Renal Replacement Therapy

CASE REPORT

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Palliative rehabilitation in end-stage renal failure

Alfred Wai Ping Seng* and Shuen-Loong Tham

Abstract

Background: In end-stage chronic kidney disease (CKD), patients experience disabilities stemming from organ failure. These can be worsened by symptoms and complications of underlying cause(s), and the conditions associated with the CKD. There is a dearth of literature regarding palliative rehabilitation in end-stage CKD. Our case highlights the complex medical and rehabilitative issues that such patients face.

Case presentation: A 64-year-old male had end-stage CKD and declined dialysis. After sustaining a myocardial infarction, he suffered a posterior circulation stroke the following month. Whilst undergoing stroke rehabilitation, his progress was further hampered by symptoms of kidney failure. The patient underwent interdisciplinary rehabilitation for 29 days. Goal-setting was performed with the patient and family to allow contextualization to the patient's stage of disease, beliefs and environment. Care-giver training was provided to facilitate discharge back home. He demonstrated improvements in physical endurance and function. His Functional Independence Measure score improved from 51 to 82. He outlived his prognosis of 3–6 months and demised 15 months after discharge.

Conclusions: In end-stage CKD without renal replacement therapy, rehabilitation and palliative care efforts align to enhance quality of life, in the face of unlikely cure. While palliative care provides symptom management and supportive care, rehabilitation safeguards physical endurance and ability. It is in the hope of doing so, independence and thence, self-esteem, can be maintained. Future research should explore the benefits of palliative rehabilitation in renal failure.

Keywords: Rehabilitation, Palliative care, Kidney failure chronic

Background

Rehabilitative interventions are often neglected in patients receiving palliative care. Physical therapy and rehabilitation have been found to be valuable in mitigating symptoms experienced by this patient population [1]. Though much research is available supporting physical therapy in end-stage cancer patients, there is a growing body of evidence supporting exercise and rehabilitative therapy in non-oncological end-stage conditions too [1, 2]. The burden of end-stage Chronic Kidney Disease (CKD) patients requiring palliative care is a significant one. Murtagh et al. [3] found that for every new patient who received dialysis or transplant, there was one new patient who declined renal replacement therapy (RRT). Patients who declined dialysis initiation would have a median survival of at least 6 months [4]. We describe herein our experience in delivering a short spurt of inpatient rehabilitative therapy to a patient with end-stage CKD on palliative care, afflicted with concomitant cardiovascular and cerebrovascular diseases.

Case presentation

A 64-year-old gentleman had Stage 5 CKD secondary to diabetic nephropathy and hypertensive nephrosclerosis. He declined dialysis and was referred to palliative care.

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In August 2019, he sustained a myocardial infarction with ensuing ischaemic cardiomyopathy. In the following month, he developed ischaemic strokes over bilateral occipital lobes and right cerebellum. His admission NIHSS (National Institutes of Health Stroke Scale) score was 5. At the time of his stroke, he was given a prognosis of 3–6 months in view of his declining renal function. He was transferred to the Rehabilitation Centre 2.5 weeks after stroke onset. His admission FIM (Functional Independence Measure) score was 51 (Table 1). He scored positively on the HADS (Hospital Anxiety and Depression Scale—15 points). At presentation to the Rehabilitation Centre, he had left-sided hemiplegia (MRC (Medical Research Council) scale for muscle strength: left shoulder abduction 2/5, elbow flexion and extension 4/5, finger flexion and extension 3/5, hip flexion 2/5, knee extension and flexion 3/5, ankle dorsiflexion 3/5). He also had right-sided proximal muscle weakness with truncal ataxia affecting his sitting balance (Trunk Impairment Scale score 0). Proprioception and light touch sensation were preserved in all limbs. There was no orthostatic hypotension suggestive of significant autonomic dysfunction. Confrontation visual field testing was normal. The MoCA (Montreal Cognitive Assessment) demonstrated mild cognitive impairment (MoCA score of 23).

The patient underwent inpatient interdisciplinary rehabilitation for 4 weeks, receiving physiotherapy and occupational therapy sessions, 30–45 min each, on Mondays to Fridays (Fig. 1). In the first week (Phase 1: Reconditioning), the occupational therapist focused on bilateral upper limb (e.g. closed chain activities inclusive of eccentric and concentric exercises) and core strengthening exercises which were crucial in performing transfers and seated activities of daily living (ADLs). An Oswestry standing frame was used to facilitate upright standing while performing reaching tasks and stepping exercises. Due to truncal ataxia and lower limb weakness, a ceiling hoist was utilized for safety during physiotherapy sessions. Whilst there were no episodes of orthostatic hypotension, therapy was occasionally halted due to hypertensive episodes, with systolic BP (blood pressure) exceeding 160 mmHg (Heart rate remained less than 100/min). BP control improved after the first week with titration of anti-hypertensive medications and his weight was closely monitored twice a week to detect hypervolaemia. Exercise intensity was determined using the Borg RPE (Rating of Perceived Exertion). A 5-min break was enforced whenever the patient reported an RPE of more than 11. To cope with fatigue, physiotherapy and occupational therapy sessions were spaced several hours apart.

Table 1 Patient's Functional Independence Measure (FIM) scores and its components on admission to and discharge from rehabilitation

Motor items	Admission	Discharge		Admission	Discharge
Self-Care			*Locomotion*		
Eating	1	5	Wheelchair	1	1
Grooming	3	4	Stairs	1	1
Bathing	2	4			
Dressing—Upper	2	4	*Sphincter control*		
Dressing—Lower	2	4	Bladder	1	3
Toileting	1	5	Bowel	1	5
Transfers					
Bed, Wheelchair	3	4			
Toilet	3	4			
Tub, Shower	2	4	**Motor sub-score**	**23**	**48**

Cognitive items	Admission	Discharge
Communication		
Comprehension	5	7
Expression	7	7
Social cognition		
Social interaction	5	7
Problem solving	4	6
Memory	7	7
Cognitive sub-score	**28**	**34**
Total FIM score (Motor + Cognition)	**51**	**82**

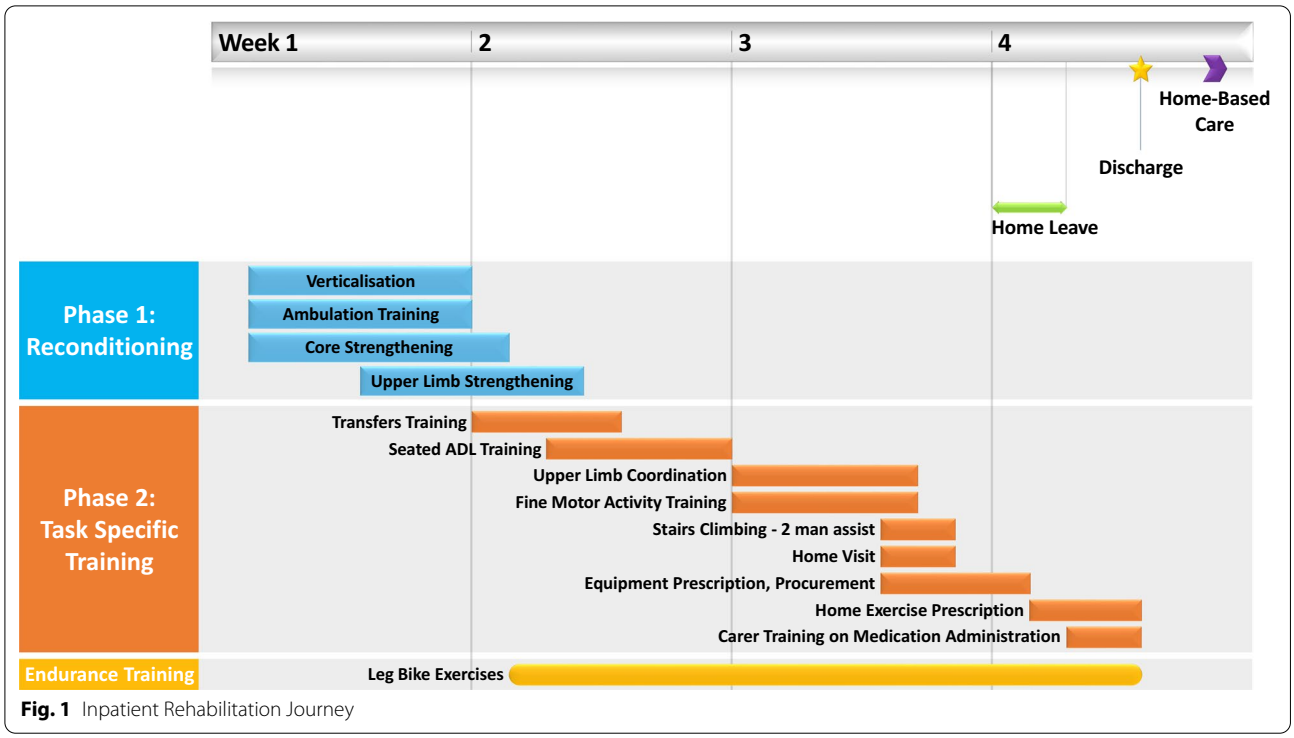

Fig. 1 Inpatient Rehabilitation Journey

In the subsequent 3 weeks (Phase 2: Task-Specific Training), the patient's left-sided limb strength improved globally to an MRC strength grading of 4/5. Now that he could tolerate more than 15 min of continuous therapy, the rehab team focused on training his seated ADLs including transfers using a transfer belt, wheelchair transfers and showering. Upper limb rehabilitation progressed to fine motor and coordination training with the use of pegboards and tool manipulation to strengthen pincer and tripod grasps. This second phase of rehab was also interspersed with mild-to-moderate intensity exercises on the cycle ergometer to build endurance. To facilitate community access, both his carers were trained to assist him in stair-climbing and wheelchair transfers. The occupational therapist performed a home environment evaluation and advised on equipment prescription. Energy conservation techniques were imparted to further enhance independence in ADLs. Given the anticipated decline in his condition, the equipment's time from purchase-to-receipt, cost-versus-benefit and longevity of use were taken into consideration. A dietician was integral in educating and prescribing judicious protein (1 g/kg/day) and caloric requirements (30 kcal/kg/day). Days before discharge, home-based self-supervised exercises were taught to the patient and his carers. This was done with the aim of maintaining the achieved functional gains whilst the patient continues to be cared for by a home-based care team. His motor FIM score more than doubled from 23 to 48 on discharge, with improvements noted across all components of self-care, transfers and continence. Given his complex medical and psychological issues, an inpatient psychiatry consult was obtained. The mainstay of treating his affective disorders was psychotherapy, given his good response to it and unsuitability of psychotropic medications (due to poor renal function). Concurrent management of his low mood led to increased motivation, participation and self-empowerment. This in turn led to improvement in cardiovascular endurance and strength, which consequently improved sleep and mood (discharge HADS score decreased to 6).

At outset, goal-setting was undertaken by the rehabilitation team with active involvement of the patient and a family member. It was determined that whilst functional walking was not a goal, physical therapy (including therapeutic walking) would be delivered during his 4-week stay. He articulated his goals well: he was keen to return home soonest to spend time with his family; to reduce the assistance required for his ADLs; to tend to his flowers, a QOL (Quality of Life) goal. As he sought to employ a stay-in caregiver, carer-training provision was also established as a goal before discharge.

On experiencing significant physical progress, the patient subsequently expressed a wish to further extend his stay and "get better". Given the context of his medical prognosis, the original goal of "going home, with reduced care-giver burden" was reinforced to him and his family.

Higher goals, including adaptive gardening and guitar playing, were relayed to the home-based care team for follow-up on discharge.

The patient continued to make functional gains at home for the next 6 months; he scored 60% on the Palliative Performance Scale (only requiring occasional assistance in self-care) during a Palliative Medicine clinic visit, and even declined home hospice services. He went on to survive another 9 months before experiencing functional decline and recurrent hospitalizations for fluid overload. He eventually demised, 15 months after his inpatient rehabilitation stay.

Discussion

Exercise in the palliative rehabilitation of end-stage CKD patients

The Japanese Society of Renal Rehabilitation published the first renal rehabilitation guideline in 2012, and its latest edition in 2019 [5]. This guideline reviewed literature on the evidence of exercise in CKD patients and outlined recommendations for renal rehabilitation in patients with nephritis/nephrotic syndrome, non-dialysis dependent CKD, end-stage CKD patients on haemodialysis, and renal transplant recipients. Exercise therapy was proposed to be prescribed to all these patient groups as it improves their exercise tolerance, but the ideal intensity, duration and dose of exercise remain undetermined. Though palliative end-stage CKD patients without RRT were not specifically mentioned in this guideline, similar rehabilitation principles would remain pertinent.

Numerous studies have alluded to the beneficial effects of physical therapy and exercise in patients with CKD [5–9] and those under palliative care [1, 2]. Zhao et al. [10] reviewed 13 studies involving 614 adults with end-stage CKD on dialysis and reported that exercise (ranging from leg ergometry, walking and yoga) significantly improved physical activity and QOL. Another systematic review by Clarkson et al. concluded that exercise regardless of modality is beneficial for improving physical function among dialysis patients [11]. The American College of Sports Medicine (ACSM) guidelines recommend that all CKD patients (CKD patients not on dialysis, as well as those on haemodialysis and peritoneal dialysis) perform mild to moderate intensity aerobic exercises (40–59% of VO2 peak, RPE 12–13) for 20–60 min/day, 3–5 days/week [12]. The guidelines also recommend resistance training, at 65–75% of one-repetition maximum for a minimum one set of 10–15 repetitions on 2–3 days/week. Flexibility exercises involving static stretches per joint for 60 s 2–3 days/week should also be prescribed. Despite several studies and guidelines reporting the benefit of exercise and its prescription in CKD patients, there was a deficiency in recommendations for end-stage CKD patients on palliative care. Patients with end-stage CKD who decline dialysis grapple not just with concerns common to palliative patients (e.g. fatigue, depression), but complex medical and psychosocial issues that are frequently seen in CKD. Patients are often laden with complications of CKD itself (e.g. renal bone disease, encephalopathy), treatment effects or concomitant conditions arising from aetiologies underlying the CKD (e.g. strokes, myocardial infarction, peripheral vascular disease) [13]. The authors propose that such patients first undergo a phase of reconditioning, followed by a second phase of task-specific training to attain patient-specific goals. Close attention to the fluid status of the patient is required, especially those who are oliguric or anuric. In delivering exercise therapy, concerns largely revolve around possible musculoskeletal injury (e.g. tendon rupture, bone fracture) and cardiac risks (e.g. dysrhythmia, ischaemia, sudden death) [7]. It is recommended thus, that longer warm-up and warm-down periods are enforced. High impact exercises should be avoided. Lower intensity exercises, possibly with gradual progression in terms of duration rather than increased intensity, have been suggested for the initial phase of the exercise program [7, 13]. Using the patient's heart rate to adjust exercise intensity may be inappropriate given that dysrhythmia or use of beta-blockers may be present (as in our patient). The RPE or the Talk Test may be useful alternatives to gauge exercise intensity in these situations [12].

Other benefits of palliative rehabilitation in end-stage CKD patients

Table 2 shows the role of rehabilitation in end-stage CKD goes beyond exercise and physical medicine. Barawid et al. [14], have suggested additional roles rehabilitation can have in the management of palliative care patients. Issues with fatigue, pain, poor sleep, impaired cognition and mood disorders, notwithstanding specific disabilities arising from concomitant conditions like stroke, requires interdisciplinary management [1, 7, 13]. The systematic review by Zhao et al., reported that exercise significantly reduced fatigue, anxiety and depression [10, 13, 22]. Sleep disorders, such as sleep apnoea with daytime somnolence, insomnia and restless legs syndrome, are highly prevalent in CKD [13, 20]. Treatment of these disorders (Table 2) would enhance patient's participation in rehabilitation and improve QOL [17–23]. Concurrent management of low mood would lead to increased motivation, participation and self-empowerment. The role of rehabilitation medicine is to improve and promote function, reducing disability, improving independence and perhaps thereby, re-establishing self-esteem. The use of equipment can assist in patient care to these ends. It is

Table 2 Role of Palliative Rehabilitation in persons with End-Stage CKD not on RRT

Role of Palliative Rehabilitation	Rehabilitation Interventions
Improvement/Maintenance of ADLs and physical function	Physiotherapy [5—9, 15]: aerobic exercise, resistive exercise Occupational Therapy [5—9]: resistive exercise, task training, energy conservation techniques, prescription of aids, appliances and equipment, caregiver training
Pain control	Physiotherapy [24]: Stretching of muscles, passive ranging of joints, proper posture positioning, manual therapy, application of physical modalities (e.g. thermal therapy) Psychotherapy e.g. Cognitive behavioural therapy Pharmacotherapy
Fatigue	Physiotherapy [15, 16]: aerobic exercise, resistive exercise Occupational Therapy: energy conservation techniques Pharmacotherapy
Mood and mental wellness	Physiotherapy [10]: aerobic exercise Occupational Therapy: improved mental wellness (e.g. Self-esteem) through functional independence Psychotherapy Pharmacotherapy
Sleep management	Physiotherapy [17, 18]: aerobic exercise (cycling, walking, jogging, elliptical machine), resistive exercise Pharmacotherapy [19, 20]: melatonin, tricyclic antidepressants, serotonin reuptake inhibitors, anxiolytics Prescription of continuous positive airway pressure (CPAP) for obstructive sleep apnoea [19, 20] Psychotherapy [20]: cognitive behavioural therapy, relaxation training Complementary and alternative medicine [22, 23]: acupressure
Goal setting	Establishing patient-centric goals within context [29, 30] (e.g. extent of disease, prognosis) Advance care planning

necessary, however, to safeguard against overzealous procurement of equipment given the limited prognosis without RRT. Care-giver training is also an important component of this overall care. The care-giver is not only responsible for the physical care of the patient, but can be educated to augment the rehabilitative process (e.g. joint ranging, facilitating task training, maintenance exercises to delay physical decline).

At life's end, when improvements in or maintenance of function are not sustainable or expected, symptom control becomes the central focus. Rehabilitative therapy (e.g. stretching/passive ranging, application of physical modalities, posture positioning) may augment the work of the Palliative Care team in managing these discomforts experienced by the patient [24].

Dietary protein and caloric intake in palliative renal rehabilitation

Several guidelines on nutrition in CKD patients state that daily caloric consumption should range 30–35 kcal/kg and daily protein intake of 0.6–0.8 g/kg to reverse protein-energy wasting [5, 25]. Kidney Disease Quality Initiative-National Kidney Foundation (KDOQI-NKF) guidelines for nutrition in CKD (2020 Update) recommended a low protein diet (0.55–0.60 g/kg) in stage 3–5 CKD who are metabolically stable and not on dialysis [26]. If the patient also has diabetes, a dietary protein intake of 0.60–0.80 g/kg is recommended. In managing end-stage CKD patients who decline dialysis, and are also at high risk of developing sarcopaenia, clinicians may have to decide between increasing or restricting dietary protein intake. Based on recent studies, Sabatino et al. suggested that an energy and protein recommendation of 30 kcal/kg/day and 0.8–1.0 g/kg/day would likely cover for the nutritional needs of sarcopaenic elderly CKD patients not on dialysis and can be used as a starting point with close monitoring of renal function [27]. Isaka et al. reviewed existing guidelines on nutrition in CKD patients and acknowledged a lack of guidance specifically for those at high risk of sarcopaenia [28]. In this patient who was also afflicted with a recent stroke, the neurological impairments reduced his physical activity level, further increasing his risk of developing sarcopaenia. As this patient received daily therapy and exercise in the rehabilitation hospital, efforts to prevent sarcopaenia were prioritized. His dietary protein intake was increased temporarily from 0.8 to 1.0 g/kg/day during hospitalization, and his renal function remained stable during his rehab stay. Upon discharge to the community, he was counselled to reduce daily dietary protein intake back to 0.8 g/kg/day.

Goal-setting in palliative renal rehabilitation

Rehabilitation and palliative care are similar in that the goal is not to seek cure, but to enhance quality of life (QOL). In a structured review by Boa et al., goal-setting in palliative care was slightly different from goal-setting in rehabilitation, primarily because the former deals with patients with deteriorating conditions, often at unpredictable rates [29]. In palliative rehabilitation,

there exists a tension between maintaining hope and having realistic expectations of the inevitable decline. Intiso et al. also concurred that palliative rehabilitation in a patient with end-stage CKD requires goals to be tailored to the individual's effective needs, whilst giving due consideration to the stage of disease, complications and concomitant conditions [6]. The rehabilitation team must be cognizant of the various factors that could affect patients' engagement in goal-setting [30]. Although patient-centric goal-setting is essential, patients and caregivers should be discouraged from setting unrealistic rehabilitation goals.

Conclusion

End-stage CKD patients on palliative care may benefit from rehabilitation. This, however, needs to be contextualized to the patient's stage of disease, symptoms and environment. In end-stage CKD, the manifested disabilities may be attributable to the organ failure, the complications of the underlying cause(s) and associated medical disorders. Rehabilitative efforts can be complex and protracted. A short stint of intensive inpatient rehabilitation may be helpful to jumpstart the process.

It is important that rehabilitative efforts be planned in the context of the patient's prognosis and established goals. Setting realistic and meaningful goals will need to involve the patient, family, care-givers and the rehabilitative team. There must be an appreciation that rehabilitation is but part of the final journey in a palliative care patient.

Abbreviations

ACSM: American College of Sports Medicine; ADL: Activities of daily living; CKD: Chronic kidney disease; CPAP: Continuous positive airway pressure; FIM: Functional Independence Measure; HADS: Hospital Anxiety and Depression Scale; KDOQI-NKF: Kidney Disease Quality Initiative-National Kidney Foundation; MoCA: Montreal Cognitive Assessment; MRC: Medical Research Council; NIHSS: National Institutes of Health Stroke Scale; QOL: Quality of Life; RPE: Rating of Perceived Exertion.

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AWPS and SLT drafted and revised the manuscript. All authors read and approved the final manuscript.

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Declarations

Ethics approval and consent to participate

In accordance with the rules of publishing case reports by the ethics committee of our hospital, we have obtained written consent from the patient on publishing this report.

Consent for publication

The patient consented to publishing details of his medical condition. All co-authors approved this submission.

Competing interests

The authors declare that they have no competing interests.

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