

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



ACCORDS Upcoming Events

May 23, 24, & 25
10:00 - 3:00 PM MT

COPRH Con 2022: *Disseminating, Scaling and Sustaining Pragmatic Research: Improving Health in Diverse Settings*



Reporting and Presenting Data from Qualitative and Mixed Methods Studies

Presented by:

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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

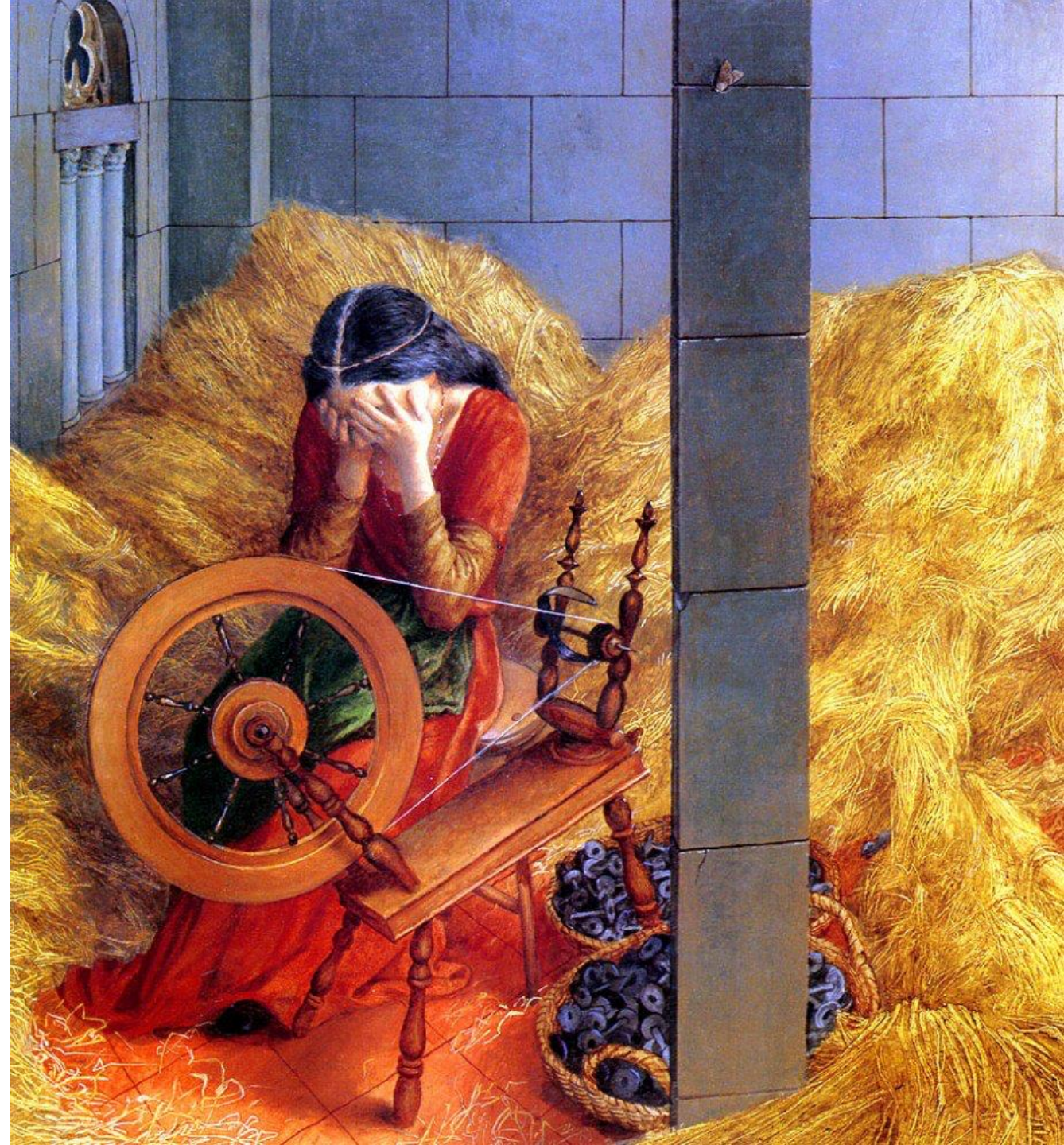


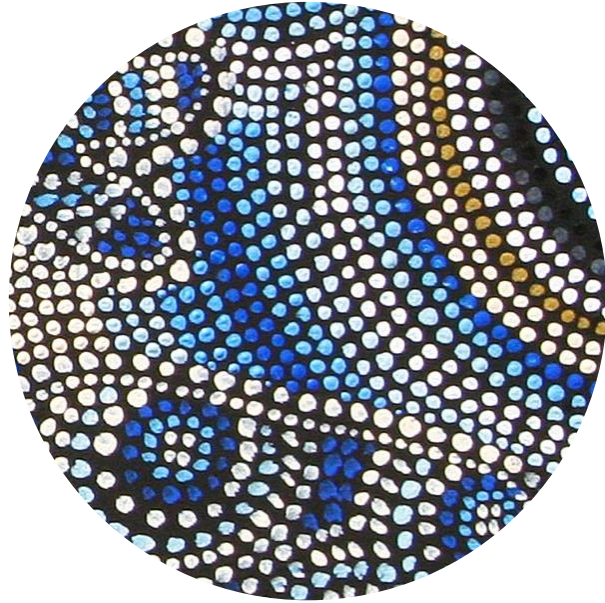
1. Methods of analyzing qualitative data
2. Reporting qualitative data and demonstrating rigor
3. Presenting qualitative data in a visual manner

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



Quantitative

- Descriptive statistical analysis, variance of responses, determine general trends
- Inferential analysis and refined analysis using the appropriate statistical tests
- Software used to conduct statistical analysis
- Quantified estimates of effect or associations, statistics
- Frequency
- Emphasis on **generalisability** (involves statistical analysis to determine the extent to which the findings can be extrapolated to another population)

Qualitative

- Reading of the data, making memos, conceptualizing the data, grouping concepts into themes, identifying patterns and relationships among themes
- **Coding** and identifying concepts, grouping into themes
- Software used to store, label, retrieve data (facilitates but does not do analysis)
- Narrative and rich description
- Breadth and depth
- Emphasis on **transferability** of concepts and theories (the reader determines whether the findings “fit” or resonate in their own context or experience)

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

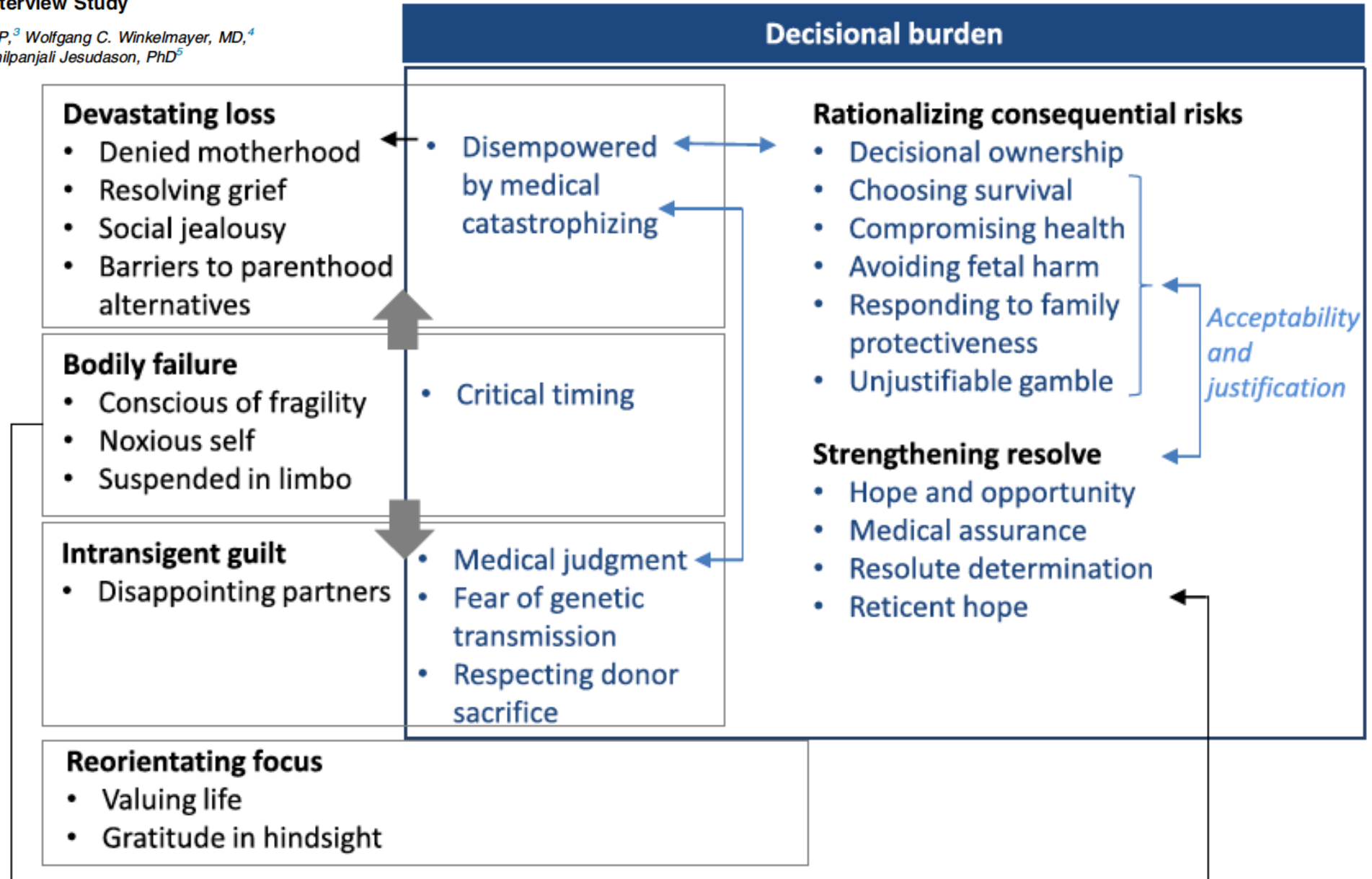
And I just remember sitting with my endocrinologist when I was child, because I'd had it at a younger age, and he said, "You're gonna lose your eyesight. You're going lose your kidneys. You're never going to have children... It affected me greatly because you're going through adolescent so you envision 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)

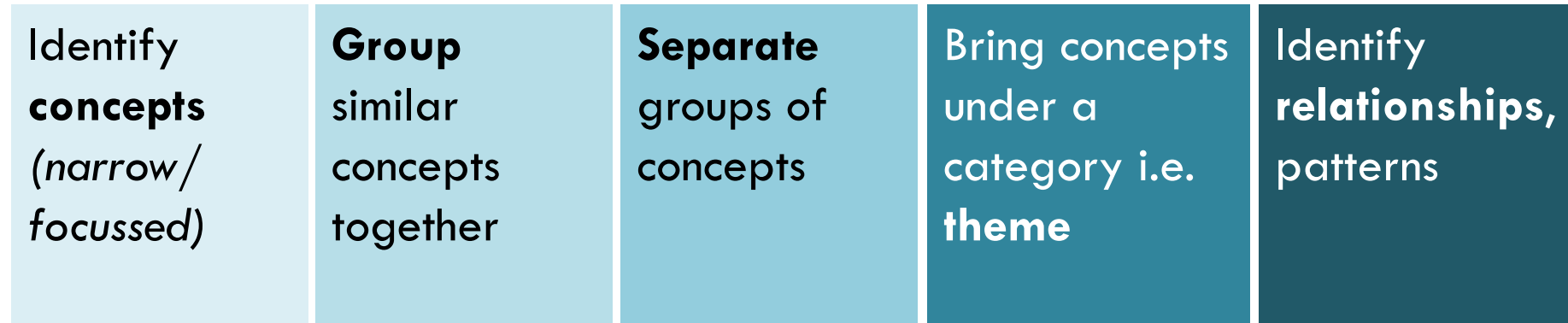
**Perspectives on Pregnancy in Women With CKD:
A Semistructured Interview Study**



Allison Tong, PhD,^{1,2} Mark A. Brown, FRACP,³ Wolfgang C. Winkelmayr, MD,⁴
Jonathan C. Craig, PhD,^{1,2} and Shilpanjali Jesudason, PhD⁵



An iterative process



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 pregnancy, 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

The screenshot displays the HyperRESEARCH 3.5.2 software interface. It is divided into several panes:

- Case List (Top Left):** A table listing cases with columns for Code Name, Source, Type, and Position. A red box highlights the text "Codes/themes may be revised during this step" above this pane. A black box labeled "Case (interviewee)" is placed over the first row of the table.
- Code Book (Bottom Left):** A list of codes with checkboxes. A black box labeled "Codes" is placed over the list.
- Source Transcript (Right):** A window titled "Source: Albert_Lam_151113.rtf" showing a transcript of an interview. A black box labeled "Source (transcript)" is placed over the top portion of the text.
- Code Application (Middle Left):** A pane showing a list of codes being applied to the selected source text. A black box labeled "Codes" is placed over this list.
- Window Navigation (Bottom Right):** A blue box labeled "Window → default layout 2" is placed over the bottom right corner of the interface.

4. Generate a report

The screenshot displays the HyperRESEARCH 3.5.2 application window. The main window shows a report titled "Report 1" with page number 1 of 34. The report content includes text from a source material, such as "Interviewee: Yeah. Well I did this, because this is what our peers are suggesting should happen. If it went horribly wrong, I did my best. So there is protection for the practitioners by following the rules." and "Interviewee: The first thing that comes to mind to me is that we should have evidence for what we're doing. That's what comes up in my mind, and I guess we work with that quite a bit because if you think of it that if we treat these livers and have I got evidence to treat them, I haven't had but I now have. You know because 600 patients later, analysing them and writing them up, it makes a difference, but you could still criticise me because it's retrospective. It's not a...".

The "Report Builder" dialog box is open, showing various options for report generation:

- Report Elements to Include**
 - Header Elements**
 - 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**
 - 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)
- Display Options**
 - Document
 - Table
- Buttons:** Use Settings File..., Save Settings As..., Export Report..., Display Report, Open Exported Report

6. Table

Theme	Description	Illustrative quotations
<p>Bodily failure</p> <p>Noxious self</p> <div data-bbox="109 386 499 618" style="background-color: #800080; color: white; padding: 10px; text-align: center;">Expand and describe</div>	<ul style="list-style-type: none"> • Being damaged • Insecurities • Toxic body cannot provide • bo • Tic <div data-bbox="580 386 975 618" style="background-color: #800080; color: white; padding: 10px; text-align: center;">Key points</div>	<p>There is a side of feeling like you're damaged or there's nothing else.</p> <p>Your body is a failure. Your body has completely failed you.</p> <p>I thought to have to have a relationship, and it's made me very nervous about proceeding.</p> <p>I'm hesitant to know that this will come up.</p> <p>Even if you have still look at your body like it's a ticking time bomb. JF</p> <p>Your feel like</p> <p>You feel like and you can't carry on that legacy.</p> <p>The fact that patients she was receiving from my body at the same time because my body was toxic itself being on dialysis. CB</p> <p>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.</p>
<p>Critical timing</p>	<ul style="list-style-type: none"> • Racing against deteriorating health, pressure • Accelerating transplant • Missed opportunity 	<p>Even though 30 is still young, you're body may not be that age. Like with all the medications and everything.</p> <p>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.</p> <p>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.</p> <p>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</p> <p>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.</p>

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.”

- Write from the participants’ perspective
- Use quotations
 - Gold nuggets only (compelling)
 - Trim and edit to make sense
 - Vary use (embedded, as an example)
- Table of quotations (3 pages max)
- Tag quotations
- Consider including eTables
- Comparisons

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)

Quantitative

- Objective reality to be observed and discovered
- Reliability: stability of findings
- Validity: truthfulness of findings i.e. measurement

Qualitative

- Reality is socially constructed by an individual, which cannot be measured but it can be interpreted; contextual
- Reliability: consistency and trustworthiness of findings (Kvale)
- Validity: whether a method investigates what it purports to investigate (Kvale)

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

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

Reporting

- | | |
|--------------------------|--|
| 29. Quotations presented | Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i> |
|--------------------------|--|

General tips when presenting findings (themes)

Convey meaning: Develop a phrase/statement that is rich in meaning such that it 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

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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

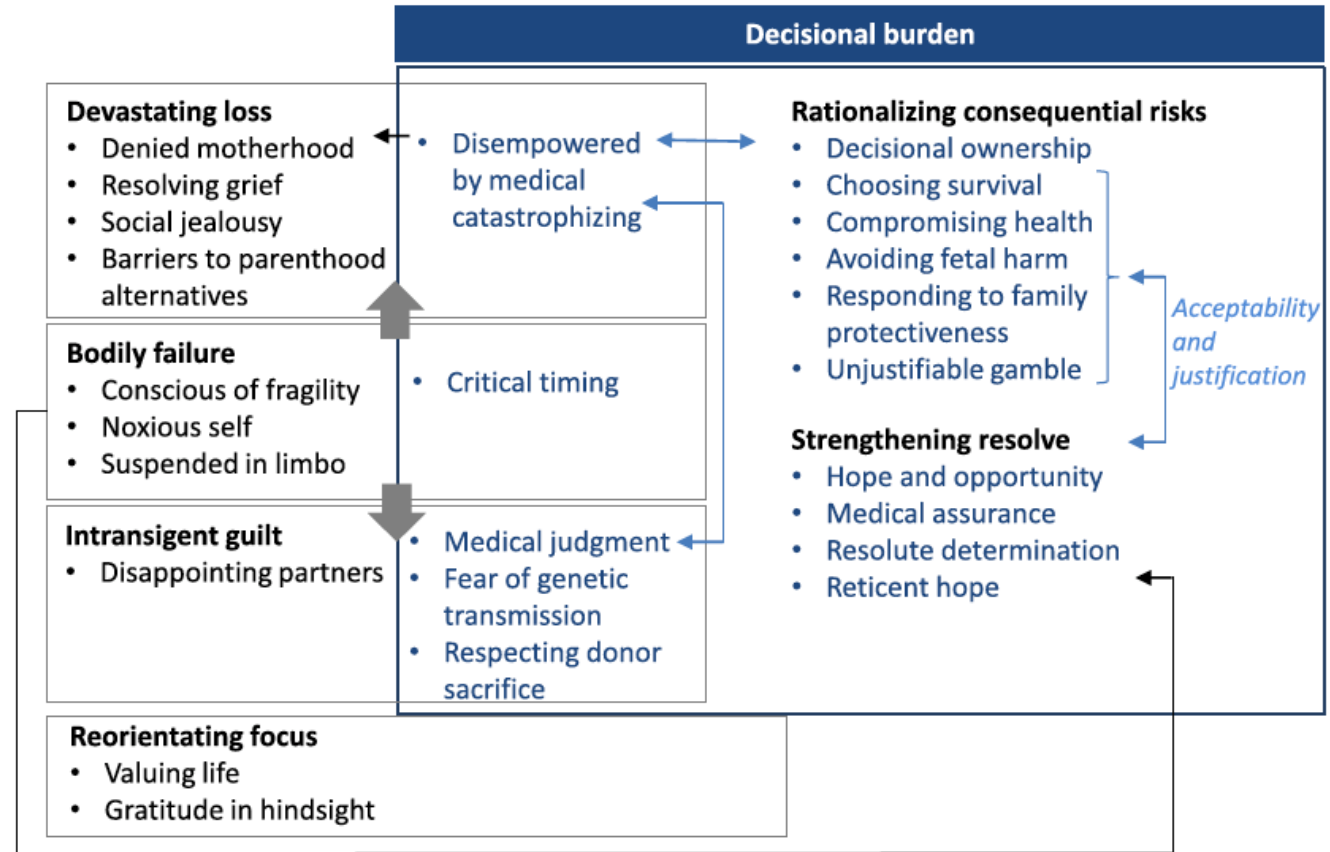


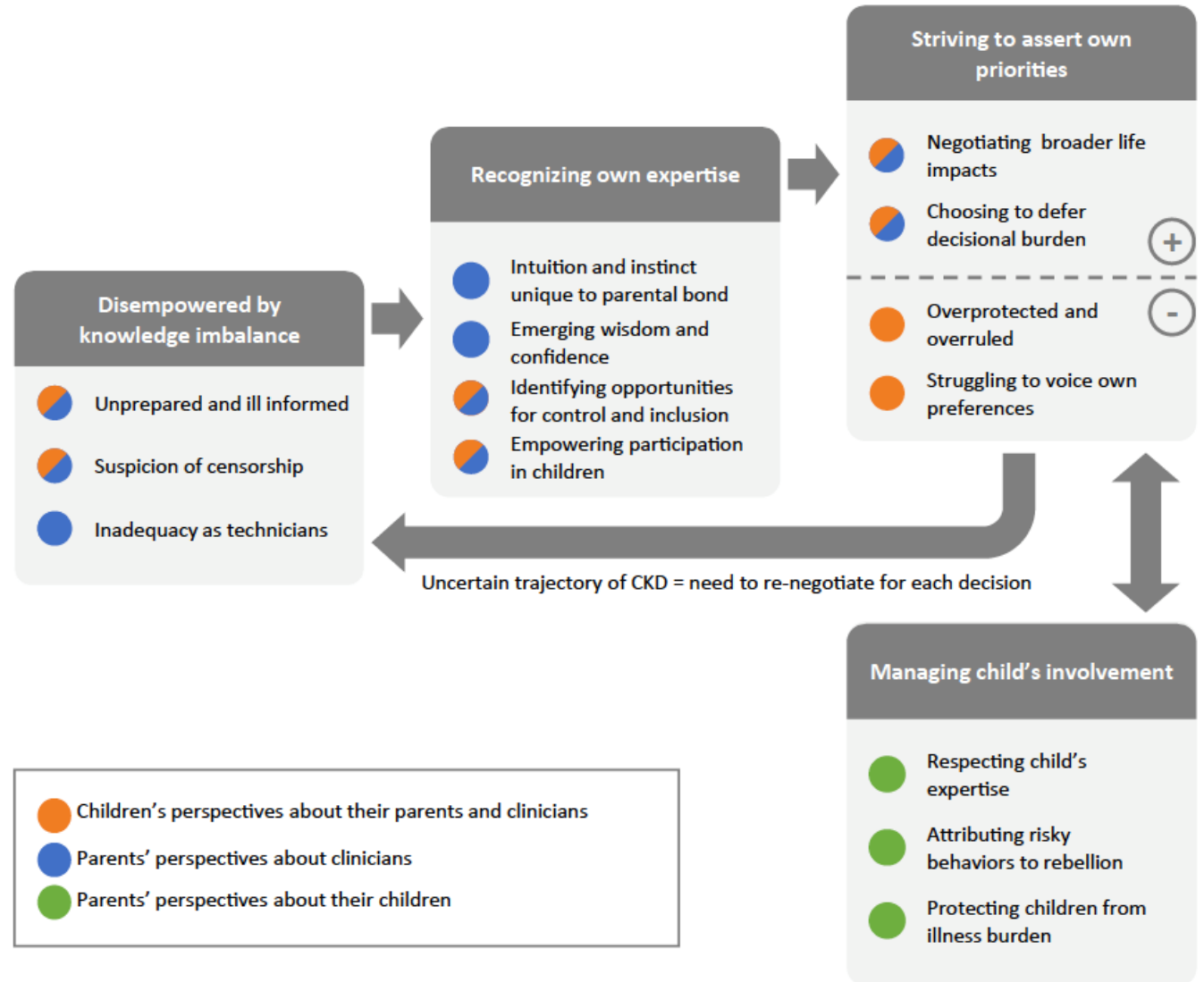
Figure 1. Thematic schema. Bodily failure due to chronic kidney disease (CKD) and treatment intensified the sense of loss and guilt in women with CKD who were unable to have a successful pregnancy. These weighed into difficult decisions about pregnancy, in which women contended with an emotionally charged 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

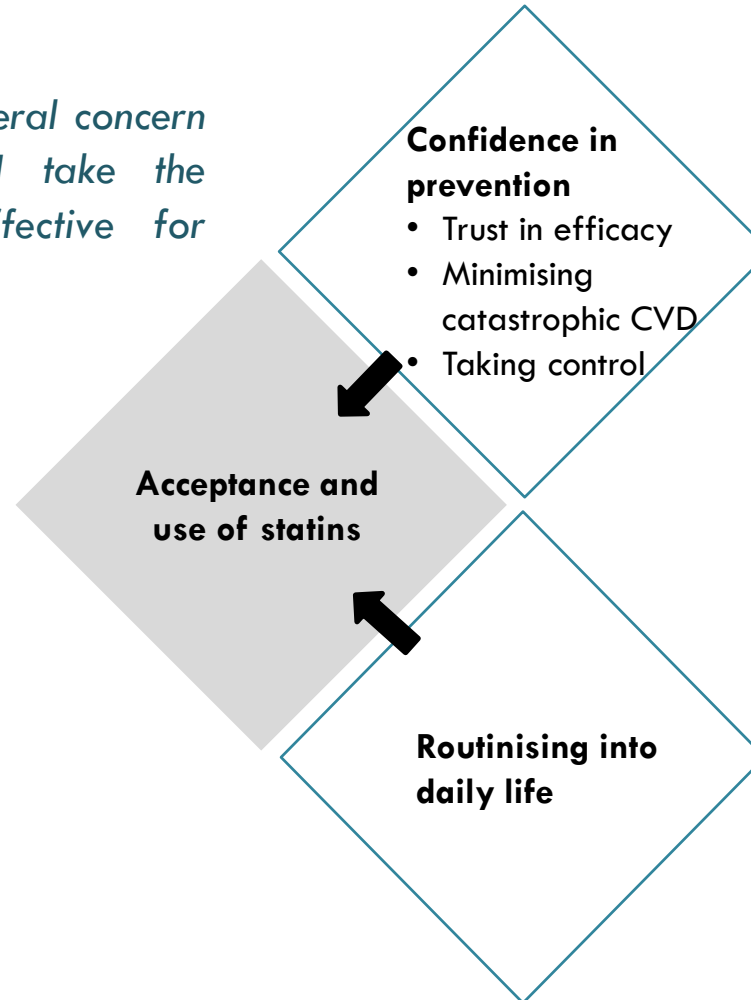


Patient beliefs and attitudes to taking statins for preventing CVD

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

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

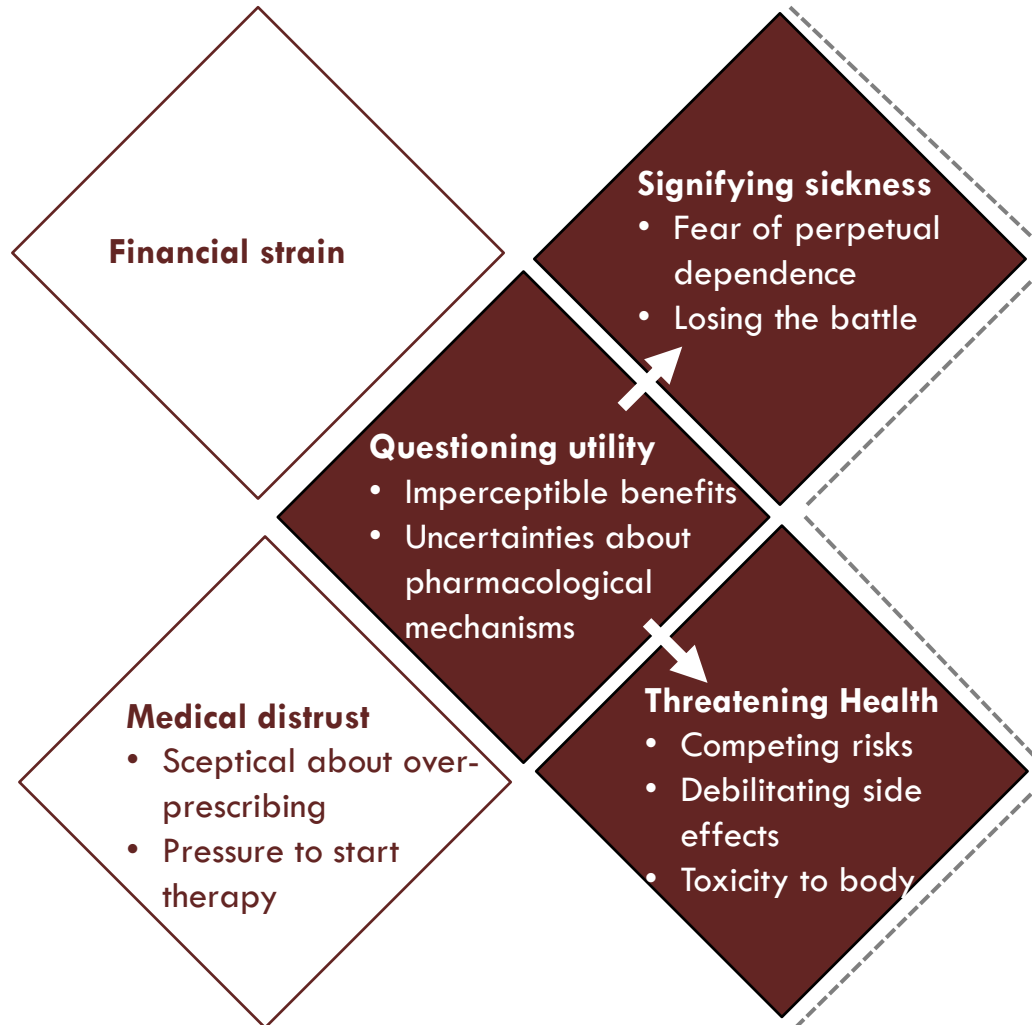
“It gives me a peace of mind. ... my general concern about my health decreases because I take the medication that ultimately is very effective for regulating cholesterol levels.”



Patient beliefs and attitudes to taking statins for preventing CVD

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

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

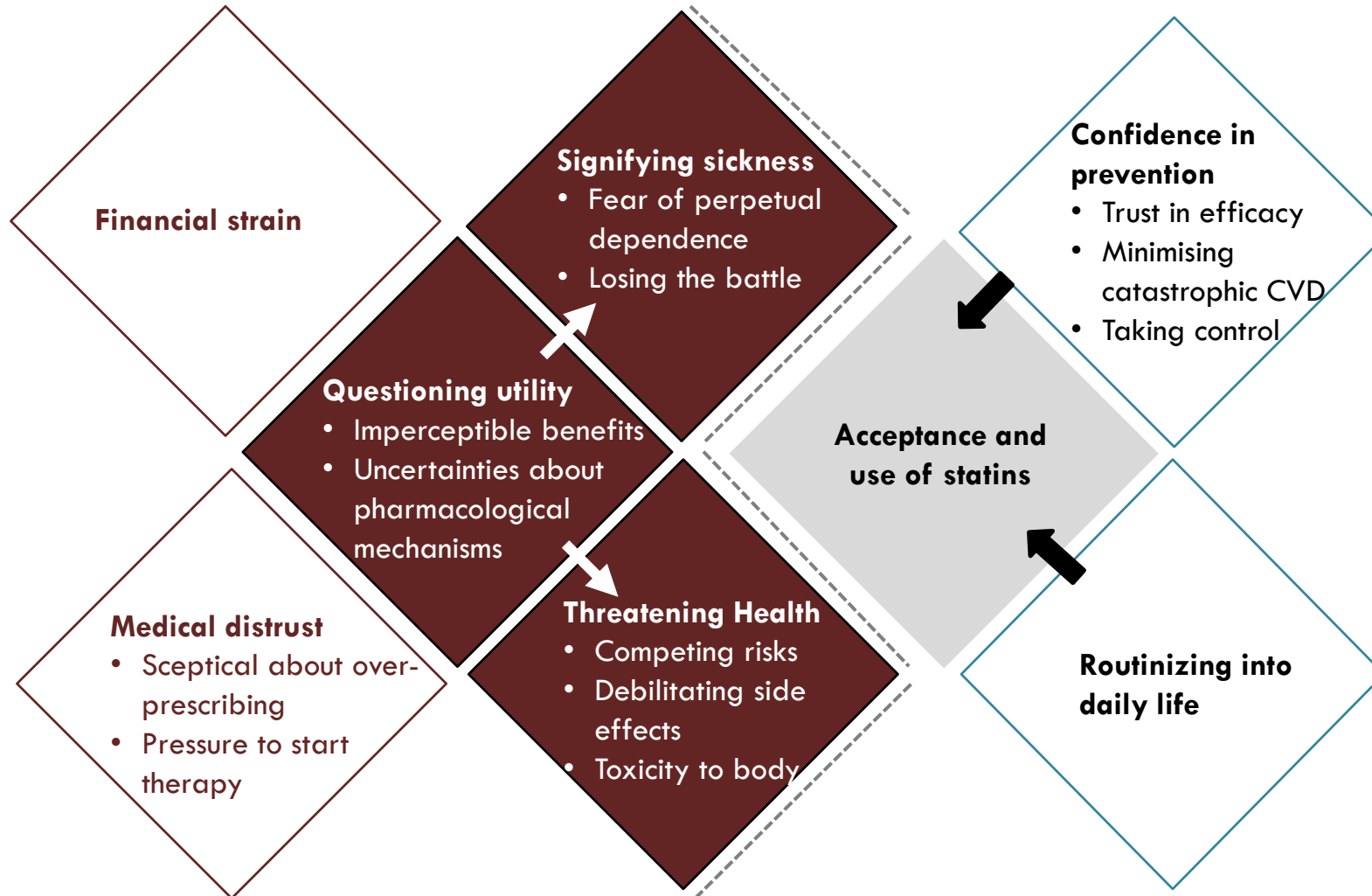
“I was on [statins] for two years until I got muscle weakness and actually crashed my car into other cars twice in one week...then when I realised it was because of [my medication], I stopped taking it immediately and told my doctor I'd rather die of a heart attack than die in a car accident.”

“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).”

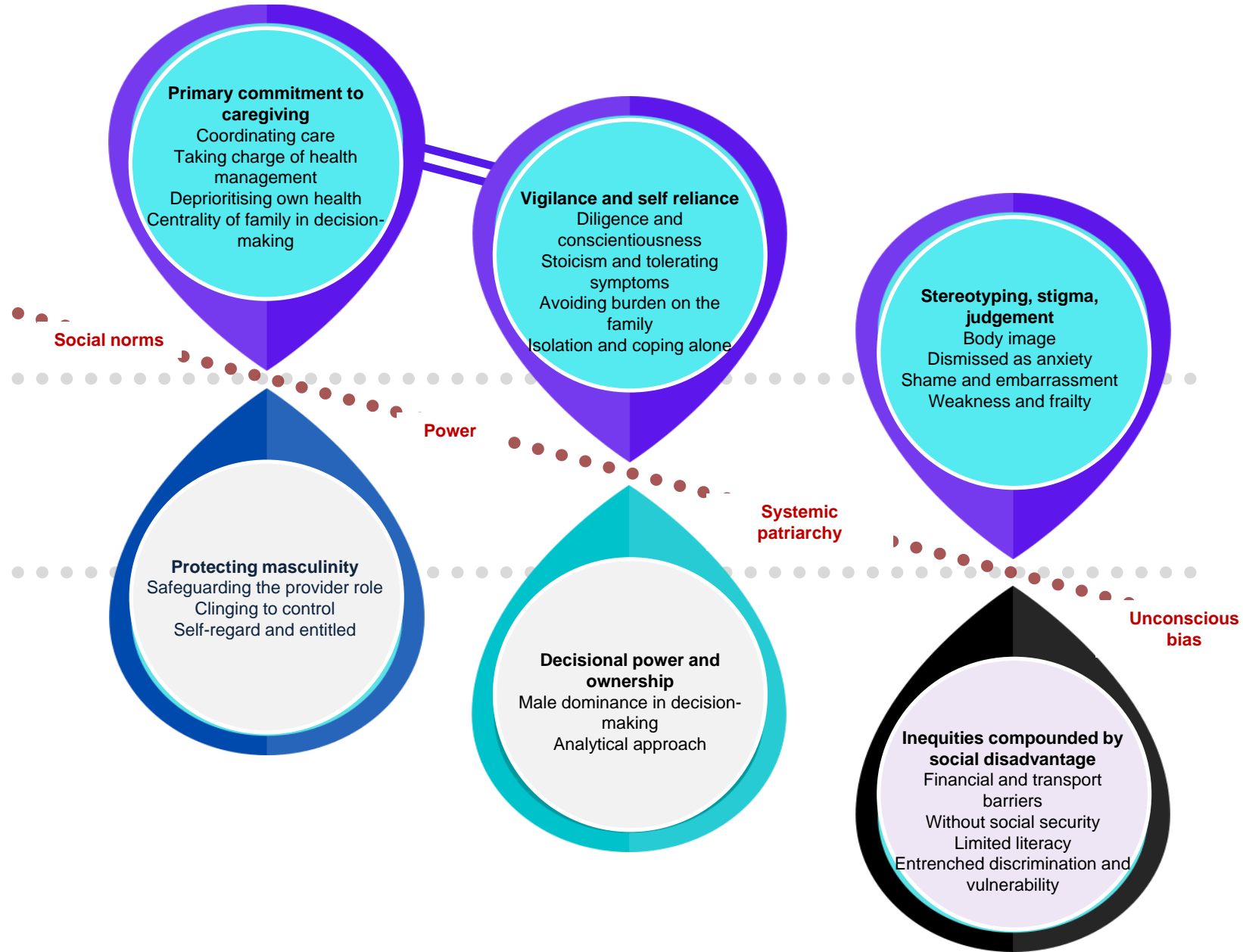
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Nephrologists' perspectives on gender disparities in chronic kidney disease and dialysis



Translate into implications

Domain	Suggestions
Empowerment in decision-making and self-management	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Emphasise and encourage ownership of treatment (men) Identify care-partners to provide support (women)
Communication	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Establish and provide outreach or mobile clinics (for dialysis, medical consultation, educational sessions)
Accountability	<ul style="list-style-type: none"> 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 b

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 ma

Post-biopsy

- Delivery of results: schedule clinic to deliver results as soon as pos

Demonstrate impact

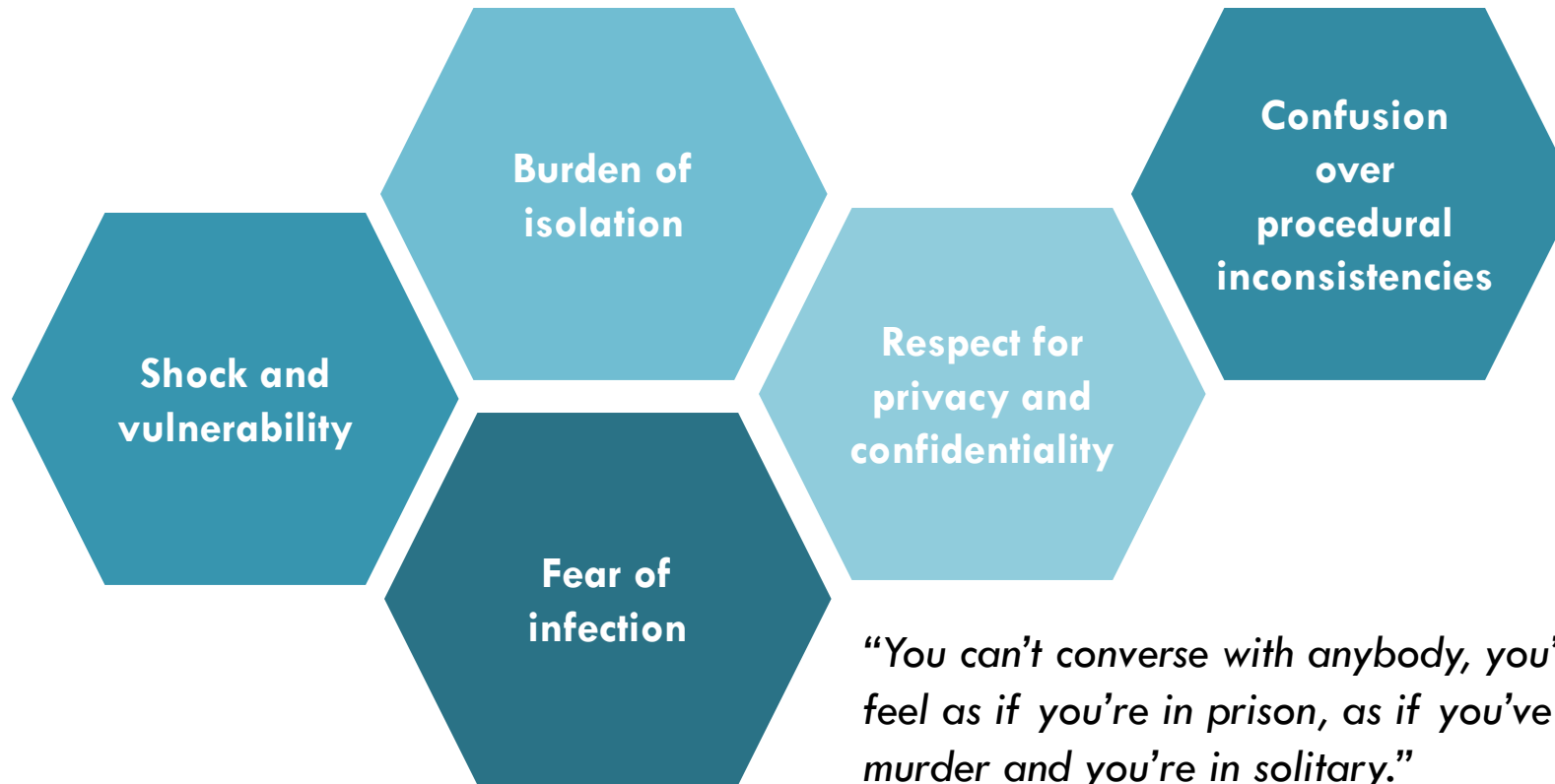
Original Article

Infection

Identifying and integrating patient and caregiver perspectives for clinical practice guidelines on the screening and management of infectious microorganisms in hemodialysis units

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)

DISEASE NOTIFICATION -
WHO-HOW-WHEN

OUTCOME - REASSURANCE
& PATIENT CONFIDENCE / PRIVACY.

TRANSPORT - (NEPT): TAXI v. ^{PATIENT} TRANSPORT
CROSS-CONTAMINATION ISSUES

EDUCATION - INFORM FULL OUTCOMES.

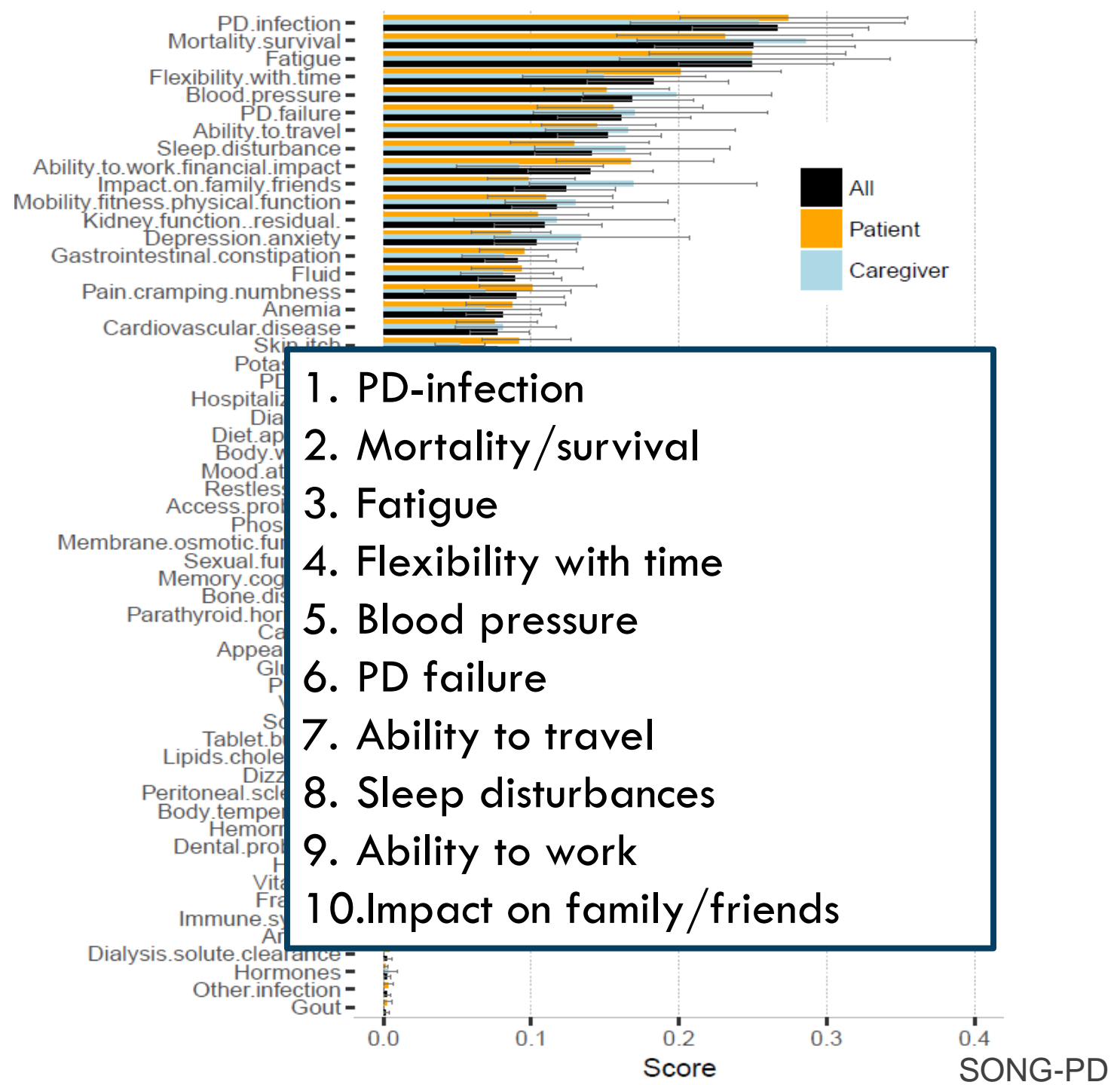
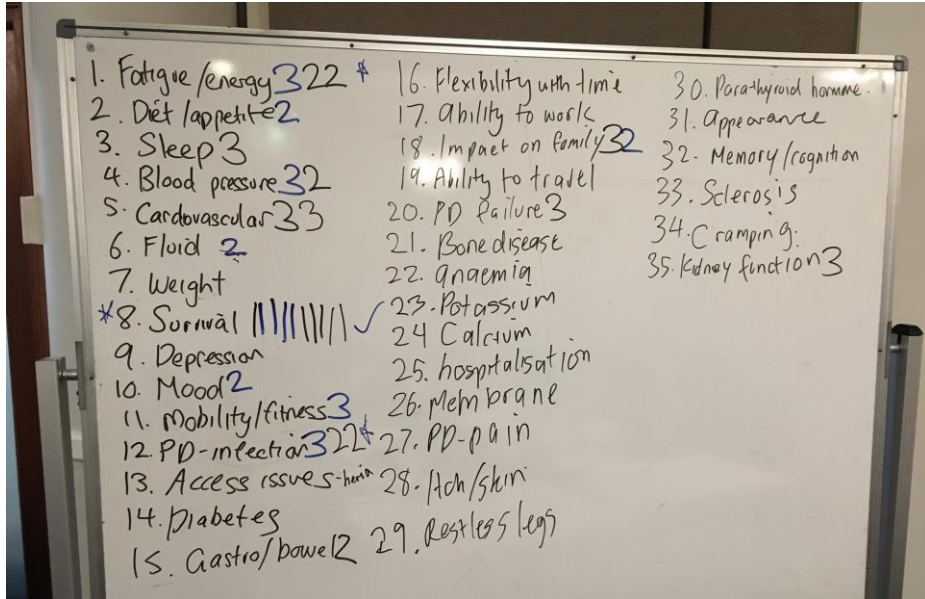
FREQUENCY OF SCREENING
- SPREAD OF INFECTION CONTROLS

SOCIAL WORKER - COUNSELLING
- DEAL WITH BEING INFORMED
x DEPRESSION: SHOCK: PANIC

PREVALENCE / HOW OFTEN OCCURS
& METHOD OF INFORMING WHEN IT HAPPENS
IN EACH DIALYSIS UNIT.
(INCLUDING HOSPITAL UNITS)

Presenting data from mixed methods approaches

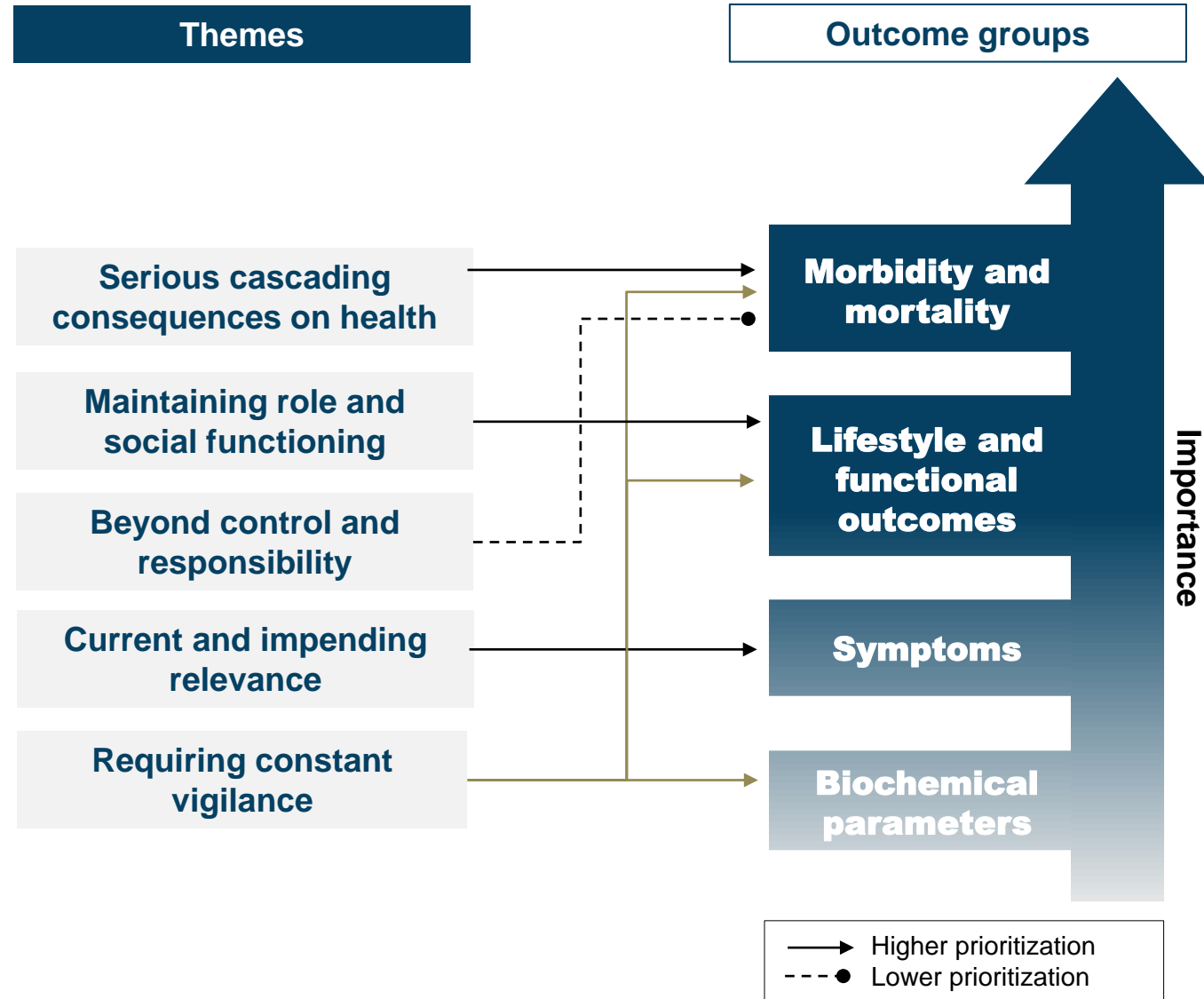
Nominal group technique



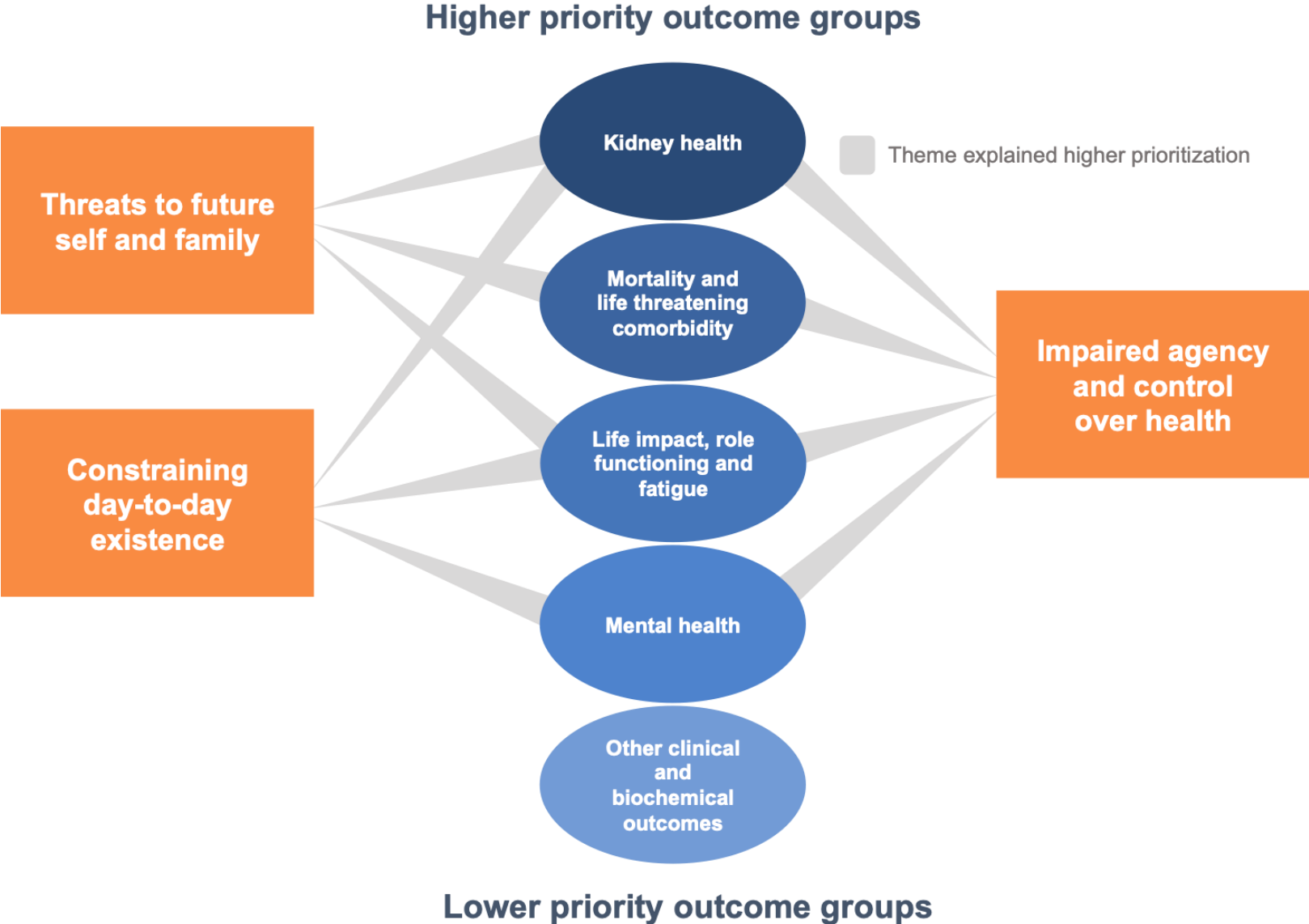
1. PD-infection
2. Mortality/survival
3. Fatigue
4. Flexibility with time
5. Blood pressure
6. PD failure
7. Ability to travel
8. Sleep disturbances
9. Ability to work
10. Impact on family/friends

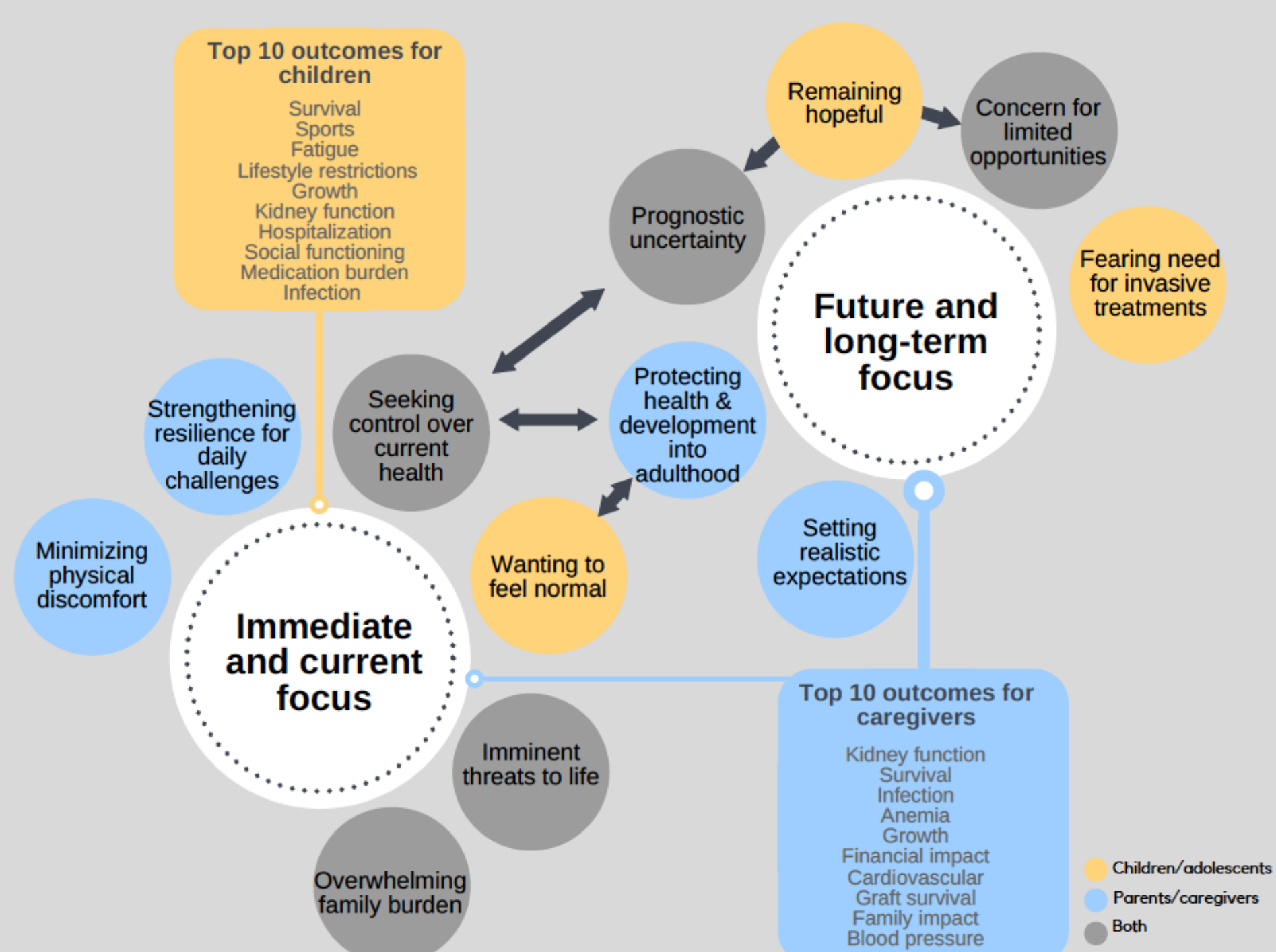
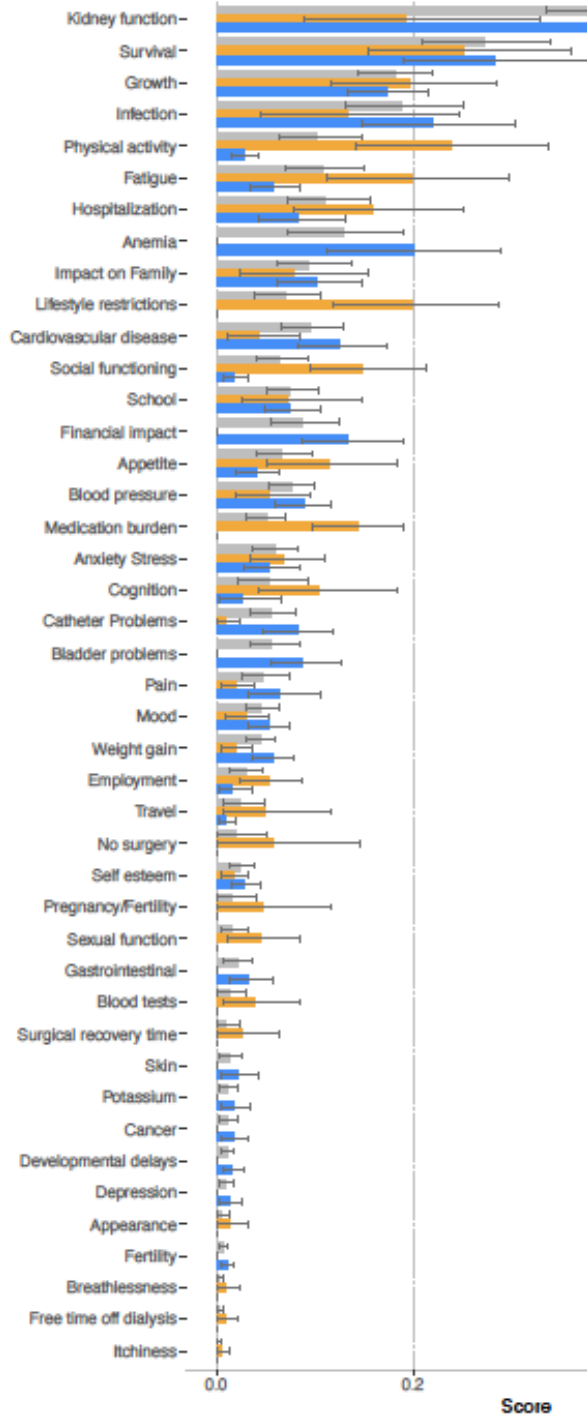
Nominal group technique

“without that [flexibility with time, energy, mobility] you’re really just sitting at home not doing anything.”



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.