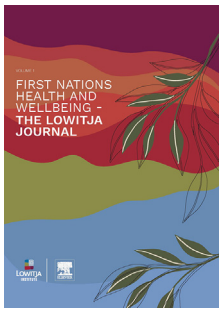

Original Research

Physiotherapy-led restorative care enabling improved frailty measures in adults after starting dialysis in Northern Territory of Australia: The 'Frailty-to-Fit' pilot study

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Abstract

Purpose Aboriginal and Torres Strait Islander peoples' culture is integral to health and wellbeing; this includes access to traditional Country, maintenance of kinship relationships, to speak traditional language and participate in cultural practices. Most clients commencing dialysis in remote Australia, including the Northern Australia region, identify as Aboriginal and/or Torres Strait Islander peoples. Aboriginal people who need kidney replacement therapy and are physically fit to access home dialysis report additional health and cultural benefits beyond achieved dialysis adequacy. This study aimed, within the setting of local COVID-19 pandemic preparations and response phases, to design and pilot a physical frailty assessment tool to inform the support needs of physically frail adults in the Northern Territory of Australia after starting haemodialysis.

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[§]Aboriginal and/or Torres Strait Islander peoples.
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Methods Informed by a literature review and patient advisors, the tool incorporated patient-important domains of dyspnoea, strength, mobility and fitness using the Medical Research Council dyspnoea scale, hand grip strength, de Morton Mobility Index and 1-minute sit-to-stand test. During April to September 2021, frailty measures were recorded at baseline and 16 weeks at one outpatient location, alongside optional restorative care and individualised physical function goal setting. Data were presented as median (IQR) and percentage.

Main findings Twenty adults completed the baseline assessment: median age was 51 (47, 67) years, 80% were Aboriginal and/or Torres Strait Islander peoples, 80% were utilising haemodialysis and 53 (35, 74) days after incident dialysis. All study participants identified physical function goals, including walking improvement. Baseline measures for the dyspnoea scale and de Morton Mobility Index were 3 (1, 4) and 74 (67, 96); hand grip strength was 21.1 (21.1, 27.4) kg, and 1-minute sit-to-stand repetitions was 16.0 (3.3, 21.0), respectively. Ten patients returned for follow-up measures, with a 70% goal achievement and statistically significantly improved measures for hand grip strength (P = 0.03), de Morton Mobility Index (P = 0.04) and 1-minute sit-to-stand (P = 0.02).

Principal conclusions Baseline physical frailty and subsequent personal physical goal attainment were associated with improvements in strength, fitness and mobility in adults after starting dialysis.

Keywords: Patient-partnered; Kidney failure; Dialysis; Frailty; Aboriginal and Torres Strait Islander peoples; First Nation peoples

Highlights

- It is believed that the 'Frailty-to-Fit' physiotherapy program is suitable for renal care units to immediately adopt to support health outcomes of Aboriginal and Torres Strait Islander peoples and non-Indigenous peoples who have kidney failure and seek pathways to near-home dialysis and self-care home dialysis.
- The main aim of this program was to make physical restorative care, which is a usual care activity of physiotherapy healthcare professionals, available in the best way that patients with high frailty support needs themselves wanted to support their life participation and renal care goals.
- The 'Frailty-to-Fit' program was developed and refined based on patient feedback, including from Indigenous Patient Reference Group members. Healthcare users were evaluating the program throughout.
- The program was underpinned by person-centred and patient health professional partnership approaches, which helped to promote an empathetic, respectful and culturally safe care.

Introduction

Kidney failure occurs when reduced kidney function (<15/mL/min/1.73m^2) results in retention of uraemic waste within the body, dysfunction of other organs, and experienced as uraemic symptoms and lower survival. Kidney replacement therapy, as dialysis or a kidney transplant, along with health and functional support, improve survival, life participation and quality of life. Dialysis and related healthcare for people with kidney failure impact individuals, their families, and

affect all populations of the world, including First Nations peoples (Bikbov et al, 2020; Cockwell & Fisher, 2020; Kerr et al, 2022; Smith et al, 2021). Haemodialysis use in Australia has doubled since 2000 and now involves 17.5% of hospital admissions. Aboriginal and Torres Strait Islander peoples, the First Nation people of Australia, access dialysis at a 5.5 times higher rate than other Australians and commence dialysis at a younger adult age. Diabetes is the major cause of kidney failure among Aboriginal and Torres Strait Islander peoples, and hospital-based haemodialysis has been the predominant treatment location (Hughes et al, 2018; Kerr et al, 2022; Khanal et al, 2018; Smith et al, 2021). Many Aboriginal and Torres Strait Islander peoples have relocated to live closer to hospitals so that they can access dialysis (Hughes et al, 2018). Self-care dialysis (delivered by the patient or a family carer) requires direct health professional support for the training period but can then be utilised independent of hospital-based care. Close-to-home care for people who have kidney disease is a patient-important outcome for Aboriginal and Torres Strait Islander peoples (Tunnicliffe et al, 2022).

Life participation with COVID-safe dialysis access

Australian jurisdictions enacted public health protection strategies to reduce viral transmission, following the coronavirus pandemic declaration on 11 March 2020 (www.health.gov.au/health-alerts/covid-19/about, accessed on 18 November 2022). By 26 March 2020, the Northern Territory (NT) applied the Biosecurity Act 2015, so that remote NT communities were closed to all non-essential travel, citing a need to support 'remote Aboriginal people (to be) safe during a pandemic in the context of severe overcrowding, inadequate repairs and maintenance and sub-standard health hardware' (Paterson, 2020). Territorians with diabetes, cardiac and kidney disease and who needed dialysis were identified as likely to have higher illness morbidity and mortality following a coronavirus infection. In Darwin, the Royal Darwin Hospital established a COVID-19 care ward, where COVID-infected persons were admitted and cared for, and established other COVID-mitigation strategies, while continuing usual hospital services including incident and maintenance haemodialysis treatments.

Life participation enabled by physical restorative conditioning

Life participation is promoted through physical function, or aided when there is impaired function and frailty. Frailty contributes to declines across physical, social and psychological domains of human function (Gobbens et al, 2010; Nixon et al, 2018; Wu et al, 2019) and additive to age-related frailty (Clegg et al, 2013; Gill et al, 2010). Advanced frailty is associated with reduced quality of life (Iyasere et al, 2016; Nixon et al, 2020) and higher personal care needs, hospitalisation and morbidity (Chowdhury et al, 2017; McAdams-DeMarco et al, 2013). Frailty is disproportionately prevalent in remote-living Aboriginal Australians (Hyde et al, 2016) and an increased risk of geriatric syndromes has been observed due to high rates of coexisting chronic conditions (LoGiudice, 2016). Frailty is a component of kidney failure symptoms, common in diabetes, and a barrier to undertaking treatment that requires self-care. Access challenges for self-care dialysis are contributed by socioeconomic disadvantage, remote living (distance to health infrastructure) and cultural discrimination within mainstream health services (Cass et al, 2004; Hughes et al, 2018; Huria et al, 2021; King et al, 2009; Liyanage et al, 2015). In contrast, improvements in frailty and functional capacity have been shown in adults with kidney failure who access physical activity and exercise interventions (Clarkson et al, 2019). Furthermore, non-frail adults who utilise self-care dialysis possess the physical fitness required for the

high metabolic and physical needs of acute kidney transplantation (McAdams-DeMarco et al, 2022). Physical frailty detection and improvement, which improve physical function, can lower morbidity and reduce carer burdens when accessed through holistic multidisciplinary care (addressing financial, geographical, cultural and physical-medical factors).

This paper aimed to describe the design and implementation of a culturally safe renal physiotherapy pilot service to assist patient goals of care after starting dialysis, within the setting of the coronavirus pandemic preparation and response phase of the Top End of the Northern Territory (of Australia).

Methods

Context and setting: accessible kidney replacement therapy supporting life participation

Two hospitals provide incident haemodialysis care in the NT (Gorham et al, 2018; Hughes et al, 2019a). The NT has a land and waterway area of 1.35 million km^2 and 72,000 km^2, respectively (Geoscience-Australia, 2021), and the highest national incidence rates of Aboriginal and Torres Strait peoples requiring dialysis (ANZDATA-Registry, 2021). In the north, or the Top End NT, haemodialysis is commenced at the Royal Darwin Hospital dialysis unit, then patients transition to maintenance care as home dialysis (following self-care dialysis training) or nurse-assisted haemodialysis at a satellite haemodialysis locality, as capacity permits (Hughes et al, 2019a). In late 2018, the Top End Renal Service - Renal Home Therapy Unit co-located haemodialysis training, peritoneal dialysis and transplantation support staff within the hospital campus. In addition, to assist clients to pathways for near-home dialysis, a weekly half-day nephrologist clinic supported medical optimisation at this location for all patients after starting haemodialysis, (Hughes et al, 2019b). In late 2019, with inclusion of a senior Aboriginal and Torres Strait Islander Health Practitioner, it became known as the New Start Dialysis Transition Program (NSDTP) (Zabeen et al, 2023), so that personalised health support was accessible (if required) until clients reached stability of their health condition (Hughes et al, 2019b). This health support included clinical care, chronic condition optimisation, health information and service navigation. Referral for outpatient-based renal allied health, and education about home dialysis and transplantation, was also facilitated. Clients with physical frailty optimisation goals were referred to physiotherapy through primary healthcare or the hospital outpatient department.

Early in the coronavirus pandemic preparation phase, Top End Renal Services - Renal Home Therapy Unit considered COVID-safe and equity-enabling services (ANZSN, 2022) that could maintain patient access to care provided by the NSDTP. Patient leaders, patients and staff of the local dialysis unit recognised that services that improved a patient's physical function were important but likely less accessible due to social distancing requirements, so they requested delivery of on-site renal physiotherapy within the NSDTP. This research describes the design of a renal physiotherapy restorative care program, implemented during the COVID-19 pandemic in the Top End of the Northern Territory and nested within the NSDTP (Zabeen et al, 2023).

Activities that took place as part of this research

Renal physiotherapy service

The first objective was to identify (or create as necessary) a physical frailty assessment (PFA) tool relevant to client and local service needs within the COVID-safe environment. Subsequent objectives were to describe baseline physical frailty of NSDTP

participants and report utility of physiotherapy-led restorative care within the NSDTP. A literature review, using a scoping review search strategy, was first completed to review any available literature. This identified zero research describing frailty assessment developed or tested in adult Aboriginal and Torres Strait Islander peoples with kidney failure. The preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) checklist was followed (Moher et al, 2010). Eligibility criteria were contemporary peer reviewed studies published in English from January 2011, which included Aboriginal and Torres Strait Islander adults (aged >18 years) with chronic kidney disease and a measure of frailty. Population, concept and context elements (Peters et al, 2015) were used to search for literature using Medline, CINAHL and Embase. Searches were undertaken in February 2021 and repeated in May 2021. A broad search strategy was developed with a medical librarian, aiming to capture any research on the topic (Supplementary material S1). To extend identification of relevant literature, the reference lists of the retrieved articles were reviewed, and unpublished content was searched for on Google Scholar. The process confirmed zero existing frailty assessments in Aboriginal and Torres Strait Islander adults with kidney failure (Supplementary material S2).

Physical frailty assessment development: stakeholder consultation and partnership

It was intended to create a PFA relevant to the client, suitable for COVID-safe delivery within the service and culturally safe, feasible and acceptable. Therefore, it was not appropriate to adapt an existing frailty assessment tool, such as the popular Fried Frailty phenotype (Fried et al, 2001) or Clinical Frailty Scale (Moorehouse & Rockwood, 2012), as they were not developed or tested in Aboriginal and Torres Strait Islander adults with kidney failure. Therefore, clinical and consumer consultations were approached to inform the design of a contextually relevant PFA for Aboriginal and Torres Strait Islander adults with kidney failure, and suitable for the clinical service setting.

Consultation included informing interviews, meetings, in-services and electronic correspondence. Targeted feedback was sought from Indigenous renal clinician experts (nephrologist JH and renal Aboriginal health practitioner OP), multidisciplinary renal clinicians (nursing, occupational therapy, physiotherapy) and Aboriginal and Torres Strait Islander patients with experience in kidney replacement therapy (peritoneal dialysis, nurse-assisted haemodialysis and self-care home haemodialysis). Patients included usual care dialysis users and members of the NSDTP Live Strong Project Patient Reference Group (AMP, WA, EW, TG), which is a specifically convened leadership group established through expression of interest. Patient-important PFA included quantification of dyspnoea, muscular strength, functional mobility and exercise capacity; clinician consultation further identified outcome measures needed to be efficient, practical, suitable for men and women and appropriate given the existing constraints (resources and competing patient interests). The process of selecting PFA outcome measures was informed by stakeholder consultations and shown in Figure 1.

Physical frailty assessment development: selection of physical frailty assessment outcome measures

The four selected PFA outcome measures were the Medical Research Council Dyspnoea scale (MRC scale), hand grip strength (HGS), de Morton Mobility index (DEMMI) and 1-minute sit-to-stand test (1-min STS). Those outcome measures reflected patient-reported impairments, could accommodate individuals across the spectrum of physical functioning, and were time, space and resource efficient. Justification for outcome

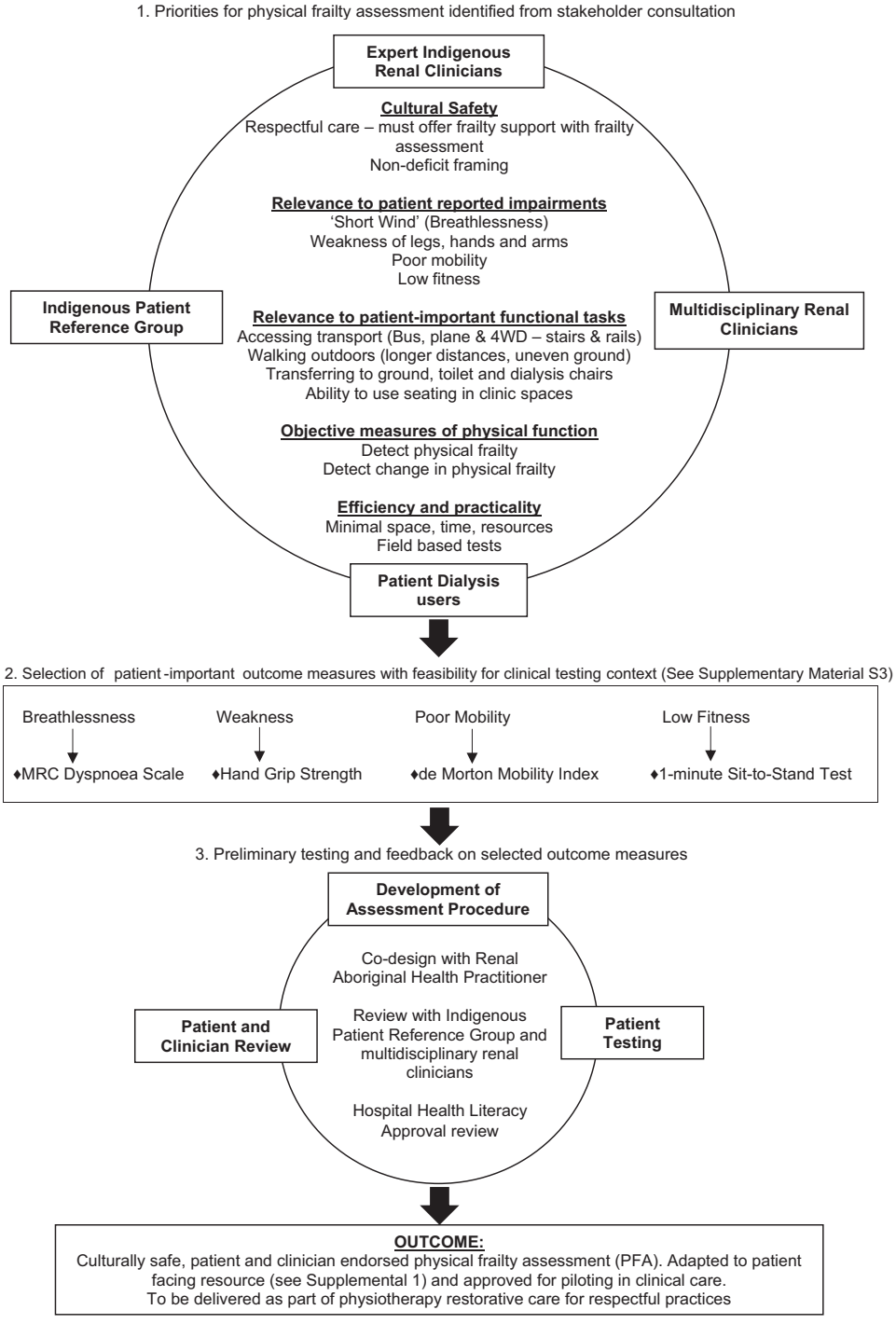

Figure 1: Summary of consultation process and findings applied for PFA development

Referral process	• Referral for physiotherapist administered Physical Frailty Assessment (PFA) invited by the NSDTP medical team, who assessed clients within 14-28 days of incident dialysis.
Assessment procedures for PFA	• Baseline PFA completed 14 days* after medical referral using standard procedures for each outcome measure (see Table 2) • Clients invited to self-identify individualised physical function goals with physiotherapy using the following guiding questions: ○ 'In what ways would you like to be stronger or more fit, and why?' ○ 'What things would you like to be doing if you were more strong or more fit?'. • PFA and goal setting took approximately 10 minutes. • Follow-up PFA and goal achievement (yes/no) reviewed 16 weeks* after baseline PFA.
Physiotherapy care	• Physiotherapy care offered to all consenting participants as a usual care service** • Maximum frequency that participants could attend face to face care was weekly. • Restorative care and usual care offered as clinically indicated and to support client goals. • Physiotherapy services followed local COVID-19 safety guidelines due to active pandemic, which included patient screening, mask use, hand hygiene, physical distancing, and support for vaccinations when these became locally available. • Restorative care details: ○ Delivered in any combination of three scenarios, selected based on patient preference: 1. Self-directed at home exercise program 2. Self-directed at dialysis exercise program*** 3. Physiotherapy supervised exercise program (individual or group) ○ Individualised based on functional goals and informed by international guidelines on physical activity (PA) (Bull et al, 2020), and exercise recommendations for kidney disease (Koufaki et al, 2015, Koufaki et al, 2015, Koufaki et al, 2015). ○ Due to contextual factors, space was limited, and large exercise equipment was not available. This necessitated the prescription of bodyweight exercises. TheraBand and Inspiratory Muscle Trainers (Phillips Threshold IMT) were also available for participants. • Physiotherapy usual care details ○ Offered as indicated and in accordance with standard physiotherapy practice at RDH. ○ Standard care includes mobility aid prescription, cardiorespiratory interventions, management of musculoskeletal pain/injury and support to access services or follow-up care. ○ Within the NSDTP, physiotherapy contributed to existing programmed group education sessions ('Renal Yarning Circles').

*Target timeframes that were liable to fluctuate dependent on individual client basis due to clinical context and concurrent treatment priorities **Inclusion of physiotherapy as a usual care service during the pilot responded to feedback from Indigenous patient stakeholders during consultation, which specified that restorative care services would need to be offered alongside PFA to ensure respectful practices that were strength framing, not deficit shaming ***Clearance for intra-dialytic exercise was nephrologist directed

Table 1: Operating procedures and physiotherapy care during 'Frailty-to-Fit' pilot study.

measures and assessment procedures are listed in Supplementary material S3. The PFA was then developed into a patient-facing resource with an Aboriginal Health Practitioner (OP) and the Hospital Health Literacy committee (Supplementary material S4) and endorsed by clinical and patient stakeholders prior to pilot testing.

The Frailty-to-Fit program

During April to September 2021, renal physiotherapy was resourced 2 days/week as part of routine care for NSDTP clients, co-located within the Renal Home Therapy Unit, and receiving referral from the NSDTP medical officer or Aboriginal Health Practitioner.

Clients were eligible for renal physiotherapy in this setting if they were adults (at least 18 years old), participating in the NSDTP and receiving hospital-based haemodialysis. Data from those clients who also provided written consent for research reporting are described. The physiotherapist provided usual care, delivered the PFA and recorded outcome measures and individual goal setting, and offered individualised restorative care if desired (Table 1).

Participant recruitment, variables and data collection

Study data were prospectively collected following written informed consent and entered into a secure

electronic data form. Baseline characteristics of participants – including demographics, comorbidities and dialysis history – were identified from the hospital records. The dialysis commencement date was recorded in the hospital records, and duration of admission calculated as discharge date – admission date. Incident dialysis admission more than 1 day was defined as unplanned. Uptake of restorative care was recorded through a count of bookings and attendances in the physiotherapy clinic and confirmed by physiotherapy documentation in the hospital records.

Data analysis

Continuous variables were not normally distributed and reported as median (interquartile range) and mode, and categorical variables as n (%). Differences in baseline and follow-up PFA outcome measures were described using a Wilcoxon signed rank test, with alpha set at 5%. A non-parametric method was used due to the small sample size and lack of control. The small sample size also precluded multivariate analysis. Quantitative data were analysed with IBM SPSS statistics version 26 (Armonk, NY: IBM Corp.).

In addition to the statistical analysis of the Frailty-to-Fit (FTF) data, patient-reported physical function goals were analysed in partnership with an Indigenous Health Qualitative Scientist (AME) and co-interpreted with the Live Strong patient reference group. The FTF project was one of three service innovations within the Live Strong project, implemented during the COVID-preparation phase in the local hospital unit. This paper describes responses of clients when asked by the physiotherapist: 'what are your goals?'. Responses were further analysed and organised using 'content analysis' techniques (Krippendorff, 2018).

Governance and ethics

Site-specific ethical approval was granted by the Northern Territory Government (RGO EFILE2021/12495), Department of Health Governance Committee, Menzies School of Health Research (HREC 2021-4023) and Flinders NT Human Research Ethics Committee (HREC 5582). The study was also approved by an Aboriginal Ethics sub-committee that held power of veto over research involving Aboriginal and Torres Strait Islander peoples.

Results

Baseline physical frailty assessment

There were 42 patients who were supported by the NSDTP during the 6-month pilot period. This study describes 20 (48%) adults who provided written consent to participate in the FTF pilot and completed baseline PFA. Their median age was 51 years (47, 67), 11 were female (55%) and 16 were Aboriginal or Torres Strait Islander peoples (80%). All participants had dialysis requiring kidney failure, and 16 (80%) received haemodialysis treatment. The median time since starting dialysis was 52 days (35, 74). Table 2 summarises participant characteristics and PFA measures.

Functional limitation due to breathlessness was reported by 11 participants (MRC scale 3 = three participants, MRC scale 4 = eight participants). The remaining participants reported no or minimal impairment to daily living, scoring either 1 (eight participants) or 2 (one participant). No participants reported severe dyspnoea that restricted their ability to leave their home (MRC score 5). The DEMMI scores ranged from 53 to 100. Fifteen participants had reduced functional mobility on the DEMMI, with a median score of 74 (67, 96.3). Median HGS was 21.1 kg (21.1, 27.4) (men 27.8 kg, women 18.6 kg) and median 1-min STS was 16.0 (3.3, 21.0) repetitions. Five participants were unable to complete the 1-min STS test procedure (could not stand without using their arms). Five chronic maintenance dialysis clients with

Demographics (n = 20)	
Age (Year) (median, IQR)	51 (47, 67)
Men	49 (45, 61)
Women	52 (49, 67)
Women, n (%)	11 (55)
Aboriginal or Torres Strait Islander, n (%)	16 (80)
Comorbidities, n (%)	
Type 2 diabetes	7 (35)
Cardiovascular disease	11 (55)
Hypertension	10 (50)
Chronic lung disease	3 (15)
Obesity	2 (10)
Other conditions	12 (60)
Dialysis Type, n (%)	
Haemodialysis (HD)	16 (80)
Peritoneal Dialysis (HD)	4 (20)
Dialysis History	
Planned initiation, n (%)	7 (30)
Unplanned initiation, n (%)	13 (70)
Time (days) since commencing dialysis, median (IQR)	52 (35, 74)
Baseline PFA measures (n = 20)	
MRC Score	3 (1, 4)
HGS, kg	21.1 (21.1, 27.4)
Men	27.8 (23.1, 39.3)
Women	18.6 (15.4, 19.7)
DEMMI Score	74.0 (67.0, 96.3)
1 min STS repetitions	16.0 (3.3, 21.0)
Nominated Physical function goal(s)	20 (of 20 participants)

All participants were clients of the NSDTP with kidney failure as primary diagnosis. Data are presented as median (interquartile range) for continuous variables, and n (%) for categorical variables.

Table 2: Characteristics of study participants and Physical Frailty Assessment (PFA) outcome measures

frailty-identified needs were seen by physiotherapy outside of the new NSDTP program and completed PFA, but their data were excluded from the analysis (Figure 2).

All 20 participants nominated physical function goals (Table 3). Goals of 12 participants identified specific physical function tasks for improvement, including walking ability (100%) and independent transfers (20%). Sixteen participants self-identified physical impairments, including weakness, poor functional mobility, breathlessness, low fitness, fatigue and impaired balance. Co-interpretation of patient goals identified five meanings attached to several factors, including: independence for fundamental mobility or instrumental activities (65%), being at home or on Country (50%), physically interacting with family (20%), engaging with important activities (vocational, recreational and cultural) (75%) and having a healthy body (including eligibility for transplantation) (35%).

Repeat physical frailty assessment and goal achievement

Ten participants (50%) completed repeat PFA and reviewed their physical function goals. The median time since starting dialysis was 114 days (52, 133). Improvement in HGS ($P = 0.03$), DEMMI score ($P = 0.04$) and 1-min STS score ($P = 0.02$) was demonstrated, but there was no change in MRC scale ($P = 0.18$) (Table 4 and Figure 3). Seven of the 10 participants (70%) achieved their physical function goals. For the remaining 10 participants, repeat measures could not be completed because they had either: a) been discharged to be closer to home whilst receiving renal care during the study period and were no longer available to attend appointments in Darwin; or b) had their outpatient care transferred to an alternative dialysis centre where there was no site-specific ethics approval and that was also observing restricted visitor access consistent with COVID-safe mitigation that was in place at that time.

Uptake of physiotherapy restorative care

Physiotherapy restorative care was utilised by 20 NSDTP clients and five additional chronic maintenance dialysis clients with frailty identified needs (Figure 1). A total of 360 physiotherapy appointments were made for those participants, with 211 attended (59%). Non-attendance was recorded as concurrent medical commitments, family commitments, logistical priorities (housing and financial) or emergent leave to access Country for activities of cultural significance.

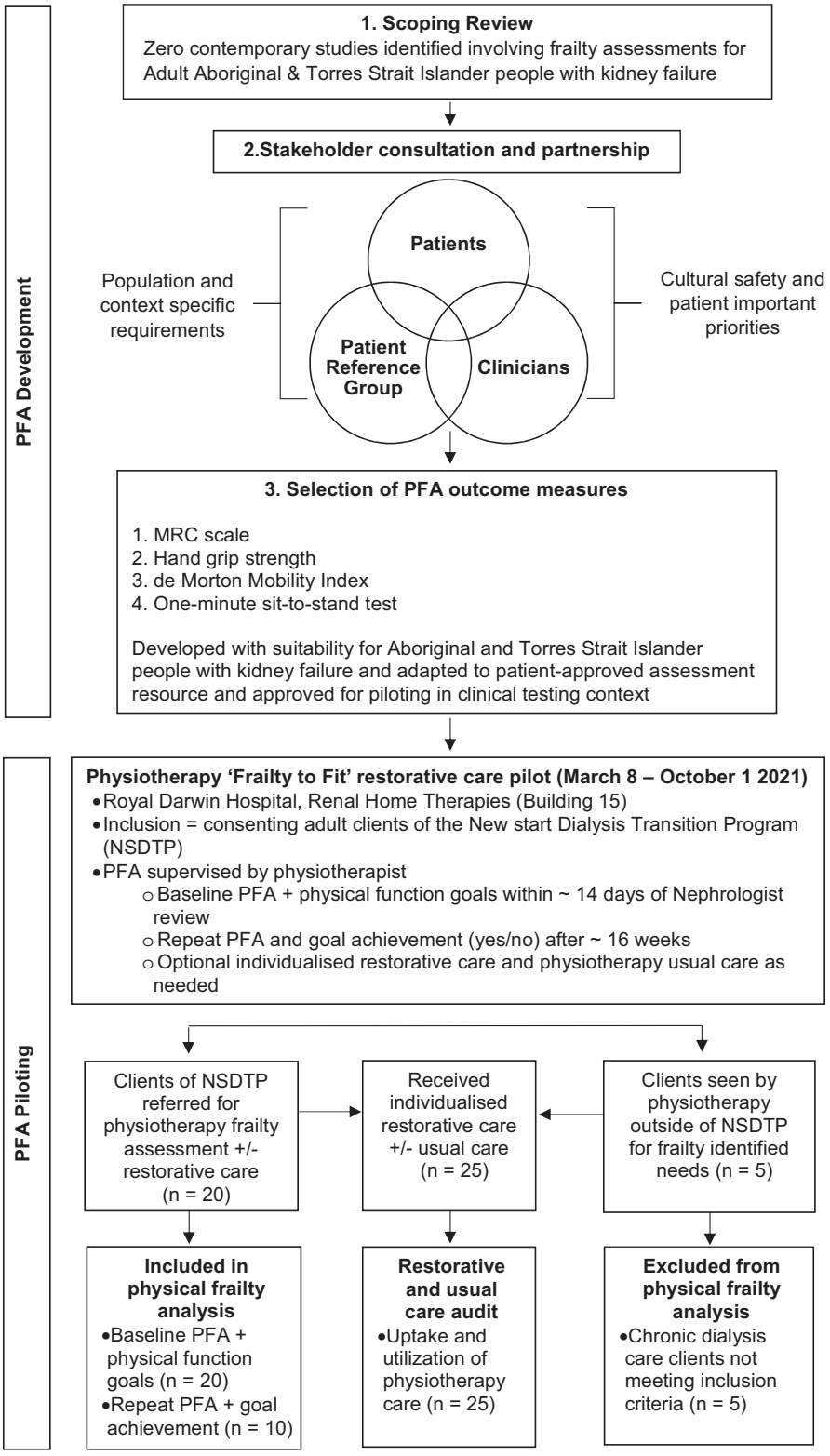

Figure 2: Flow diagram of study and participants. PFA = physical frailty assessment.

Individualised physical function goals	Attached meaning(s)				
	Independence for fundamental mobility/ instrumental activities	Being at home or on Country	Physically interacting with family	Engaging with important activities*	Having a healthy body**
To return to physically demanding aspects of work such as off-site installations, improve cardiorespiratory fitness, reconnect with outdoor hobbies (fishing) and stay fit for transplant				√	√
Keep strong to return home		√			
To stay fit and healthy whilst receiving renal care, to keep up regular walking and maintain mobility, would love to go fishing or boating again	√			√	√
To be able to walk around house without walking aid in 2 months	√				
To be able to balance well to walk on sand and mangroves, to have enough strength to go fishing	√	√		√	
To be able to walk around home without four wheeled walkers (4WW), to have enough leg strength to get on and off bus or four-wheel drive (4WD)	√	√			
To be able to walk confidently outside for long distances, to be able to get on and off the ground independently	√	√	√	√	
To be able to walk longer distances and not rely on wheelchair, in long term wants to walk without 4WW	√			√	
Keep fit to get home, have more energy for everyday tasks (cook, clean, family)	√	√			
Maintain physical fitness, reconnect with sports				√	√
Improve physical endurance for work demands as chef, keep fit for transplant workup				√	√
Keep strong for transplant, improve balance and strength for walking long distances on uneven ground	√	√		√	√
Stay strong for getting on and off ground to play with grandchildren, keep body fit for transplant, to be able to walk further without stopping due to short wind	√		√		√
Keep strong for returning to hunting and fishing on Country, stay strong to be able to work on country		√		√	
To have enough energy and strength to go walking every day for 20-30 mins for health. To be able to go outside and do gardening	√			√	
To be stronger in legs to get on ground to play with grand kids, to be strong to go fishing again, to walk further without short wind	√		√	√	
To be strong enough to walk up and down riverbanks with good balance and to throw net to go fishing, to be able to walk long distances without being tired or short wind	√	√		√	
To be able to walk further without rests to access country for bush medicine, to have strength and balance to navigate riverbank and go fishing, to have enough endurance for ADLs	√	√		√	
To be strong enough to play with kids and engage with hobbies of fishing again, to be able to improve strength to engage with mechanic work, to improve fitness for transplant			√	√	√
Improve endurance to be able to go fishing/hunting again back on Country		√		√	

*Important activities included recreation/vocation/cultural significance **Having a healthy body included wanting to be eligible for kidney transplant

Table 3: Participant physical function goals and attached meaning(s) from content analysis.

Change for repeat PFA measures (n = 10)	Baseline	Follow-up	P value
MRC Score	2.5 (1.0, 4.0)	2.0 (1.0, 3.0)	0.18
HGS, kg	19.7 (18.2, 26.3)	26.3 (20.5, 28.6)	0.03
DEMMI Score	70.5 (53.0, 88.8)	87.0 (67.0, 100.0)	0.04
1 min STS repetitions	16.0 (3.0, 18.8)	22.0 (2.8, 26.3)	0.02
Goal achievement (n(%))	7 (70)		

All participants were clients of the NSDTP with kidney failure (Stage 5 CKD) as primary diagnosis. Data are median (IQR) for continuous variables, or n(%) for 10 participants had both baseline and repeat measures. A Wilcoxon signed ranks test was used to compare medians of PFA measures for this sample.

Table 4: Baseline and Follow-Up PFA measures

A combination of physiotherapy supervised exercise and self-directed home exercise was preferred for restorative care (n = 16, 64%), with most attending supervised small group exercise sessions (n = 14). In addition to restorative care, clients also accessed a range of physiotherapy usual care. Table 5 summarises attendance and utilisation of physiotherapy during the FTF pilot.

Discussion

This study confirmed physical function as a patient-identified goal when commencing dialysis treatment for kidney failure, and that it was related to wellbeing and participation in daily living and other meaningful activities. Through follow-up measurement, this study confirmed physical frailty improvements coincided with attainment of patient-identified goals. Despite improvements in muscular strength, functional mobility and exercise, there was little change in objectively measured disability due to breathlessness, which may have reflected an insensitivity of MRC score to changes over short timeframes (Stenton, 2008). During the 16-week eligible time frame for follow-up, it was noted many unavailable clients had achieved a care close to home plan or been transferred to a satellite unit; thus, the extent of physical function improvement may have been underestimated.

These data have contributed, for the first time, PFA measures among Aboriginal and Torres Strait Islander adults who have kidney failure, addressing a knowledge gap about the range of physical function ability and limitation. Those baseline PFA results suggest that more than half of local participants reported breathlessness-related disability, being consistent with people with chronic obstructive pulmonary disease (COPD) (Bestall et al, 1999). Mean measures of hand grip strength were approximately 15 kg lower for men and 10 kg lower for women than reported among community-based Australian adults of a similar age (Massy-Westropp et al, 2011). Functional mobility among local participants was lower than expected for age, with summary DEMMI scores comparable with older community-dwelling adults requiring informal care (De Morton et al, 2011), people with COPD (Camp et al, 2019), elderly adults with arthritis (Jans et al, 2011) and mild Parkinson's disease (Johnston et al, 2013). Exercise capacity was also impaired, with mean 1-min STS repetitions far less than older Australians from the general population (Ritchie et al, 2005) and lower than found in previous studies in kidney failure (Koufaki et al, 2002; Majchrzak et al, 2005; Segura-Ortí & Martínez-Olmos, 2011). This study therefore objectively confirmed a range of physical limitations of strength, mobility, fitness and dyspnoea among Aboriginal and non-Aboriginal adults who had recently started dialysis. These encouraging results from a proof-of-concept pilot project suggest that locally accessible PFA screening and accessible restorative care programs may benefit many adults in the NT living with kidney failure.

Aboriginal healthcare users were leaders in commissioning, designing and evaluating this service innovation. Their experience guided the selection of each measure, so they were suitable for men and women, were non-shaming, had ease of patient and

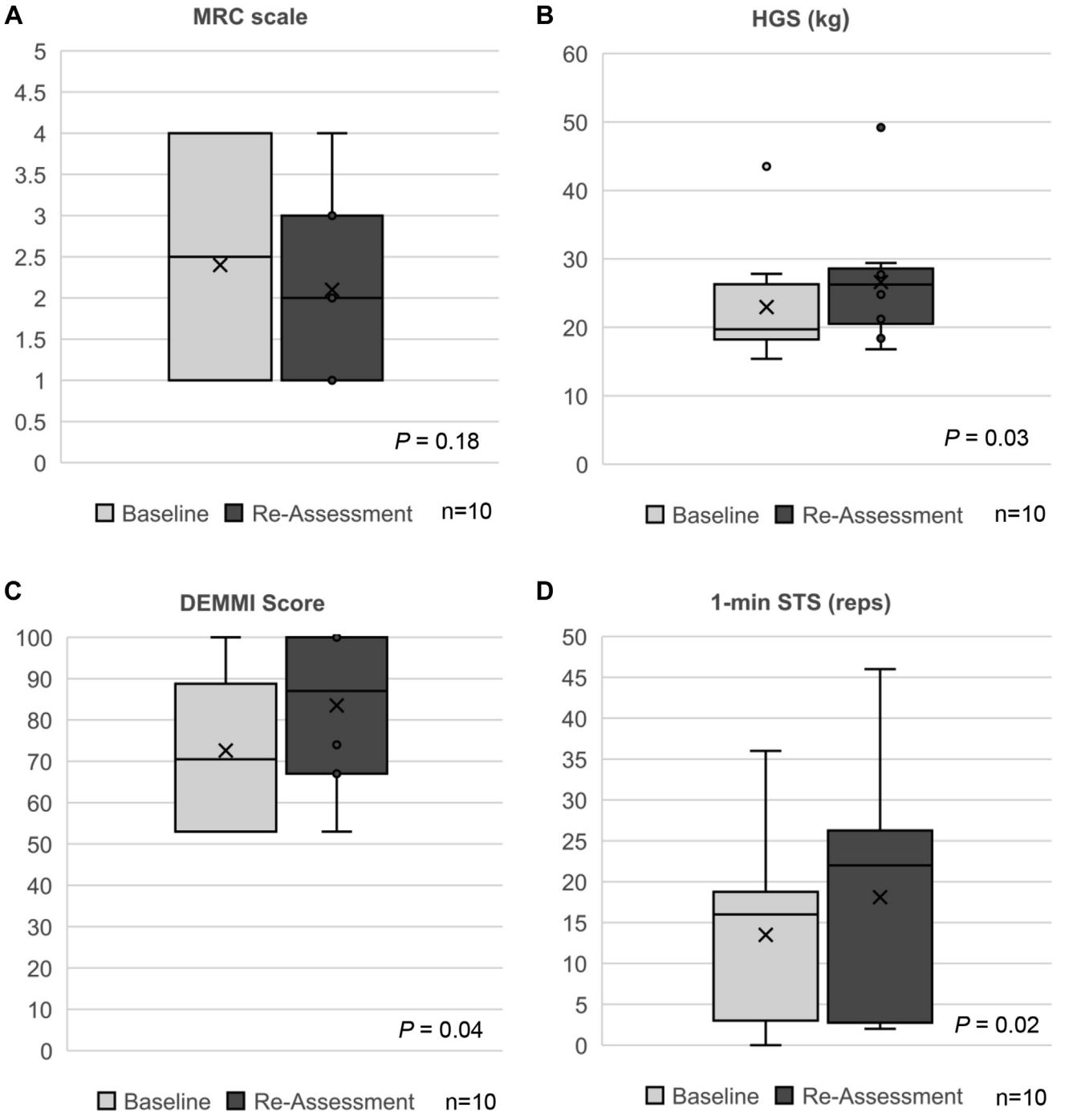

Figure 3: Change in physical frailty outcome measures for the 10 participants who completed repeat assessment

Physiotherapy care (n = 25)	
Attendance	
Total physiotherapy appointments booked, n	360
Total physiotherapy appointments attended, n (%)	211 (59)
Physiotherapy appointments per participant, median (IQR)	6 (4, 9)
Total days engaged with physiotherapy support, median (IQR)	863 (36, 133)
Care utilised, n (%)	
Restorative care	25 (100)
Self-directed home exercise program only	7 (28)
Physiotherapy supervised exercise program only	0 (0)
Physiotherapy supervised exercise program + self-directed home exercise program	16 (64)
Physiotherapy supervised small group exercise	14 (56)
Physiotherapy supervised individual exercise	2 (8)
Self-directed at dialysis exercise program only	2 (8)
Other usual care	25 (100)
Mobility aid prescription	7 (28)
Management of musculoskeletal pain/injury	12 (48)
Cardio-respiratory interventions	20 (80)
Telehealth	5 (20)
Functional assessment to support disability support applications	5 (20)
Physical fitness optimisation to support transplant listing	6 (24)

Utilisation of restorative care and usual care is described for all clients seen by physiotherapy during the 'Frailty-to-Fit' pilot (20 clients of NSDTP, 5 chronic maintenance dialysis clients with frailty identified needs). For the 20 NSDTP clients, 75% (n = 15) also attended group learning (Renal Yarning Circles) and 80% (n = 16) used the program's dedicated transport service to attend physiotherapy appointments. There were no adverse events.

Table 5: Uptake of physiotherapy care during 'Frailty-to-Fit' pilot study.

clinician completion, and permitted patient choice to participate in repeated measures at follow-up. It was confirmed that the PFA delivery was acceptable for patients and clinicians, who could incorporate this within the already high time-competing needs of dialysis and other health-optimising appointments. The data, which reported physical function goals and goal-attainment over time, affirmed the experience within the initial stakeholder consultation, in identifying innovations to address patient-important service gaps. It is recognised that those beneficial outcomes were likely supported by intentional cultural-safety grounding, design and leadership with Aboriginal and Torres Strait Islander peoples who were technical experts from lived experiences and clinical carers (Duff et al, 2018; Hughes et al, 2019c). It is emphasised that the utility of the pilot was enabled by an existing and locally designed model of dialysis transition care, which had endorsement from Indigenous governance and reciprocal leadership from patients and clinicians.

Australian healthcare accreditation standards emphasise quality and safe healthcare, patient-prioritised goals of care and quality of healthcare outcomes. Context-appropriate exercise interventions have been shown to improve clinical outcomes in other kidney failure populations (Mallamaci et al, 2020; Nixon et al, 2020) and for managing other chronic diseases in Aboriginal Australians (Canuto et al, 2012; Mendham et al, 2015). The FTF participants voluntarily engaged with physiotherapy restorative and usual care, and no adverse events were observed. These data support the hypothesis that a physiotherapy-led FTF service locally available at the renal unit is beneficial for all adults commencing dialysis in Northern Australia, and specifically addressed a health equity and cultural safety priority of Aboriginal patients. A Live Strong Dialysis Patient Transport Service was implemented during months 2 to 6 of the physiotherapy program, which bolstered patients' confidence in frailty-accessible COVID-safe transport and supported their attendance at related healthcare appointments (the NSDTP, dialysis treatments and physiotherapy). While those results will be presented elsewhere, it addressed the importance of transport as a social determinant of good health outcomes. Within this context, transport assisted patients with kidney failure, and concurrent health optimisation needs, who were presently without personal transport (as relocated from remote NT).

This pilot study directly responded to requests for frailty support from the Top End Renal Indigenous Patient Reference Group and was endorsed by the Live Strong Patient Reference Group. The inbuilt priority of culturally safe practice supported a physiotherapy service that avoided shaming and helped participants to feel believed, supported and confident to access care, which are all indicators of quality, safe and high valued healthcare services. Furthermore, collaboration in design and delivery supported the health of individuals as part of a collective, promoted culturally secure partnership (Northern Territory Government, 2021), and was consistent with definition of Aboriginal health, that it is 'not just the physical well-being of the individual but the social, emotional, and cultural well-being of the whole community' (Australia-DoP, 2013).

Implications and future directions

Physical function was confirmed as an important patient goal in this study. At a population level, it is recognised that routine recording of prospective PFA can confirm normative values of physical function when assessed in other Australian settings, involving a wider range of chronic kidney disease (with and without dialysis), and involving Aboriginal and Torres Strait Islander people beyond this study location (Darwin, Australia). Regionally to the Top End NT, high generalisability and scalability of the PFA and FTF physiotherapy service to the wider Top End population (approximately 400 adults accessing haemodialysis) is expected, of whom approximately 80% identify as Aboriginal. Because it is also expected that chronological changes in frailty will be compounded by chronic disease (Clegg et al, 2013; Weiss, 2011), expanding access to renal physiotherapy for more patients, particularly those living longer with dialysis-treated kidney failure, is recommended. Accessing PFA measures routinely entered into healthcare information systems (Hughes et al, 2019a), as undertaken in this pilot, and which improves access to restorative physiotherapy, may also reduce acute care health expenditure (measured as hospital length of stay and admission frequency). At a family level, continued participation in life for Aboriginal and Torres Strait Islander peoples, through maintaining physical function and restored function after illness, is very important. When people are living with dialysis, this might also be measured by access to dialysis on Country and outside hospital-dependent dialysis services.

Strengths and limitations

Indigenous leadership, partnership with patients, clinicians and a mixed-methods co-design process enabled the conceptualisation of a population-specific PFA, and its pilot implementation as an innovative renal physiotherapy-led restorative care program. The partnership supported patient-important outcomes during the study, was present before the study and has continued to date. Indigenous-led methodologies are inherent strengths of Aboriginal and Torres Strait Islander peoples, so adopted in this study; it supported patient-priority to be inserted in the service design and translation into clinical practices. For example, the FTF component of renal physiotherapy was beneficial for individuals with advanced comorbidity and made the benefits of exercise interventions accessible to those clients. The study has provided insight into patient-important physical function priorities for Aboriginal and Torres Strait Islander peoples with kidney failure in Northern Australia.

Stakeholder endorsement has supported extending the FTF service as usual practice, across the renal service, with 3.9 FTE renal physiotherapists commencing in September 2023. This work offers insight into how frailty support can be approached in other First Nations populations of the world with their own cultural values and dialysis healthcare contexts.

Although frailty has been measured in kidney failure with a variety of subjective and objective measures (Chowdhury et al, 2017; Nixon et al, 2018), existing assessments can have practicality issues (Nixon et al, 2018). Furthermore, the multidimensional nature of frailty (physical, social, psychological) is complex (Xue, 2011) and the clinometric value of existing assessments is largely uncertain (De Vries et al, 2011). This targeted approach to objective, patient-important physical frailty assessment supported a feasible assessment and avoided confusion. However, it is acknowledged that PFA cannot be used to prognostically define individuals as grades of 'frail' or 'pre-frail' (Fried et al, 2001). This pilot was intended to respond to patient-defined needs and demonstrate proof of concept, feasibility and acceptability. Resource limitations and COVID-safe public health directives showed that only these four selected outcome measures taken at two time points would be suitable to pilot PFA in a small sample of eligible, comorbid participants with concurrent treatment priorities.

The study design did not permit a control group and potential for volunteer and assessor bias may have existed. It is also acknowledged that improvement in physical frailty may reflect metabolic factors that were unmeasured in this study, such as achieving euvolaemia and electrolyte balance (potassium, vitamin D, parathyroid hormone, iron) with dialysis. These limitations may be prospectively addressed with extended data collection to larger samples, and multi-sited and longer follow-up including additional unmeasured clinical covariates. Investigating time to attain home-based dialysis or transplantation and in-depth qualitative interviews may reveal the extent of positive impacts for clients and the healthcare system (Hughes et al, 2019b), and are reported elsewhere.

Conclusions

In Northern Australia, the COVID-19 infection was expected to severely impact health service delivery for adults with kidney failure and reliant on dialysis. Pandemic mitigation strategies impacted usual care within renal services and dialysis units, and this opportunity enabled patients and clinicians to implement locally accessible outpatient renal physiotherapy within the established NSDTP. Stakeholder consultation confirmed that frailty improvement was important to daily living and may provide specific support for clients to access home dialysis. It had been recognised home-based self-care dialysis is a way for patients and family to manage close and frequent contacts (recommended by Public Health Directives at that time). Research funding was crucial to support a patient–clinician research collaboration that enabled the design and then use of a contextually relevant PFA.

This study confirmed the existence of objectively assessed physical frailty among Aboriginal and non-Aboriginal adults after starting dialysis in Northern Australia. Four measures of physical function were incorporated into PFA and guided clients' access to usual physiotherapy care and restorative care. It confirmed the presence of physical frailty, including advanced frailty, and the high utility of culturally-safe physiotherapy restorative care that supported improvement in patient-important physical frailty outcomes. Extending renal physiotherapy services is recommended to support many more patients who need to regain physical function to access care close to home after starting dialysis.

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of this project, and all patients who are partners in their care with Top End Renal Services. We acknowledge this research study was initiated at, and supported by, the Menzies School of Health Research, and supported by other study partners including Top End Health Services, NT Health and Flinders University.

Authorship and contributions

This paper was led by RM and JH, who prepared the first draft. All other authors made substantial contributions to study design, data acquisition, analysis or data interpretation. All authors approved the final version of the paper before submission.

Declaration of interests

This enhancement to usual care was conceptualised within the Top End Renal Service NSDTP and delivered with a clinical-research partnership within the Live Strong COVID-safe Frailty-Free after Starting Dialysis Project, co-funded by Northern Territory Department of Health and APPRISE-Ramsay First Nations COVID-19 research grants (University of Melbourne). The study physiotherapist (RM) received clinical governance support and Indigenous governance support from the Royal Darwin Hospital physiotherapy manager (CT) and leads of the NSDTP (OP, JH). The study received advice from the Live Strong Patient Reference Group and an Aboriginal Health Qualitative Scientist (AME). Throughout the pilot study, the physiotherapist (RM) liaised with governing stakeholders in formal meetings and reported findings and progress, to ensure culturally-safe, service-sustainable and accountable practices in line with local healthcare policy. JTH reports financial support and administrative support were provided by Northern Territory Top End Health Service, and JTH received a funding grant from APPRISE to deliver this clinical research activity. Except for SZ, AME and four Indigenous Patient Reference Group members, other authors were employed by the NT Top End Health Services where the project took place.

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Indigenous Data Sovereignty

Indigenous Data Sovereignty refers to the use of health data by Aboriginal and Torres Strait Islander peoples as individual and collective of their represented nations, to understand their own health journeys, through interpretation of their own data that remain within the ownership of Aboriginal and Torres Strait Islander peoples, even when licensed to a health service provider. As an adjunct to Aboriginal and Torres Strait Islander peoples' millennia of ancestral knowledge, the more recent informing research collaborations with Aboriginal and Torres Strait Islander patients and clinicians prior to 2020 informed the design of the NSDTP, demonstrating actions of Indigenous Data Sovereignty and this subsequent service innovation with locally accessible renal physiotherapy. The authors acknowledge that Indigenous cultural and intellectual property remains within the ownership of Aboriginal and Torres Strait Islander peoples.

Author bios

Richard Modderman: Richard Modderman was a senior physiotherapist employed by Royal Darwin Hospital during this project to deliver the 'Frailty-to-Fit' pilot innovation that was evaluated in this research. Mr Modderman is also an associate lecturer at Flinders

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Onika Paolucci: Onika Paolucci is a proud descendant of Muran/Iwaidja people from Minjilang Country, West Arnhem Land. She has been an Aboriginal and Torres Strait Islander health practitioner in renal since 2019. She is passionate about empowering mob through knowledge sharing about kidneys in a culturally respectful and safe way.

Sara Zabeen: Sara Zabeen is a Bangladeshi woman who has called Australia home since 2012. She is a public health professional, with over seven years' experience as a health researcher. Her topic of interests and research expertise include chronic condition self-management, integrated care, Indigenous health and wellbeing, and implementation science. Ms Zabeen believes in health equity and social justice and works accordingly.

Clee Tonkin: Clee Tonkin is a senior physiotherapist with 12 years' experience working at Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Clee is passionate about providing individualised patient-important care with particular focus on improving access to quality physiotherapy care for Aboriginal and Torres Strait Island people.

Anne-Marie Eades: Dr Eades is a Noongar woman from Western Australia and a descendant of a Wiilman father and Minang mother. Dr Eades' research interests relate to the role of psychosocial factors in chronic disease and building resilience in Aboriginal and Torres Strait Islander health. She has a particular interest in women's issues and children in out-of-home care. Dr Eades has a background in nursing and her PhD study looked at how individual, family and societal influences impact on Indigenous women's health.

Deborah Roe: Deborah Roe is a qualified occupational therapist with over 20 years' experience working in a variety of acute and community settings. She is currently working at Royal Darwin Hospital inpatient services as an Allied Health team leader. She enjoys the rich diversity her current position provides and is grateful to work with diverse cultures. Debbie is passionate about working with older people and delivering quality services to clients through patient-centred care and has completed research in patient-centred practice.

Rebecca Jarman: Rebecca Jarman is a senior occupational therapist. She is currently based at Royal Darwin Hospital renal unit, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Rebecca plays a significant role in improving the renal health of Aboriginal and Torres Strait Islander peoples.

Kerry Dole: Kerry Dole has 29 years of clinical nursing experience, with 24 of those years being in renal nursing. She commenced her renal career in the United Kingdom, moving to Central Australia in 1998, then to the Top End Renal Service in 2006 before relocating back to Central Australia in 2022. Kerry has demonstrated compassion and commitment to renal nursing, especially in the kidney transplant area, raising the profile of kidney transplants in the Northern

Territory and improving access to kidney transplants for all Territorians, especially Indigenous Australians. Kerry has authored and co-authored publications relating to kidney transplants in the NT.

Gwendoline Lowah: Gwendoline Lowah is a Torres Strait Islander woman, living and working on Larrakia Country (Darwin, Northern Territory, Australia). Ms Lowah is a clinical nurse consultant supporting dialysis access and provision at Royal Darwin Hospital dialysis unit.

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Jacqueline Kent: Jacqueline Kent is the senior health information manager of the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Jackie is an experienced health professional who stresses importance on improving the social determinants of health. She has a great understanding of the socio-environmental factors that influence the health seeking behaviours of Aboriginal and Torres Strait Island patients.

Kirsty Annesley: Kirsty Annesley is the Director of Financial Modelling, based at the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). Kirsty leads a dedicated and compassionate team that promotes value-based care in the NT. She has a deep understanding of Indigenous health needs and works accordingly to fulfil them.

Matthias Jing: Matthias Jing worked as a health information manager for the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia) until late 2021. Currently, he is enrolled at Flinders University, NT as a medical student.

Margaret Purnell: Margaret Purnell is working as the health service librarian for the Royal Darwin Hospital, Northern Territory Department of Health (Darwin, Northern Territory, Australia). She also has an academic background in midwifery and nursing.

Tolbert Dharromanba Gaykamangu: Tolbert Dharromanba Gaykamangu is a Gapuwiyak leader (Ramingining, Northern Territory) and an artist. He is the vice-chairman of the local art centre. In Darwin, he teaches and encourages his renal hostel peers about COVID-safe practices, good way and right way (to live), and healthy lifestyle for renal patients (for example, walking). Mr Gaykamangu obtained a certificate on art from the Darwin Museum and completed a computer course at the Charles Darwin University.

Wayne Alum: Wayne Alum belongs to the Jingli tribe (Darwin, Northern Territory) and considers himself a community role model. He has 16 years' work experience with Mission Australia as a community service worker. He also worked six years as a medical transport officer with the Northern Territory health service. He is a trainer, educator and supervisor. Mr Alum also supports his community people with

housing and mental illness issues. He has obtained certificates on suicide prevention and alcohol and other drugs (AOD).

Edna May Wittkopp: Edna May Wittkopp is a Goba woman from Moa Island (Torres Strait, Queensland), living on Larrakia Country, Northern Territory. She is an educator and interpreter. Ms Wittkopp completed her certificate III in business administration. In the past, she worked for NT Health as an administrative officer. Before retirement, she was working with Australia Post.

Anne-Marie Puruntatameri: Mrs Puruntatameri is a Tiwi Elder. She has been a leader in clinical research partnerships, which informed this collaboration, and recently served as Chairperson of the Top End Health Service Renal Indigenous Patient Reference Group (2019-2021). She holds a Diploma in Aboriginal Health and is now retired from her role as Aboriginal Health Practitioner in the Tiwi Islands. She is also involved in a range of community works including alcohol, diabetes and kidney awareness programmes. Anne-Marie also raises awareness about the need of nutrition and COVID safety in remote areas.

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Supplementary material

Supplementary material associated with this article can be found at https://doi.org/10.1016/j.fnhli.2024.100020.

References

ANZDATA-Registry, 2021. Chapter 10 – End Stage Kidney Disease in Aboriginal and Torres Strait Islander Australians. In: *ANZDATA Annual Report*, Australia & New Zealand Dialysis & Transplant Registry. https://www.anzdata.org.au/wp-content/uploads/2021/09/c10_indigenous_2020_ar_2021_v1.0_20220224_Final.pdf. (Accessed 1 March 2022).

ANZSN, 2022. *Equity in kidney care: Position statement*. Australian and New Zealand Society of Nephrology. https://nephrology.edu.au/int/anzsn/uploads/Equity%20in%20Kidney%20Care%20(1).pdf. (Accessed 1 September 2023).

Australia-DoP, 2013. National Aboriginal and Torres Strait Islander Health Plan: 2013-2023. (10290). Department of Health, Australia. https://www.health.gov.au/sites/default/files/documents/2021/02/national-aboriginal-and-torres-strait-islander-health-plan-2013-2023.pdf. (Accessed 3 February 2023).

Bennett, P.N., Bohm, C., Harasemiw, O., Brown, L., Gabrys, I., Jegatheesan, D., Johnson, D.W., Lambert, K., Lightfoot, C.J., MacRae, J., Meade, A., 2022. Physical activity and exercise in peritoneal dialysis: International Society for Peritoneal Dialysis and the Global Renal Exercise Network practice recommendations. Peritoneal Dialysis International 42 (1), 8–24.

Bestall, J., Paul, E., Garrod, R., Garnham, R., Jones, P., Wedzicha, J., 1999. Usefulness of the Medical Research Council (MRC) dyspnoea scale as a measure of disability in patients with chronic obstructive pulmonary disease. Thorax 54 (7), 581–586. https://doi.org/10.1136/thx.54.7.581.

Bikbov, B., Purcell, C.A., Levey, A.S., Smith, M., Abdoli, A., Abebe, M., Adebayo, O.M., Afarideh, M., Agarwal, S.K., Agudelo-Botero, M., 2020. Global, regional, and national burden of chronic kidney disease, 1990–2017: a systematic analysis for the Global Burden of Disease Study 2017. The Lancet 395 (10225), 709–733. https://doi.org/10.1016/S0140-6736(20)30045-3.

Bull, F.C., Al-Ansari, S.S., Biddle, S., Borodulin, K., Buman, M.P., Cardon, G., Carty, C., Chaput, J.P., Chastin, S., Chou, R., Dempsey, P.C., 2020. World Health Organization 2020 guidelines on physical activity and sedentary behaviour. British Journal of Sports Medicine 54 (24), 1451–1462.

Camp, P.G., Sima, C.A., Kirkham, A., Inskip, J.A., Parappilly, B., 2019. The de Morton mobility index is a feasible and valid mobility

assessment tool in hospitalized patients with an acute exacerbation of chronic obstructive pulmonary disease. Chronic Respiratory Disease 16, 1479973119872979. https://doi.org/10.1177/1479973119872979.

Canuto, K., Cargo, M., Li, M., D'Onise, K., Esterman, A., McDermott, R., 2012. Pragmatic randomised trial of a 12-week exercise and nutrition program for Aboriginal and Torres Strait Islander women: clinical results immediate post and 3 months follow-up. BMC Public Health 12 (1), 1–11. https://doi.org/10.1186/1471-2458-12-933.

Cass, A., Cunningham, J., Snelling, P., Wang, Z., Hoy, W., 2004. Exploring the pathways leading from disadvantage to end-stage renal disease for Indigenous Australians. Social Science & Medicine 58 (4), 767–785. https://doi.org/10.1016/S0277-9536(03)00243-0.

Chowdhury, R., Peel, N.M., Krosch, M., Hubbard, R.E., 2017. Frailty and chronic kidney disease: a systematic review. Archives of Gerontology and Geriatrics 68, 135–142. https://doi.org/10.1016/j.archger.2016.10.007.

Clarkson, M.J., Bennett, P.N., Fraser, S.F., Warmington, S.A., 2019. Exercise interventions for improving objective physical function in patients with end-stage kidney disease on dialysis: a systematic review and meta-analysis. American Journal of Physiology-Renal Physiology 316 (5), F856–F872. https://doi.org/10.1152/ajprenal.00317.2018.

Clegg, A., Young, J., Iliffe, S., Rikkert, M.O., Rockwood, K., 2013. Frailty in elderly people. The Lancet 381 (9868), 752–762. https://doi.org/10.1016/S0140-6736(12)62167-9.

Cockwell, P., Fisher, L.-A., 2020. The global burden of chronic kidney disease. The Lancet 395 (10225), 662–664. https://doi.org/10.1016/S0140-6736(19)32977-0.

De Morton, N.A., Meyer, C., Moore, K.J., Dow, B., Jones, C., Hill, K., 2011. Validation of the de Morton Mobility Index (DEMMI) with older community care recipients. Australasian Journal on Ageing 30 (4), 220–225. https://doi.org/10.1111/j.1741-6612.2010.00497.x.

De Vries, N., Staal, J., van Ravensberg, C., Hobbelen, J., Rikkert, M.O., Nijhuis-van der Sanden, M., 2011. Outcome instruments to measure frailty: a systematic review. Ageing Research Reviews 10 (1), 104–114. https://doi.org/10.1016/j.arr.2010.09.001.

Duff, D., Jesudason, S., Howell, M., Hughes, J., 2018. A partnership approach to engage Aboriginal and Torres Strait Islander peoples with clinical guideline development for chronic kidney disease. Renal Society of Australasia Journal 14 (3), 84–88. https://search.informit.org/doi/abs/10.3316/informit.018526878247237.

Fried, L.P., Tangen, C.M., Walston, J., Newman, A.B., Hirsch, C., Gottdiener, J., McBurnie, M.A., 2001. Frailty in older adults: evidence for a phenotype. The Journals of Gerontology Series A: Biological Sciences and Medical Sciences 56 (3), M146–M157. https://doi.org/10.1093/gerona/56.3.M146.

Geoscience-Australia, 2021. Area of Australia - States and Territories. Commonwealth of Australia (Geoscience Australia). https://www.ga.gov.au/scientific-topics/national-location-information/dimensions/area-of-australia-states-and-territories. (Accessed 14 November 2022).

Gill, T.M., Gahbauer, E.A., Han, L., Allore, H.G., 2010. Trajectories of disability in the last year of life. New England Journal of Medicine 362 (13), 1173–1180. https://doi.org/10.1056/NEJMoa0909087.

Gobbens, R., Luijkx, K., Wijnen-Sponselee, M.T., Schols, J., 2010. Towards an integral conceptual model of frailty. The Journal of Nutrition, health & aging 14 (3), 175–181. https://doi.org/10.1007/s12603-010-0045-6.

Gorham, G., Majoni, S.W., Lawton, P., Brown, S., Dube, B., Conlon, T., Sajiv, C., Wood, P., Signal, S., Cass, A., 2018. Interesting times-evolution of dialysis in Australia's Northern Territory (1980-2014). Renal Society of Australasia Journal 14 (3), 108–117. https://doi.org/10.3316/informit.018657309046045.

Hughes, J., Dembski, L., Kerrigan, V., Majoni, S.W., Lawton, P., Cass, A., 2018. Gathering Perspectives-Finding Solutions for Chronic and End Stage Kidney Disease. Nephrology 23, 5–13. https://doi.org/10.1111/nep.13233.

Hughes, J., Majoni, S.W., Barzi, F., Harris, T.M., Signal, S., Lowah, G., Kapojos, J., Abeyaratne, A., Sundaram, M., Goldrick, P., 2019a. Incident haemodialysis and outcomes in the Top End of

Australia. Australian Health Review 44 (2), 234–240. https://doi.org/10.1071/AH18230.

Hughes, J., Kirkham, R., Min, O.A., Hall, H., Currie, B., Majoni, S.W., 2019b. Patient-identified health service transformation: an Aboriginal patient's experience with extensive chronic tinea corporis and delayed kidney transplantation wait-listing. Renal Society of Australasia Journal 15 (3), 92–96. https://onlinelibrary.wiley.com/doi/pdf/10.1111/nep.13233.

Hughes, J., Lowah, G., Kelly, J., 2019c. Re-framing the Indigenous kidney health workforce. The Medical Journal of Australia 211 (1), 6. https://doi.org/10.5694/mja2.50210.

Huria, T., Pitama, S.G., Beckert, L., Hughes, J., Monk, N., Lacey, C., Palmer, S.C., 2021. Reported sources of health inequities in Indigenous Peoples with chronic kidney disease: a systematic review of quantitative studies. BMC Public Health 21 (1), 1–10. https://doi.org/10.1186/s12889-021-11180-2.

Hyde, Z., Flicker, L., Smith, K., Atkinson, D., Fenner, S., Skeaf, L., Giudice, D.L., 2016. Prevalence and incidence of frailty in Aboriginal Australians, and associations with mortality and disability. Maturitas 87, 89–94. https://doi.org/10.1016/j.maturitas.2016.02.013.

Iyasere, O.U., Brown, E.A., Johansson, L., Huson, L., Smee, J., Maxwell, A.P., Farrington, K., Davenport, A., 2016. Quality of life and physical function in older patients on dialysis: a comparison of assisted peritoneal dialysis with hemodialysis. Clinical Journal of the American Society of Nephrology 11 (3), 423–430. https://doi.org/10.2215/CJN.01050115.

Jans, M.P., Slootweg, V.C., Boot, C.R., de Morton, N.A., van der Sluis, G., van Meeteren, N.L., 2011. Reproducibility and validity of the Dutch translation of the de Morton Mobility Index (DEMMI) used by physiotherapists in older patients with knee or hip osteoarthritis. Archives of Physical Medicine and Rehabilitation 92 (11), 1892–1899. https://doi.org/10.1016/j.apmr.2011.05.011.

Johnston, M., de Morton, N., Harding, K., Taylor, N., 2013. Measuring mobility in patients living in the community with Parkinson disease. Neuro Rehabilitation 32 (4), 957–966. https://content.iospress.com/articles/neurorehabilitation/nre919.

Kerr, M., Evangelidis, N., Abbott, P., Craig, J.C., Dickson, M., Scholes-Robertson, N., Sinka, V., Vastani, R.T., Widders, K., Stephens, J., 2022. Indigenous Peoples' perspectives of living with chronic kidney disease: systematic review of qualitative studies. Kidney International 102 (4), 720–727. https://doi.org/10.1016/j.kint.2022.05.030.

Khanal, N., Lawton, P.D., Cass, A., McDonald, S.P., 2018. Disparity of access to kidney transplantation by Indigenous and non-Indigenous Australians. Medical Journal of Australia 209 (6), 261–266. https://doi.org/10.5694/mja18.00304.

King, M., Smith, A., Gracey, M., 2009. Indigenous health part 2: the underlying causes of the health gap. The Lancet 374 (9683), 76–85. https://doi.org/10.1016/S0140-6736(09)60827-8.

Koufaki, P., Greenwood, S., Painter, P., Mercer, T., 2015. The BASES expert statement on exercise therapy for people with chronic kidney disease. Journal of Sports Sciences 33 (18), 1902–1907.

Koufaki, P., Mercer, T.H., Naish, P.F., 2002. Effects of exercise training on aerobic and functional capacity of end-stage renal disease patients. Clinical Physiology and Functional Imaging 22 (2), 115–124. https://doi.org/10.1046/j.1365-2281.2002.00405.x.

Krippendorff, K., 2018. Content analysis: An introduction to its methodology, *4th ed.* Sage publications, Los Angeles, USA.

Liyanage, T., Ninomiya, T., Jha, V., Neal, B., Patrice, H.M., Okpechi, I., Zhao, M-h, Lv, J., Garg, A.X., Knight, J., 2015. Worldwide access to treatment for end-stage kidney disease: a systematic review. The Lancet 385 (9981), 1975–1982. https://doi.org/10.1016/S0140-6736(14)61601-9.

LoGiudice, D., 2016. The health of older Aboriginal and Torres Strait Islander peoples. Australasian Journal on Ageing 35 (2), 82–85. https://doi.org/10.1111/ajag.12332.

Majchrzak, K.M., Pupim, L.B., Chen, K., Martin, C.J., Gaffney, S., Greene, J.H., Ikizler, T.A., 2005. Physical activity patterns in chronic hemodialysis patients: comparison of dialysis and nondialysis days. Journal of Renal Nutrition 15 (2), 217–224. https://doi.org/10.1053/j.jrn.2004.08.002.

Mallamaci, F., Pisano, A., Tripepi, G., 2020. Physical activity in chronic kidney disease and the EXerCise Introduction To

Enhance trial. Nephrology Dialysis Transplantation 35 (Supplement_2), ii18–ii22. https://doi.org/10.1093/ndt/gfaa012.

Massy-Westropp, N.M., Gill, T.K., Taylor, A.W., Bohannon, R.W., Hill, C.L., 2011. Hand Grip Strength: age and gender stratified normative data in a population-based study. BMC Research Notes 4 (1), 1–5. https://doi.org/10.1186/1756-0500-4-127.

McAdams-DeMarco, M.A., Law, A., Salter, M.L., Boyarsky, B., Gimenez, L., Jaar, B.G., Walston, J.D., Segev, D.L., 2013. Frailty as a novel predictor of mortality and hospitalization in individuals of all ages undergoing hemodialysis. Journal of the American Geriatrics Society 61 (6), 896–901. https://doi.org/10.1111/jgs.12266.

McAdams-DeMarco, M.A., Thind, A.K., Nixon, A.C., Woywodt, A., 2022. Frailty Assessment as Part of Transplant Listing: Yes, No, or Maybe? Clinical Kidney Journal. (sfac277). https://doi.org/10.1093/ckj/sfac277.

Mendham, A.E., Duffield, R., Marino, F., Coutts, A.J., 2015. A 12-week sports-based exercise programme for inactive Indigenous Australian men improved clinical risk factors associated with type 2 diabetes mellitus. Journal of Science and Medicine in Sport 18 (4), 438–443. https://doi.org/10.1016/j.jsams.2014.06.013.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., Group, P., 2010. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. International Journal of Surgery 8 (5), 336–341. https://doi.org/10.1016/j.ijsu.2010.02.007.

Moorhouse, P., Rockwood, K., 2012. Frailty and its quantitative clinical evaluation. The Journal of the Royal College of Physicians of Edinburgh 42 (4), 333–340. https://doi.org/10.4997/jrcpe.2012.412.

Nixon, A.C., Bampouras, T.M., Pendleton, N., Woywodt, A., Mitra, S., Dhaygude, A., 2018. Frailty and chronic kidney disease: current evidence and continuing uncertainties. Clinical Kidney Journal 11 (2), 236–245. https://doi.org/10.1093/ckj/sfx134.

Nixon, A.C., Bampouras, T.M., Pendleton, N., Mitra, S., Brady, M.E., Dhaygude, A.P., 2020. Frailty is independently associated with worse health-related quality of life in chronic kidney disease: a secondary analysis of the Frailty Assessment in Chronic Kidney Disease study. Clinical Kidney Journal 13 (1), 85–94. https://doi.org/10.1093/ckj/sfaa066.

Northern Territory Government, 2021. NT Aboriginal Health Plan 2021-2031. Northern Territory Government, Darwin. https://health.nt.gov.au/professionals/aboriginal-and-torres-strait-islander-health/aboriginal-health-policy. (Accessed 1 March 2022).

Paterson, J., 2020. Submission to the Select Committee on COVID-19 Inquiry into the Government's response to COVID-19. Aboriginal Peak Organisations Northern Territory (APO NT). https://www.aph.gov.au/DocumentStore.ashx?id=7529b109-11f7-48ac-a129-2831dafdfdf3&subId=690859. (Accessed 1 March 2023).

Peters, M.D., Godfrey, C.M., Khalil, H., McInerney, P., Parker, D., Soares, C.B., 2015. Guidance for conducting systematic scoping reviews. JBI Evidence Implementation 13 (3), 141–146. https://doi.org/10.1097/XEB.0000000000000050.

Ritchie, C., Trost, S., Brown, W., Armit, C., 2005. Reliability and validity of physical fitness field tests for adults aged 55 to 70 years. Journal of Science and Medicine in Sport 8 (1), 61–70. https://doi.org/10.1016/S1440-2440(05)80025-8.

Segura-Ortí, E., Martínez-Olmos, F.J., 2011. Test-retest reliability and minimal detectable change scores for sit-to-stand-to-sit tests, the six-minute walk test, the one-leg heel-rise test, and handgrip strength in people undergoing hemodialysis. Physical Therapy 91 (8), 1244–1252. https://doi.org/10.2522/ptj.20100141.

Smart, N.A., Williams, A.D., Levinger, I., Selig, S., Howden, E., Coombes, J.S., Fassett, R.G., 2013. Exercise & Sports Science Australia (ESSA) position statement on exercise and chronic kidney disease. Journal of Science and Medicine in Sport 16 (5), 406–411.

Smith, M., e Silva, V.S., Schick-Makaroff, K., Kappel, J., Bachynski, J.C., Monague, V., Paré, G.C., Ross-White, A., 2021. Furthering cultural safety in kidney care within indigenous communities: a systematic and narrative review. Kidney Medicine 3 (6), 896–904. https://doi.org/10.1016/j.xkme.2021.04.023.

Stenton, C., 2008. The MRC breathlessness scale. Occupational Medicine 58 (3), 226–227. https://doi.org/10.1093/occmed/kqm162.

Tunnicliffe, D., Bateman, S., Arnold-Chamney, M., Dwyer, K., Howell, M., Jesudason, S., Kelly, J., Lambert, K., Majoni, S., Owen, K., Pearson, O., Rix, E., Roberts, I., Stirling, K.R., Wittert, G., Yip, A., Craig, J., Phoon, R. Recommendations for culturally safe and clinical kidney care for First Nations Australians. https://www.cariguidelines.org/first-nations-australian-guidelines/. (Accessed 1 March 2023).

Weiss, C.O., 2011. Frailty and chronic diseases in older adults. Clinics in Geriatric Medicine 27 (1), 39–52. https://doi.org/10.1016/j.cger.2010.08.003.

Wu, P.Y., Chao, C.-T., Chan, D.-C., Huang, J.-W., Hung, K.-Y., 2019. Contributors, risk associates, and complications of frailty in patients with chronic kidney disease: a scoping review. Therapeutic advances in chronic disease, 10. https://doi.org/10.1177/2040622319880382.

Xue, Q.L., 2011. The frailty syndrome: definition and natural history. Clinics in Geriatric Medicine 27 (1), 1–15. https://doi.org/10.1016/j.cger.2010.08.009.

Zabeen, S., Eades, A.-M., Paolucci, O., Modderman, R., Tonkin, C., Dole, K., Lowah, G., Annesley, K., Kent, J., Coccetti, E., Weldon, A., Jing, M., Roe, D., Jarman, R., Puruntatemeri, A.-M., Wittkopp, E.M., Alum, W., Gaykamangu, T.D., Hughes, J.T., 2023. Evaluation of an innovative Live Strong COVID-mitigating healthcare delivery for adults after starting dialysis in the Northern Territory: A qualitative study. First Nations Health and Wellbeing - The Lowitja Journal 1, 100001. https://doi.org/10.1016/j.fnhli.2023.100001.