



Enhanced Psychosocial Support for Caregiver Burden for Patients With Chronic Kidney Failure Choosing Not to Be Treated by Dialysis or Transplantation: A Pilot Randomized Controlled Trial

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Background: Family caregivers of patients with chronic kidney failure have increased burden, as reflected by their high frequency of physical and mental disturbances. The impact of enhanced psychosocial support to caregivers of patients with chronic kidney failure remains unclear.

Study Design: Open-label randomized controlled trial.

Setting & Participants: All new patients referred to the renal palliative clinic were screened. Caregivers of patients who met the following criteria were recruited: (1) chronic kidney failure as defined by creatinine clearance < 15 mL/min, (2) opted for conservative management by nephrology team or patient, (3) never treated with dialysis or transplantation, and (4) able to provide informed consent.

Interventions: Random assignment to treatment with enhanced psychosocial support or standard renal care (control). Enhanced psychosocial support included counseling and psychosocial interventions by an on-site palliative care nurse and designated social worker. Each caregiver was followed up at 2- to 4-week intervals for up to 6 months.

Outcomes: Zarit Burden Inventory (ZBI) and Hospital Anxiety and Depression Scale (HADS) in caregivers and McGill Quality of Life scores in patients of both groups were compared.

Results: 29 pairs of family caregivers/patients with chronic kidney failure were randomly assigned (intervention, n = 14; control, n = 15). Mean ages of patients and caregivers were 81.6 ± 5.1 and 59.8 ± 14.2 (SD) years, respectively. The intervention group showed significantly lower ZBI scores than the control group at 1 and 3 months (22.0 ± 5.3 vs 31.6 ± 9.5 and 21.3 ± 6.6 vs 33.4 ± 7.2; *P* = 0.006 and *P* = 0.009, respectively). HADS anxiety scores of caregivers who received the intervention were significantly lower than those of controls at 1 and 3 months (7.1 ± 3.2 vs 10.1 ± 2.2 and 6.5 ± 4.5 vs 11.0 ± 3.1; *P* = 0.01 and *P* = 0.03, respectively). Insignificant reductions in ZBI and HADS scores were found at 6 months. 19 patients died (intervention, n = 10; control, n = 9) during the study period.

Limitations: The study is limited by a relatively small sample size and short duration.

Conclusions: Enhanced psychosocial support program in patients with chronic kidney failure and caregivers resulted in an early significant reduction in caregiver burden and anxiety.

Am J Kidney Dis. 67(4):585-592. © 2016 by the National Kidney Foundation, Inc.

INDEX WORDS: Enhanced psychosocial support; caregiver burden; Hospital Anxiety and Depression Scale (HADS); anxiety; quality of life (QoL); chronic kidney failure; renal palliative care; conservative management; depression; social support; social worker; randomized controlled trial (RCT).

With a growing number of elderly patients with chronic kidney failure and those with comorbid conditions receiving palliative care, burdens on their families to provide care and support have increased. Effects of chronic stress on caregivers are reflected in the high frequency of physical and

mental disturbances among them.¹ For family caregivers of patients with chronic kidney failure who receive dialysis treatment, there could be anxiety, fatigue, deterioration in family relationships, and social isolation.² One Japanese study found significantly lower scores for physical health, social

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Received April 30, 2015. Accepted in revised form September 15, 2015. Originally published online November 5, 2015.

Trial registration: www.hkuctr.com; study number: HKCTR1524.

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0272-6386

<http://dx.doi.org/10.1053/j.ajkd.2015.09.021>

functioning, vitality, general health, and mental health in high-burden caregivers of dialysis patients.³ Furthermore, with additional responsibilities of managing the patients' medical treatments, dietary requirements, clinic appointments, and psychosocial issues, family caregivers might also develop stress.⁴⁻⁶

The National Consensus Development Conference for Caregiver Assessment has recommended the following approach: identify the primary and supplemental caregivers, integrate the needs and preferences of both the care recipient and the caregiver in all care planning, help caregivers learn the skills necessary to carry out the tasks of caregiving and better understand their role, and recognize that longitudinal periodic assessment of care outcomes for the care recipient and family caregiver is necessary.⁷ Results from an international survey concluded that interventions focused on improving family caregiver psychosocial support should be a priority.⁸ However, recent systematic reviews of interventions for family caregivers showed that effective support is just in its infancy.⁹⁻¹¹

In this context, an enhanced psychosocial support program was put forward by a collaborative renal palliative care service in Hong Kong in 2012.¹² In Hong Kong, all patients with chronic kidney disease stage 5 are interviewed by nephrologists and treatment options (renal replacement therapy [dialysis or kidney transplantation] and conservative management) are discussed. Those who choose conservative management (~20% of patients) are referred to the renal palliative care clinic. This enhanced psychosocial support program was offered to both renal palliative care patients and their caregivers, but the impact of such a program on reduction of caregiver burden remained unclear. The objective of this study was to investigate the effectiveness of enhanced psychosocial support in reducing caregiver burden in those caring for patients with chronic kidney failure who opted for conservative treatment.

METHODS

Design

This 24-week, open-labeled, randomized, controlled trial (RCT) was conducted in the renal clinic of Tung Wah Hospital in the Hong Kong West Cluster during June 2012 to December 2014. This study was approved by the Institutional Review Board of The University of Hong Kong/Hospital Authority Hong Kong West Cluster, and all participants provided written informed consent. Patients with chronic kidney failure with their primary family caregivers who met the inclusion criteria (see text that follows) were randomly assigned to the intervention or control groups. Caregivers in the intervention group received enhanced psychosocial support, which included education and intervention from an on-site palliative care nurse and a designated social worker. Interventions were instituted based on published information regarding families' needs in both end-stage renal disease^{13,14} and palliative care.^{15,16} The enhanced psychosocial support program adopted a proactive, comprehensive, and multidisciplinary approach for both patients and caregivers. It emphasized symptom

advice and prevention because patients with chronic kidney failure usually have a heavy symptom burden¹⁷ and a significant proportion of them have frequent emergency department attendance.¹² A previous study showed that higher symptom scores of patients were associated with increased caregiver burden.¹³ Many caregivers were stressed when handling medical emergencies of patients.^{18,19} Notably, emotional aspects of caregivers are important predictors of caregiver burden regarding patients with chronic kidney failure.¹⁴

The intervention consisted of 30-minute sessions held once to twice monthly on the day of a patient's joint clinic follow-up with a nurse, social worker, and physician. The palliative care nurse and social worker assessed each patient/caregiver pair before physician consultation and on the same day of the patient clinic appointment for the sake of caregiver convenience. Each pair of participants was interviewed by both a social worker and palliative care nurse (usually alternately) in a consultation room. The palliative care nurse assessed the symptom burden by the Edmonton Symptom Assessment Scale,²⁰ provided symptom advice with the use of pamphlets, monitored adherence to drug treatments and fluid recommendations, and provided psychosocial-spiritual support. The role of the social worker included giving social support and advice concerning financial issues and difficulties in placing the patient in home care and arranging respite care for caregivers.

The goals and contents of each session are summarized in Table 1. The beginning of the first session was a needs assessment session in which caregivers were asked about the types of issues and problems they encounter with their care recipients and what they would like to know about their care recipient's condition in order to better manage the care recipient's medical treatments. After the needs assessment, caregivers were given appropriate counselling and information accordingly.

Patients in the intervention group received treatment from a palliative care physician and emotional support from a palliative care nurse. The nurse and social worker shared and discussed all necessary information before physician consultation. The psychosocial interventions were given based on individual needs. All patient symptoms and psychosocial problems were reported to the corresponding clinician to facilitate better communication among team members. The control group received standard renal care and caregivers could be referred to other allied health professionals if clinically indicated. Recruited patients were followed up in a renal clinic at 2- to 4-week intervals up to a total of 6 months. Home visits and telephone follow-ups were provided by a palliative care team in the intervention group. The patients and caregivers in the control group joined the collaborative palliative care service after completion of the study.

Participants

All new patients referred to the renal palliative clinic were screened. Caregivers of patients who met the following criteria were recruited for study: (1) chronic kidney failure as defined by creatinine clearance < 15 mL/min, (2) opted for conservative treatment by nephrology team or patient, (3) never treated with dialysis or transplantation, and (4) able to provide informed consent. The caregiver was denoted as the one who bears the greatest responsibility for providing care to the patient within the family. Caregivers were excluded from this study when: (1) they had participated in another psycho-educational program during the preceding year, (2) they cared for more than 1 family member with a chronic medical illness, and (3) immediate palliative care (eg, end-of-life care) was required.

Randomization

After baseline assessment by a research assistant who was blinded to the study, participants were randomly assigned to intervention or control using a computer-generated randomization table number on a 1:1 scale with a block size of 10. Randomization was concealed within sealed envelopes before assessment. Participants and care providers were aware of group allocation following randomization.

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