

A feasibility study to track the last 12 months of life in chronic kidney disease patients: Baseline characteristics.

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Background

Chronic kidney disease (CKD) is associated with a high symptom burden and reduced quality of life particularly in individuals who are in their final year of life¹. A palliative care approach that targets symptom burden would benefit many patients, however few collaborative renal/palliative care services exist.

Aims and Objectives

The aim of this study is to track and quantify the experiences and health service utilisation of people with stage 3-5 CKD over the last 12 months of life. The objective here is to describe the participants' demographic profiles and the patients' symptom experience at baseline.

Methods

Study design: An observational, prospective longitudinal design with data collected at regular intervals from multiple sources for a 12 month period or until death

Participants: Patients attending a large metropolitan renal service without a formal collaborative renal/palliative care approach, and their informal carers (see **Figure 1** for recruitment flow chart)

Inclusion criteria: Adults (≥18 years) with Stage 3-5 CKD and a prognosis of > 12 months (Consultant identified), cognitively sound and competent to give informed consent

Exclusion criteria: Extreme psychological or social distress, die within < 1 month of study entry (patient only), reside >2 hours access from recruitment site (patient only), or are non-English speaking

Data sources and collection

- Self report: Patient - using validated and reliable instruments; Carer - demographics and health history
- Clinical and administrative health records, electronic and hardcopy (see **Table 1** for data collection details)

Analysis

Descriptive statistics and frequency distributions were calculated of participants' demographic details and patients' clinical characteristics and symptom experience. The medians (ranges) are presented here.

Figure 1: Recruitment flow chart

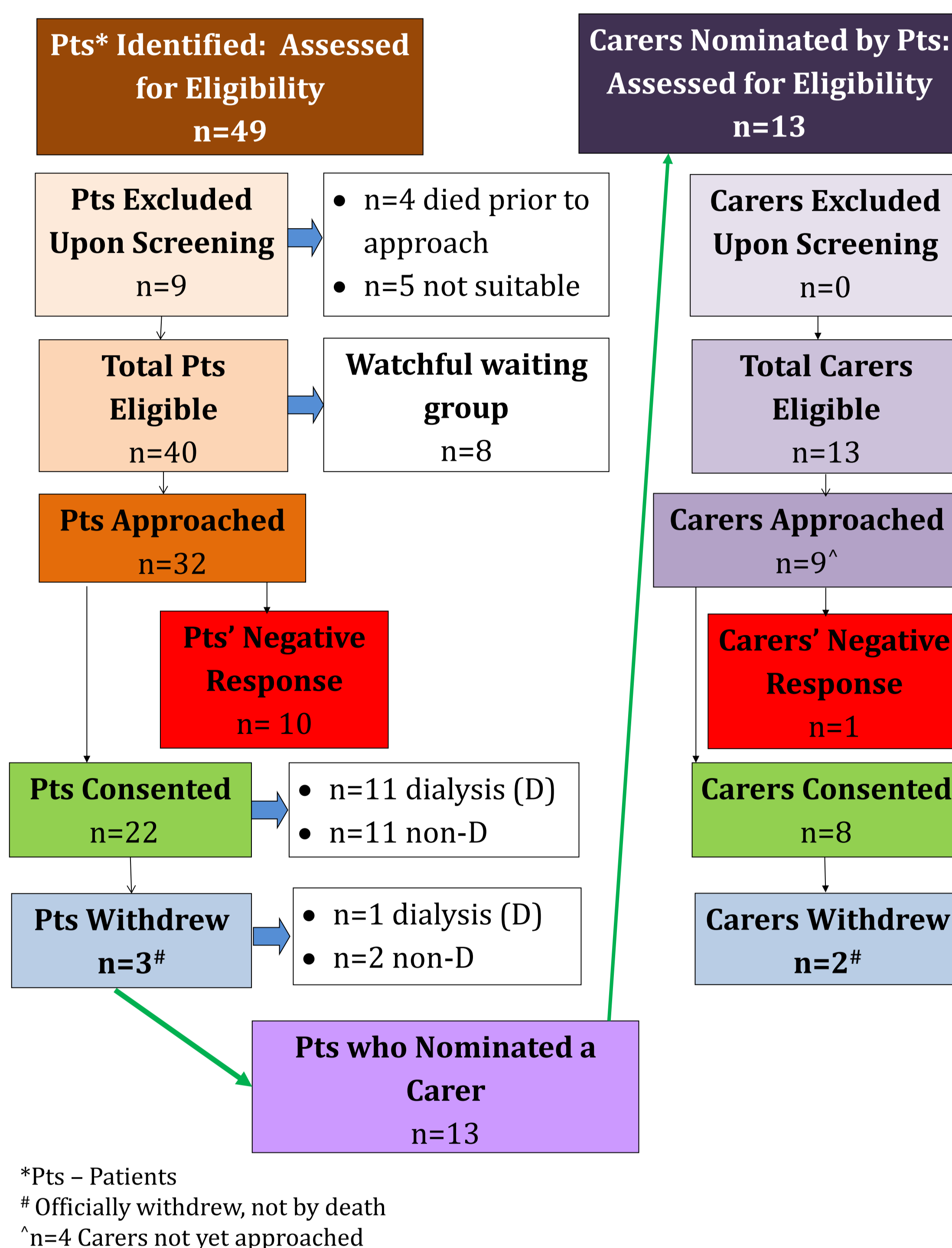


Table 2: Baseline multi-dimensional symptom experiences: highest five medians for subscales: frequency, severity and distress/bothersome

| Frequency | |
|-------------------------------------|----------------|
| Symptom | Median (range) |
| Trouble falling asleep (n=11) | 10.00 (1-10) |
| Trouble staying asleep (n=9) | 10.00 (0-10) |
| Decreased interest in sex (n=1)* | 10.00 (10-10) |
| Difficulty becoming aroused (n=3)* | 10.00 (10-10) |
| Restless legs (n=8) | 9.50 (1-10) |
| Numbness or tingling in feet (n=8)# | 9.50 (1-10) |
| Decreased appetite (n=9) | 9.00 (5-10) |
| Depression (n=6) | 8.50 (1-10) |
| Dry skin (n=13) | 8.00 (0-10) |
| Severity | |
| Symptom | Median (range) |
| Decreased interest in sex (n=1)* | 10.00 (10-10) |
| Difficulty becoming aroused (n=3)* | 10.00 (10-10) |
| Constipation (n=6) | 8.00 (5-8) |
| Decreased appetite (n=9) | 8.00 (3-10) |
| Trouble falling asleep (n=11) | 8.00 (1-10) |
| Numbness or tingling in feet | 7.50 (0-10) |
| Nausea (n=3) | 7.00 (1-10) |
| Swelling in legs (n=7) | 7.00 (1-10) |
| Shortness of breath (n=11) | 7.00 (0-10) |
| Muscle soreness (n=6) | 7.00 (5-7) |
| Difficulty concentrating (n=6) | 7.00 (1-10) |
| Diarrhoea (n=5) | 6.00 (0-8) |
| Restless legs (n=8) | 6.00 (2-10) |
| Bone or joint pain (n=11) | 6.00 (0-8) |
| Distress/Bothersome | |
| Symptom | Median (range) |
| Trouble falling asleep (n=11) | 7.00 (0-10) |
| Constipation (n=6) | 6.50 (0-9) |
| Muscle soreness (n=6) | 5.50 (0-7) |
| Nausea (n=3) | 5.00 (3-7) |
| Swelling in legs (n=7) | 5.00 (0-10) |
| Feeling worried (n=4) | 5.00 (0-10) |
| Feeling anxious (n=2) | 4.00 (0-8) |

* This symptom was reported as not applicable by n=13
This symptom was not applicable to n=1

Table 1. Data collection details

| Data Source | Data Collection Time Points | | | |
|---|-----------------------------|--------|---------|-----------|
| | Study Entry | Mthly* | 3Mthly* | Study End |
| Patient self-report | | | | |
| Palliative Phase | | | | |
| Physical Functioning | ✓ | ✓ | | |
| Symptom experience | | | | |
| Experience with health services | | | | |
| Supportive care needs | ✓ | | ✓ | |
| Quality of life | | | | |
| Clinical and administrative health databases | | | | |
| Medical history, inpatient admission details, emergency service utilisation and other health service use# | ✓ | | | ✓ |
| Inpatient admission details & emergency service utilisation | | | ✓ | |
| Co-morbidities | | | | ✓ |
| Carer self-report | | | | |
| Demographic details | ✓ | | | |
| Comorbidities | ✓ | | | |

*Cycle continues until patient's death
Via chart review only at these time points

Results

- Upon participant withdrawal, total study sample: n=19 patients and n=6 carers (see Figure 1)
- Patients' median age: 78 years (42–90); n=12 (63%) male; n=10 (53%) married/de facto
- Patients' CKD stage: 4 (n=4; 21%) and 5 (n=15; 79%); Treatment modality: n=10 haemodialysis (53%) and n=9 non-dialysis (47%)
- Carers' median age: 74 years (49-82); n=1 male (17%); spouse/partner to patient n=3 (50%)
- Patients' physical functioning: RUG-ADL²: n=4 (21%) required limited physical assistance to mobilise; n=1 (5%) needed use of a hoist to transfer. Median AKPS³: 60 (40-70)
- Number of symptoms reported MDSI⁴: Median 11 (3-19)
- Most prevalent symptoms (MDSI⁴): 1. lack of energy (n=15, 79%); 2. dry mouth, dry skin (both n=13, 68%); 3. shortness of breath, bone or joint pain, trouble falling asleep (all n=13; 68%)
- Sleeping problems were among the most frequently reported symptoms; median 10 (0-10)
- Trouble falling asleep was reported as being very severe (median 8 [1-10]) and the most bothersome of symptoms (median 7 [0-10])
- The frequency and severity of sexual related difficulties were reported as high; both subscales median 10 (10-10); Note: n=13 (68%) chose not to respond to these questions (see Table 2)
- CKD-SBI⁴: Median 14.36 (1.56 – 42.35)
- At baseline only two participants were actively engaged with a Palliative Care Service

RUG-ADL²: Resource Utilisation Group-Activities of Daily Living; AKPS³: Median Australian-modified Karnofsky Performance Status score (100=normal to 0=dead); MDSI⁴: Modified Dialysis Symptom Index (0-10 with 10 being highest score on each dimension, i.e., frequency, severity, distress/bothersome); CKD-SBI⁴: Chronic Kidney Disease – Symptom Burden Index Score (the higher the score, out of a possible 100, the greater the symptom burden)

Conclusion and Implications

As demonstrated in the baseline results, it is important to assess symptoms from multiple dimensions as the most frequent symptoms are not necessarily the most bothersome. Recruiting this cohort by Clinician identification across a large metropolitan renal service proved feasible. Studying this group of participants, who are considered vulnerable due to the patients' limited prognosis, was ethically justified by their willingness to participate. Findings from this study will inform larger studies to provide evidence to inform policy in palliative care health service development to ensure all patients have access to appropriate needs-based, consumer-centred palliative care services into the future. Ascertaining changes over time in symptom burden and functionality will assist with targeting the level and type of services needed along the end-of-life trajectory in CKD, and to ensure timely and appropriate renal and palliative care is provided.