Care for the caregivers of kidney patients

Sunshine Coast Hospital and Health Service (SCHHS) researchers, in partnership with The George Institute for Global Health, have recently completed a project exploring the quality of life and burden on caregivers when looking after people having dialysis.

This work has recently been published in the American Journal of Kidney Diseases.

SCHHS Director of Renal Services, Associate Professor Nicholas Gray, said research had been completed in this area previously although a systematic review to provide a holistic picture of the quality of life and mental health of caregivers was needed.

"Caregivers who support a chronically ill kidney patient are faced with many challenges, including managing the comfort of the patient, financial issues, meal planning, scheduling and transportation. Just keeping track of patients' multiple medications is a challenge," A/Prof Gray said.

"It isn't just the life of the patient that changes, but also the primary caregivers. As dialysis therapy is often lifelong, unless a transplant is received, things such as dreams of travel may go out the window.

"The results of the study showed most caregivers were female spouses and their quality of life was poorer than the general population, mostly comparable with caregivers of people with other chronic diseases, and often better than that experienced by the patients.

"Caregivers also reported a significant burden on their lives" he said.

The next steps will be to explore the impact of home based dialysis therapies like peritoneal and home haemodialysis on caregivers. There will also be a qualitative phase of the research project undertaken by SCHHS.

"Through deep-dive interviews we will build on our systematic study. This will allow us to create implementable strategies specific to our health network and region.

"We already have strategies in place to assist the caregiver including a strong patient support network who meet regularly. We also hold seminars for families and one-on-one teaching sessions with the multidisciplinary team.

"We would hope that the next phase of the research will let us build on our current practices and once in place, these strategies can be adopted nationally."

Maryann’s story
Maryann Fulton’s daughter Kate was just 21 when she suddenly developed renal disease, requiring her to be on dialysis for three and a half years. Maryann took immediate leave from her job to care for Kate around the clock after her diagnosis, and spent eight hours a day at Nambour General Hospital with Kate while she was on dialysis three to four times a week.

“Absolutely everything changes when you become a caregiver to a loved one with renal disease. It’s totally disruptive and you just have to be prepared to allow that to happen, there’s no point in fighting it,” Maryann said.

“Looking back on that period, the one thing that was really important was continuing with healthy patterns, such as exercising and socialising when you can. If the carer doesn’t take the time to look after themselves they will be no help to their loved one.”

Kate underwent a kidney transplant in 2015 and has since completed her Bachelor of Health Science Naturopathy.

Maryann welcomes the proactive research completed by A/Prof Gray and hopes the project improves support outcomes for carers.

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