Person-centred care in chronic kidney disease: The CKD-SMS study

Kathryn Havas
(PhD Candidate, BPsySc, Hons I)

Principal supervisor: Professor Ann Bonner
Associate supervisor: Associate Professor Clint Douglas
Person-centred care

- Patient-reported preferences, values, & needs
- Coordination & integration of care
- Information, communication & education
- Physical comfort

8 Dimensions of Person-Centred Care

- Emotional support & alleviation of fear & anxiety
- Involvement of family & friends
- Transition & continuity
- Access to care
1. What do people want?
To inform design of the program
1. What do people want?
   To inform design of the program

2. Implementation of our interpretation of what people want
1. What do people want?
   To inform design of the program

2. Implementation of our interpretation of what people want

3. How did we do?
   Evaluation of the program
1. What do people want?
   To inform design of the program

2. Implementation of our interpretation of what people want

3. How did we do?
   Evaluation of the program
Phase One
Patient Preferences

Phase Two
Main Study

Phase Three
Participant feedback

Literature review
Instrument development
Ethics approval
Data collection ($N = 97$)

Ascertains SMS desires of people with CKD.
Publications: One literature review; one research article

Intervention development
Ethics approval
Intervention delivery & evaluation ($N = 66$)

Develop, implement, and evaluate a person-centred, theory-based self-management intervention for people with stage 1-4 CKD
Publication: One research article

Brief, semi-structured interviews & analysis ($N = 64$)

Investigate participant experiences of intervention.
Publication: One research article
Phase 1: What do People with CKD want?

- Disease-specific knowledge
- Engaging & sustaining social support
- Modifying lifestyle
- Building & sustaining effective relationships with HCPs
- Actively participating in healthcare
Phase 2: CKD-SMS

• Goal-setting
• SCT strategies
  – Performance accomplishments
  – Vicarious learning
  – Verbal persuasion
  – Stress and anxiety reduction
    • Mindfulness
    • Motivational interviewing
    • CBT
• Education
• Self-monitoring
• Problem-solving
Contents

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Phase 2: Outcome Measures

Primary outcomes:
• Self-efficacy (SEMCD-6)
• Self-management (Aus.CKD-SM)

Secondary Outcomes
• HRQoL (SF-12)
• CKD knowledge (KIKS)
• Emotional distress (DASS-21)
• Understanding of physical activity guidelines (AAS) and engagement in physical activity (HAP)
• Fruit and vegetable consumption (serves yesterday)
• Communication with HCPs (PiH)
• Alcohol use (AUDIT-C)
• Physiological measures (eGFR, weight, BP)
Ineligible (n = 103):
Did not speak English: n = 13
Cognitively impaired: n = 8
Stated no kidney problems: n = 30
Already receiving extensive support through another program: n = 8
eGFR <25: n = 25
Inaccessible to researchers: n = 19

Patients Approached (Across Two Sites): N = 348

Declined (n = 167)
No interest: n = 121
Overburdened with appointments: n = 17
Too physically unwell: n = 29

Baseline (T0) Assessment (n = 78)
1) Demographic & clinical characteristics
2) Standardised patient-reported measures

Goal-setting
Lost to Follow-Up ($n = 12$)
Uncontactable: $n = 6$
Withdrawn: $n = 6$
  - No time/need: $n = 1$
  - Too unwell: $n = 4$
Deceased: $n = 1$

Follow-up (T1) Assessment ($n = 66$)
1) Clinical characteristics
2) Standardised patient-reported measures

Intervention
Session 1: Face-to-face ($n = 74$)

Intervention
Session 2: Phone session ($n = 72$)

Intervention
Sessions 3-11 (may choose 1 to 9 further sessions): Phone sessions ($n = 72$)

Intervention
Session 12: Face-to-face ($n = 68$)

Final Sample:
T0 Only: $N = 78$
T0 and T1: $N = 66$

Data Analysis
1) Descriptive background and clinical data
2) Between-groups t-tests and Fisher's exact tests to evaluate potential baseline differences between completers and non-completers
3) Repeated-measures t-tests/Wilcoxon Signed-Rank tests to test for significant differences on outcome measures pre- and post-intervention
Phase 2: Participant Characteristics

**Gender**
- Male: 40%
- Female: 60%

**Age**
- 80+: 8%
- 25-39: 18%
- 60-79: 42%
- 40-59: 32%

**Time since Diagnosed**
- ≤12 Months: 15%
- >1-3 Years: 17%
- >3-5 Years: 20%
- >5-10 Years: 16%
- ≥10 Years: 33%
- Unknown: 3%

N = 78
Phase 2: Participant Characteristics

Level of Education

- No Formal: 1%
- Grade 10: 10%
- Grade 12: 9%
- TAFE/Cert/Diploma: 27%
- Undergraduate: 18%
- Masters: 4%
- Doctoral: 3%

Employment

- Retired: 41%
- Full time: 32%
- Part time: 10%
- Casual: 3%
- Unemployed: 12%

Annual Household Income

- <$20,000: 13%
- $20,000-$39,999: 30%
- $40,000-$59,999: 10%
- $60,000-$79,999: 9%
- $80,000-$99,999: 10%
- $100,000-$119,999: 8%
- $120,000+: 8%
- Unreported: 9%
Phase 2: Participant Characteristics

**CKD Stage**
- CKD Stage 1: 16%
- CKD Stage 3A: 29%
- CKD Stage 3B: 26%
- CKD Stage 4: 10%
- CKD Stage 5: 14%

**Cause**
- SLE: 33%
- Other: 33%
- Renovascular: 17%
- GN: 17%
- DM: 16%
- Unknown: 8%

**CCI**
- 2-5: 50%
- 6-9: 43%
- 10+: 7%
Phase 2: Results

Primary outcomes:
- Self-efficacy (SEMCD-6)*
- Self-management (Aus.CKD-SM)*

Secondary Outcomes
- HRQoL (SF-12)*
- CKD knowledge (KIKS)*
- Emotional distress (DASS-21)*
- Understanding of physical activity guidelines (AAS)* and engagement in physical activity (HAP)*
- Fruit and vegetable consumption (serves yesterday)*
- Communication with HCPs (PiH)*
- Alcohol use (AUDIT-C)*
- Physiological measures (eGFR, weight, BP*)
Self-managing my CKD:

- Modifying lifestyle
- Actively participating in healthcare (including managing medications and establishing routine and planning ahead)
- Developing and sustaining a positive attitude and caring for mental and physical wellbeing
- Building and sustaining effective relationships with HCPs
- Recognising and effectively responding to symptoms
- Engaging and sustaining social support
- Maintaining social and occupational roles
Conclusions and Implications

- Self-management of CKD is multifaceted and complex, and people desire support.
- SCT shows promise as a framework for CKD self-management.
- Outcomes can be improved in a short period with relatively little intervention.
- Participants see the value in self-management support.
- This group are heterogeneous and complex, and a person-centred approach to self-management support is required.
Acknowledgements

- QUT APA Scholarship
- CKD.CRE Scholarship
- Kidney Health Australia
- Staff at MNHHS KHS & Inala Primary Care