a phrase/statement that is rich in meaning such that is elucidates the values, beliefs and perspectives of the participants. Avoid broad general/neutral phrases e.g. emotional impact, physical consequences.

**Make it distinct:** Describe each theme as a distinct concept. Avoid overlapping concepts and avoid using the same key words.

**Keep suggestions for the discussion:** Focus on the reason e.g. why do they want more education (disempowered by lack of knowledge), why do they want help with navigating the health system (bewildered and lost in the system, threat and vulnerability).

**Add ”feeling” + “context”:** Capture both the belief/feeling and the context e.g. confused by medical jargon; fear of displacement.

**Aim for 5-7 themes:** Try to condense to 5-7 themes (with a few subthemes to expand on each) for readability and digestibility.

**Focus on concepts not frequency:** Use the phrase “some participants” and avoid quantification and frequency is not a valid indicator of % agreement or importance.
Appraising the conduct qualitative research

- Highly contentious
- Guides available
  
  CASP
  
  Kuper 2008 BMJ

Box 1 Key questions to ask when reading qualitative research studies

- Was the sample used in the study appropriate to its research question?
- Were the data collected appropriately?
- Were the data analysed appropriately?
- Can I transfer the results of this study to my own setting?
- Does the study adequately address potential ethical issues, including reflexivity?
- Overall: is what the researchers did clear?
Constructs | Rigor in qualitative research

Credibility
Dependability
Transferability
Confirmability
Credibility – can the findings be trusted?

- Multiple realities exist (not measuring an objective reality)
- Offers well-rounded, reliable, and sensible explanations based on evidence

Appropriate question guide

Purposive sampling

Thick description – context and findings described in detail

Reflexivity – researchers identify and address own biases that may have influenced decisions made during the study

Triangulation – methodological, theoretical, data/sources, researcher, interdisciplinary
Dependability – is the process logical and auditable?

• Interpretation is intrinsic, not feasible to produce identical findings
• Coherent link ➔ Methodology, methods, data, findings
• Clarity about how data were collected and analyzed to demonstrate rigorous and systematic approach

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Recording of data
Transcription – verbatim
Computer software
Transferability – are the findings relevant to other settings?

- Concepts and theories are relevant and have implications elsewhere

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Comparison with other studies

Thick description – study setting and participant characteristics are described in detail
Confirmability – are the findings and interpretations linked to the data?

- I.e. not a product of the researcher’s imagination
- “Accurately” reflects participant perspectives

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Investigator checking – multiple investigators to ensure that analysis captures full breadth and depth of data

Member checking – participants provide feedback on preliminary findings; integrated

Raw data – e.g. quotations
3 | Presenting qualitative data in a visual manner
Generating a thematic schema

Tips
• Keep themes/subthemes together (one text box)
• Note broader clusters of themes + label?
• Identify central theme/s
• Draw links (tensions, uni or bi-directional pathways)
• Write a figure legend
• Tools: powerpoint, canva

Figure 1. Thematic schema. Bodily failure due to chronic kidney disease (CKD) and treatment intensified the sense of loss and guilt in women with CKD who were unable to have a successful pregnancy. These weighed into difficult decisions about pregnancy, in which women contended with an emotionally charged negotiation of conflicting values; attaining motherhood and averting risks to their own health, survival, and child. A perceived overemphasis on medical risks caused some women to feel helpless, disempowered, and judged, whereas the opportunity to process these risks in their life context provided reassurance, hope, and autonomy.
Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study

Talia Gutman, Camilla S. Hanson, Sarah Bernays, Jonathan C. Craig, Aditi Sinha, Allison Dart, Allison A. Eddy

Gaining knowledge, recognizing own expertise, and being empowered to identify and assert priorities in decision-making.

Disempowered by knowledge imbalance:
- Unprepared and ill informed
- Suspicion of censorship
- Inadequacy as technicians

Recognizing own expertise:
- Intuition and instinct unique to parental bond
- Emerging wisdom and confidence
- Identifying opportunities for control and inclusion
- Empowering participation in children

Striving to assert own priorities:
- Negotiating broader life impacts
- Choosing to defer decisional burden
- Overprotected and overruled
- Struggling to voice own preferences

Managing child’s involvement:
- Respecting child’s expertise
- Attributing risky behaviors to rebellion
- Protecting children from illness burden

Uncertain trajectory of CKD = need to re-negotiate for each decision.
Patient beliefs and attitudes to taking statins for preventing CVD

Ju et al Br J Gen Pract 2018; 68:408-419

Adherence: ~50% (primary prevention); ~70% (secondary prevention) @ 2 years

“It gives me a peace of mind. … my general concern about my health decreases because I take the medication that ultimately is very effective for regulating cholesterol levels.”

Confidence in prevention
• Trust in efficacy
• Minimising catastrophic CVD
• Taking control

Acceptance and use of statins

Routinising into daily life
Patient beliefs and attitudes to taking statins for preventing CVD
Ju et al Br J Gen Pract 2018; 68:408-419

Adherence: ~50% (primary prevention); ~70% (secondary prevention) @ 2 years

"I worry that I may have to take cholesterol medicine for the rest of my life."

"I was on [statins] for two years until I got muscle weakness and actually crashed my car into other cars twice in one week...then when I realised it was because of [my medication], I stopped taking it immediately and told my doctor I’d rather die of a heart attack than die in a car accident."

"I don’t want a load of trash in me. I won’t take medication to prevent disease. I’d rather have another herring (fish)."
Patient beliefs and attitudes to taking statins for preventing CVD

Ju et al Br J Gen Pract 2018; 68:408-419

Adherence: ~50% (primary prevention); ~70% (secondary prevention) @ 2 years
Nephrologists’ perspectives on gender disparities in chronic kidney disease and dialysis

Primary commitment to caregiving
- Coordinating care
- Taking charge of health management
- Deprioritising own health
- Centrality of family in decision-making

Vigilance and self reliance
- Diligence and conscientiousness
- Stoicism and tolerating symptoms
- Avoiding burden on the family
- Isolation and coping alone

Vigilance, stamina, and ownership
- Male dominance in decision-making
- Analytical approach

Stereotyping, stigma, and judgement
- Body image
- Dismissed as anxiety
- Shame and embarrassment
- Weakness and frailty

Inequities compounded by social disadvantage
- Financial and transport barriers
- Without social security
- Limited literacy
- Entrenched discrimination and vulnerability

Protecting masculinity
- Safeguarding the provider role
- Clinging to control
- Self-regard and entitled

Decisional power and ownership
- Male dominance in decision-making
- Analytical approach

Systemic patriarchy

Social norms
Power
Unconscious bias
Translate into implications
<table>
<thead>
<tr>
<th>Domain</th>
<th>Suggestions</th>
</tr>
</thead>
</table>
| **Empowerment in decision-making and self-management** | • Engage trained independent interpreters to support direct communication with women (women)  
  • Establish treatment regimens that are flexible with and centred around life priorities e.g. caregiving responsibility and work (women, men) |
| **Financial support**                     | • Advocate for the provision of universal healthcare coverage/insurance for CKD treatment and dialysis; particularly for those who are socio-economically disadvantaged  
  • Provide assistance in accessing financial support e.g. childcare (women)  
  • Work with stakeholder organisations including government and charity organisations to establish grants specifically for women (women) |
| **Patient awareness and education**       | • Emphasise and encourage ownership of treatment (men)  
  • Identify care-partners to provide support (women) |
| **Communication**                         | • Address appearance and body image concerns, for example in relation of vascular access  
  • Encourage lifestyle management using a sensitive and positive approach |
| **Unconscious bias in clinicians**        | • Establish system alerts for comorbidities, complications, and lab results to avoid dismissing symptoms (women)  
  • Conduct explicit and object assessment of capacity and functioning to inform treatment decisions (women) |
| **Access to clinics**                     | • Establish and provide outreach or mobile clinics (for dialysis, medical consultation, educational sessions) |
| **Accountability**                        | • Establish institutional policies and mechanism for accountability in addressing gender disparities |
Pre-biopsy
- Establish visit plan
- Deliver information for self-management pre/post procedure
- Conduct thorough consent process outlining risks and necessity for biopsy

Biopsy
- Admission: explain expected schedule
- Pre-procedure: introduce operator to patient, check patient comfort
- Post-procedure: explain restrictions/timing (moving, eating, voiding)
- Recovery: check in with patient at expected time
- Discharge: explain post-procedure care, notify caregiver
- All: Keep informed of delays, multidisciplinary communication to maintain patient safety

Post-biopsy
- Delivery of results: schedule clinic to deliver results as soon as possible
Demonstrate impact
Aim: To identify the priorities of patients and caregivers to include in clinical practice guidelines on screening and management of infectious microorganisms in hemodialysis units

- 11 patients/caregivers (4 diagnosed with infectious microorganism)
“You can’t converse with anybody, you’re just by yourself. You feel as if you’re in prison, as if you’ve been convicted of murder and you’re in solitary.”

“The evidence might say you have to isolate them, but the guideline should say what you should do to make sure that the person isolated isn’t feeling stigmatized, upset, alone.”
New guideline topics

1. Privacy and confidentiality
   • Disease notification
   • Exchange of patient information between staff

2. Psychosocial care during and after disease notification
   • Information
   • Ongoing support following diagnosis

3. Quality of transportation
   • Minimize cross-infection during transportation

4. Psychosocial treatment of patients in isolation
   • Inform about the reasons for isolation

5. Patient/caregivers education and engagement
   • Impact of infection on future treatment (dialysis, infection)
   • Transmission (to understand their own risk to others)

6. Patient advocacy
   • Empower patients to disclose information (express concerns anonymously)
Presenting data from mixed methods approaches
Nominal group technique

1. PD-infection
2. Mortality/survival
3. Fatigue
4. Flexibility with time
5. Blood pressure
6. PD failure
7. Ability to travel
8. Sleep disturbances
9. Ability to work
10. Impact on family/friends
“without that [flexibility with time, energy, mobility] you’re really just sitting at home not doing anything.”

Themes

- Serious cascading consequences on health
- Maintaining role and social functioning
- Beyond control and responsibility
- Current and impending relevance
- Requiring constant vigilance

Outcome groups

- Morbidity and mortality
- Lifestyle and functional outcomes
- Symptoms
- Biochemical parameters

Higher prioritization

Lower prioritization
Identifying outcomes important to patients with glomerular disease and their caregivers: a multinational nominal group technique study
Summary

- The findings should reflect the full range and depth of the data collected, and be presented in a comprehensible, insightful, trustworthy and "actionable" manner.
- Demonstrate credibility, dependability, transferability and confirmability.
- This may increase the potential of qualitative evidence to impact on practice and policy.