

The Kidney Supportive Care Program

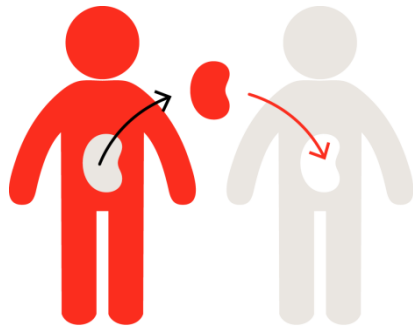
Frail & Complex Stream



Louise Purtell

Kidney supportive care

- People with advanced CKD are frail, elderly and/or complex
- Require a care pathway that addresses their needs



Transplant



Dialysis



Supportive Care

“We are inappropriately dialysing patients, I think; prolonging their suffering and not providing them alternative routes to manage their symptoms appropriately.”

~Staff member

“Patients who were electing to have conservative management in end stage kidney stage, or who were struggling on dialysis [and] were very symptomatic, really often weren’t able to access appropriate palliative care support.”

~Staff member

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What are the needs of elderly, frail, complex CKD patients?



Symptom management



Psychosocial, spiritual support for person and family



Support for dialysis decision-making

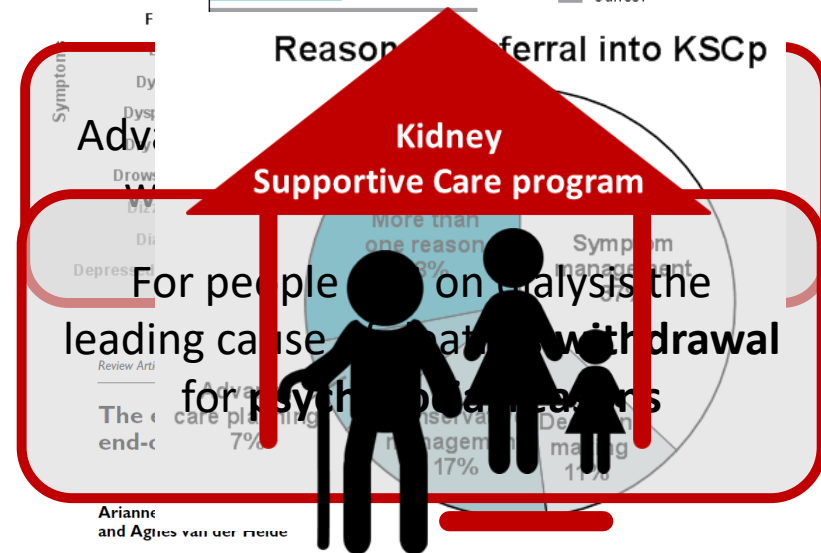


Planning for end-of-life



Personalised care

Comparison of symptoms between people with cancer and ESKD in the last month of life

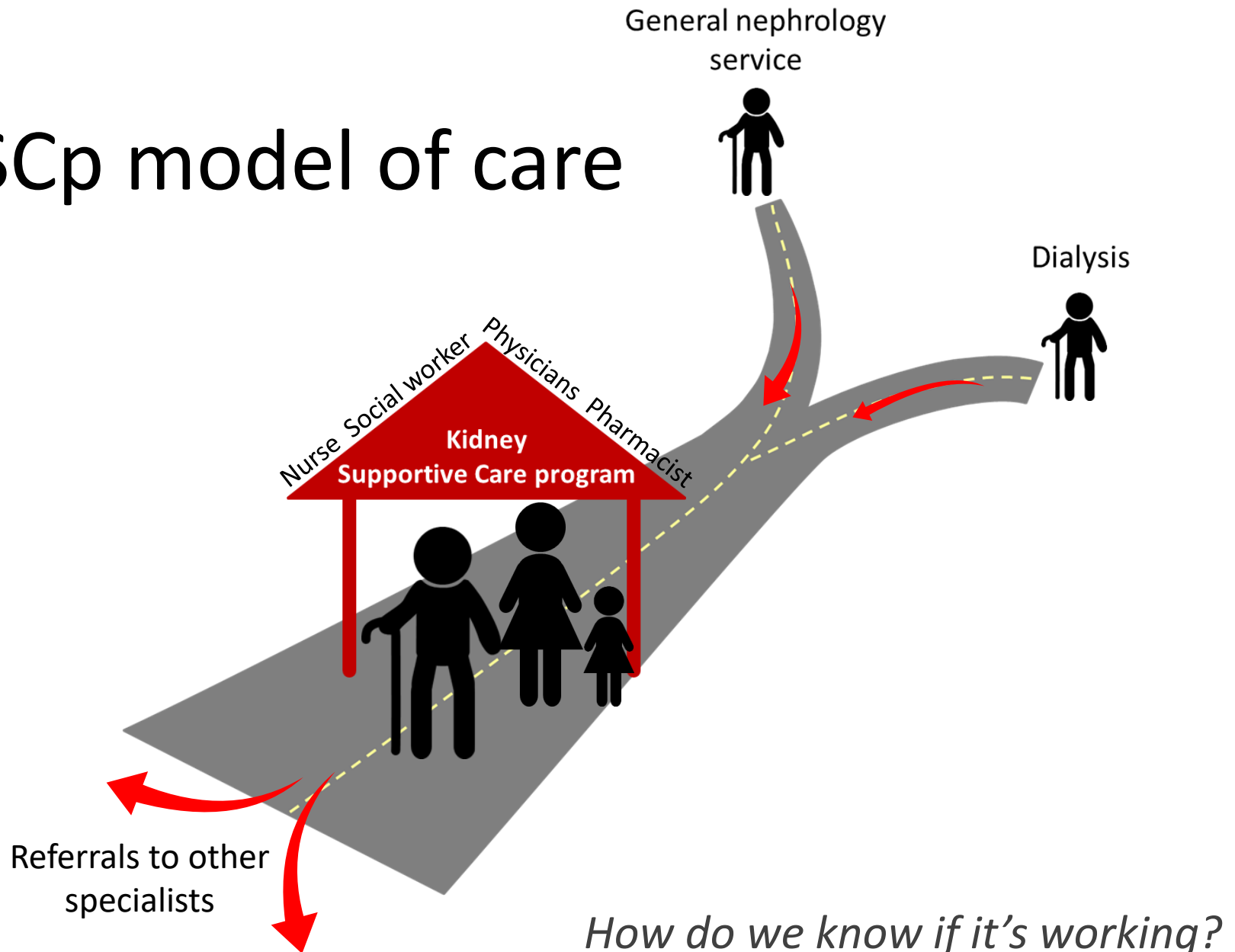


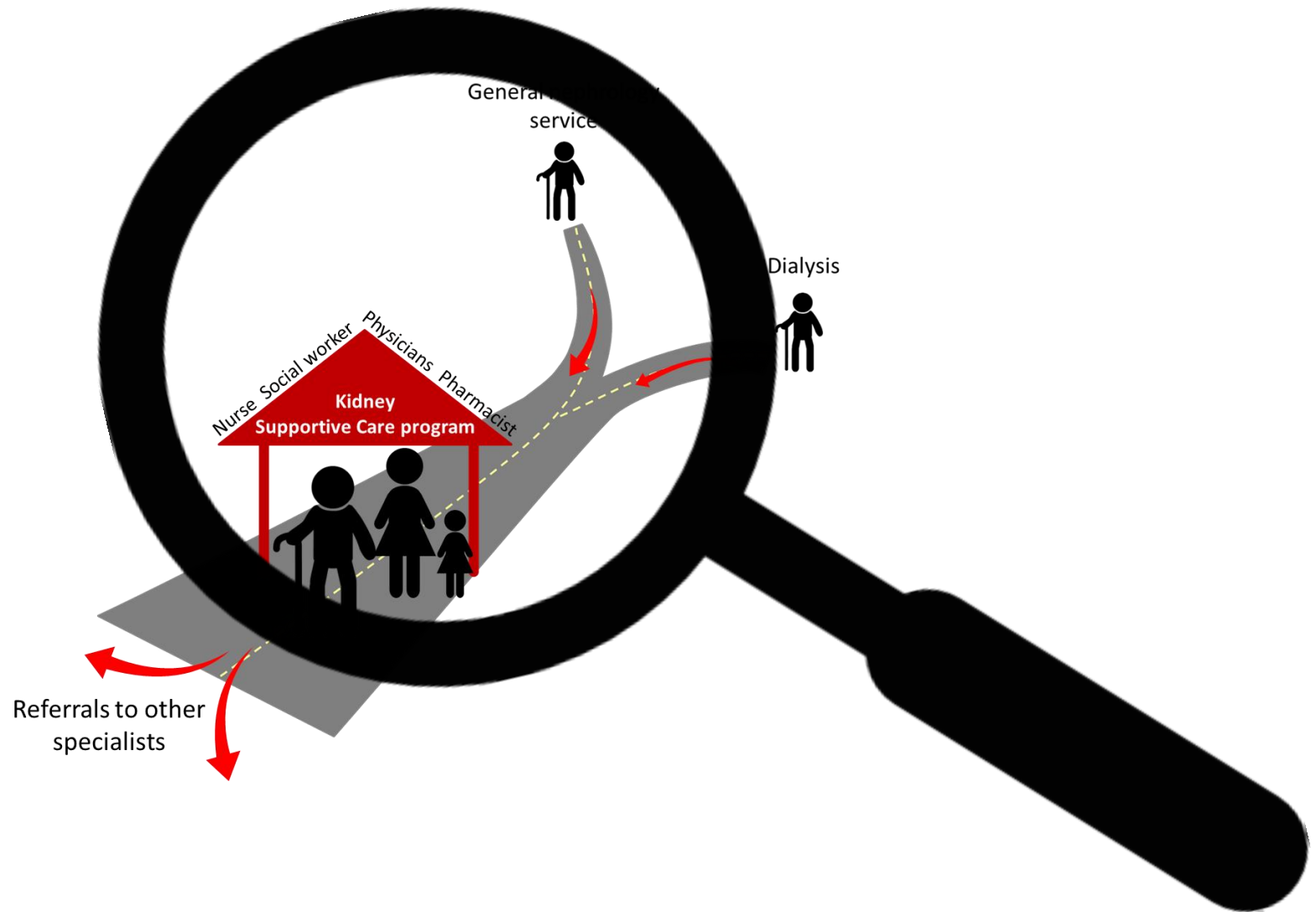
“[What’s] always been a big thing for me is the doctor’s check-up. Oh yeah, all your bloods are good, your fluids, you’re doing wonderful, you’re taking your tablets, all that, so you must be really feeling well, and you go “No, I feel like crap”.

One thing that doctors should say is it doesn’t matter what it says on the paper work—it’s easiest just to say how do you feel? How are things going with you? Bugger all the bloods; bugger all what fluid and that but how do you feel in yourself? And that’s when you get down to how a person is going.”

~Patient

KSCp model of care





“Evaluating the Implementation of a Kidney Supportive Care Program into a Hospital and Health Service”

Research methodology

- Implementation science framework
- Longitudinal mixed-methods study
 - Quantitative data
 - Qualitative data
- Research study embedded into clinical practice
- Collaboration with Health Economics CKD.CRE stream



Symptoms at baseline

Most prevalent symptoms



Weakness (90%)
Pain (82%)
Poor mobility (80%)
Drowsiness (74%)

Most severe symptoms



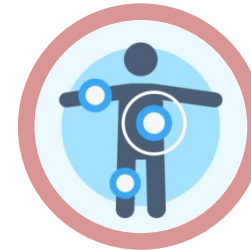
Weakness
Pain
Poor mobility
Drowsiness
Difficulty sleeping

Symptoms per patient



Median = 12
IRQ=10–14

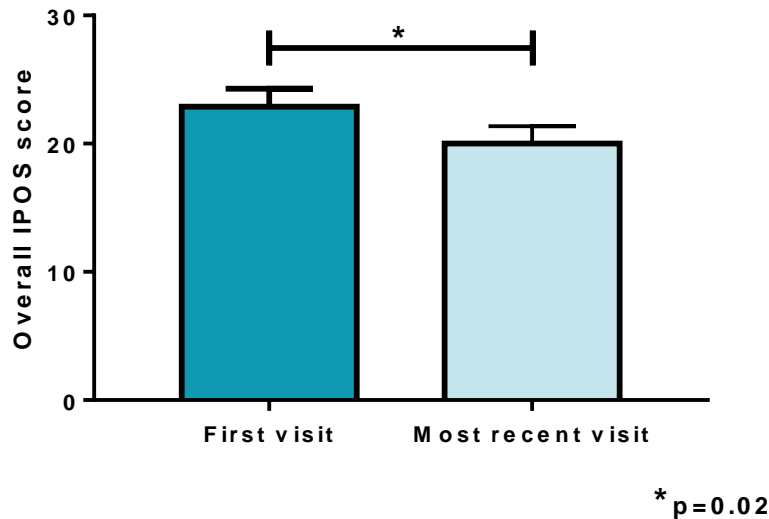
Overall symptom burden



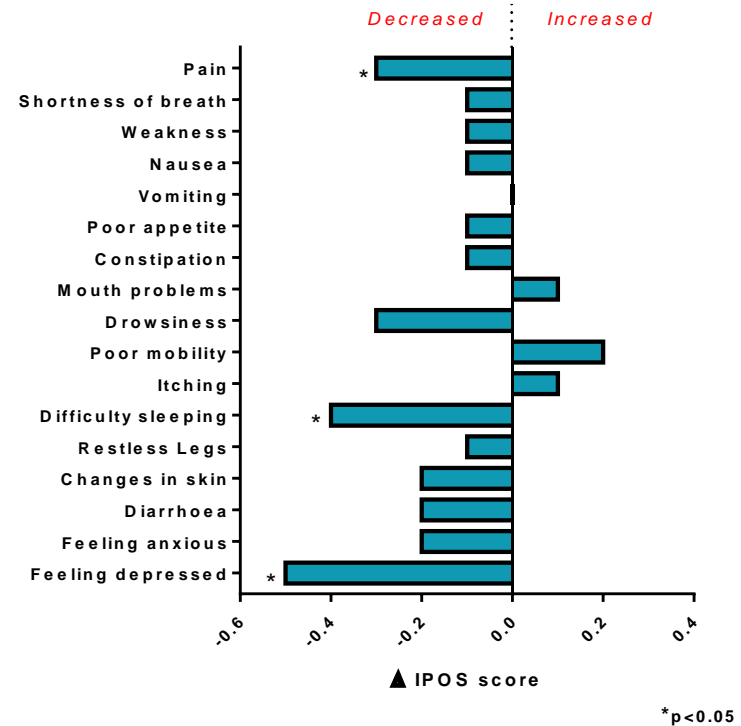
Mean score = 22.9 ± 9.7

Symptom management

Change in overall symptom scores between visits



Change in individual symptom scores between visits



69% of KSCp patients reported improvement in overall symptom burden

Summary

- KSCp care is associated with reduced symptom burden
- KSCp has progressed from pilot program to usual care service
- Analysis and dissemination are ongoing

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Examining stakeholders' perspectives of the implementation of an integrated kidney supportive care program

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“I’m grateful because we’ve done a lot of things together that we wouldn’t have been able to do because we’d be sitting at home bloody fretting. We’re going out to see the family and going out to go shopping and do stuff and things that we just weren’t going to bother doing, because what was the point?”

~Carer 1



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